

NHS National Commissioning Group – Highly Specialised Services

Chronic Pulmonary Aspergillosis National Service

Annual report 2024/2025



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1. Annual Service Overview and Highlights

This report covers the seventeenth 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 2024/25 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 129 new patients from England and Scotland (plus a further 2 patients from Wales) were assessed for CPA at the NAC between 1st April 2024 and 31st March 2025. This was an increase from 101 in 2023-2024 and from 72 in 2022-2023. A total of 297 new patients were referred and assessed for all forms of aspergillosis. We believe that the numbers of new CPA referrals have increased mostly due to 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 6 weeks.

At the end of March 2025, we had 314 patients from England and Scotland on service. Fifty 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 41 deaths, an increase from 30 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 88 such external cases in 24/25, up from 71 in 23/24 and 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 66 cases, up from 56 cases in 23/24 and 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.

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 2025, 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 several new 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. This is the first ever trial of immunotherapy in CPA, aiming to provide a new paradigm of treatment in this disease. In addition, our Trust is the lead UK site for an industry sponsored trial of a new antifungal agent for CPA, rezafungin. This is the first ever multicentre, multinational trial of a new antifungal agent in CPA. It offers our CPA patients, and CPA patients across the country with limited treatment options, the opportunity to

benefit from a novel treatment. In addition, the team delivers educational lectures and seminars nationally and internationally.

Our main aims for the next year are to:

- Improve equitable access to CPA treatment for all patients irrespective of their distance from the NAC.
- Further audit and enhance the quality of our National MDT discussions by expanding specialist participation and improving user experience and educational opportunities.
- Continue to explore new treatment approaches in CPA via research and industry engagement while encouraging patient involvement.
- Incorporate patient reported outcome measures into clinical decisions.

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 (mostly respiratory or infectious diseases specialists) and GPs are kept informed of our plans.

Initial clinical assessment includes a full clinical and medication history, Aspergillus blood and sputum tests, lung function, radiological imaging, bloodborne virus screen, 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 and pulmonary rehabilitation. 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 2024, we also introduced a treatment algorithm to help treatment decisions and facilitate discharge from service when suitable for the patient (Appendix 1).

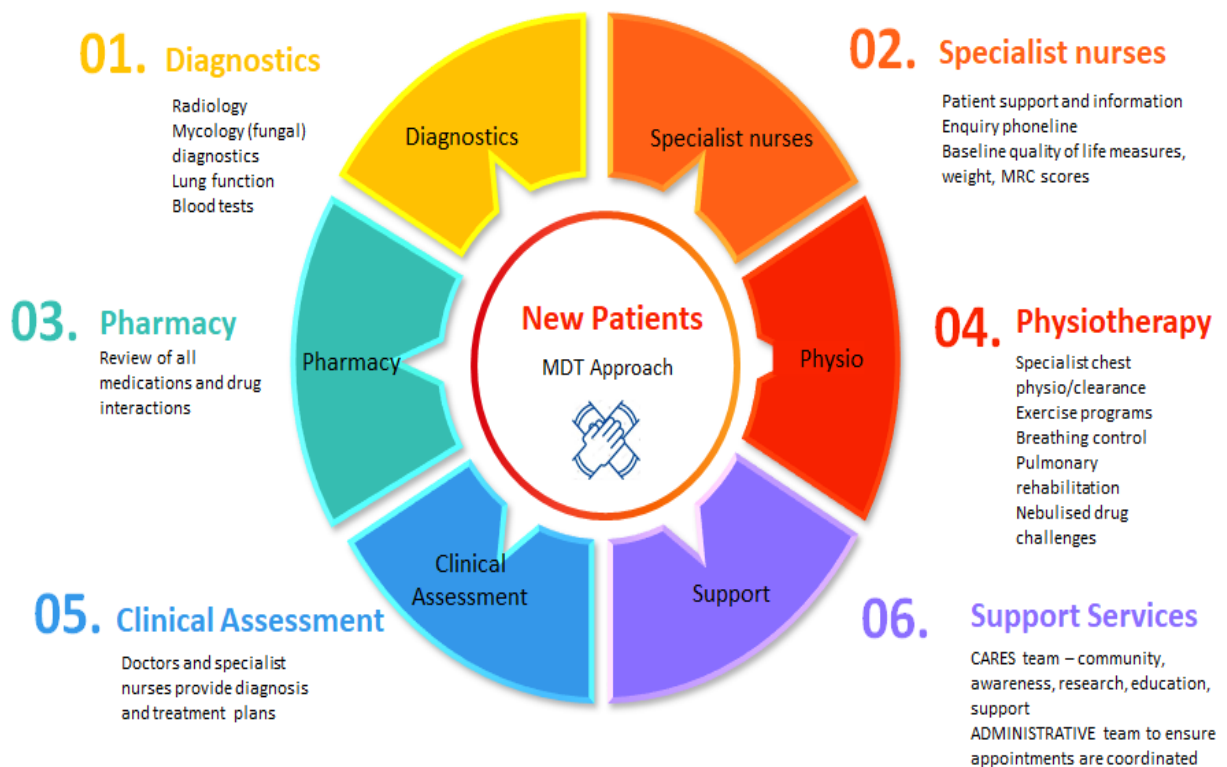
In addition to our out-patient clinics we also deliver short-term inpatient care – this includes evaluation of disease, intravenous therapy, bronchial artery embolisation, surgical resection, training in intravenous line management and delivery of iv antifungals in the community (OPAT). Hospital admissions 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.

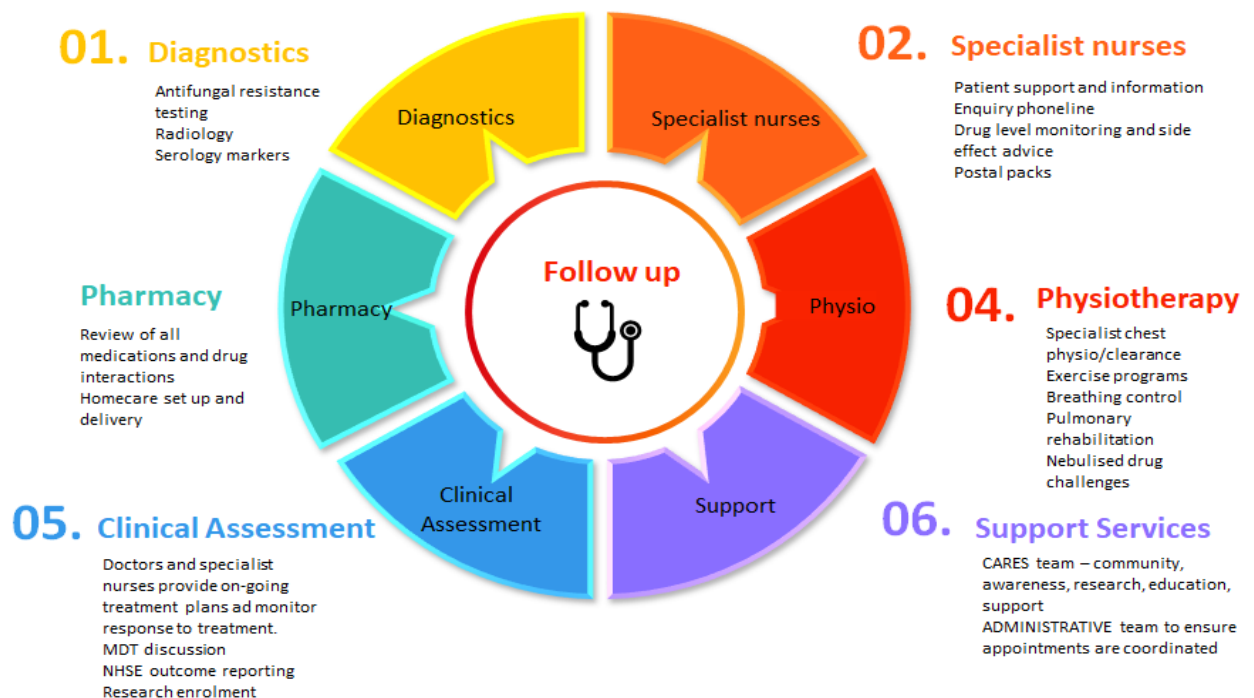
This report details the outcomes over the time period 1st April 2024 to 31st March 2025.

Schematic diagrams of NAC services

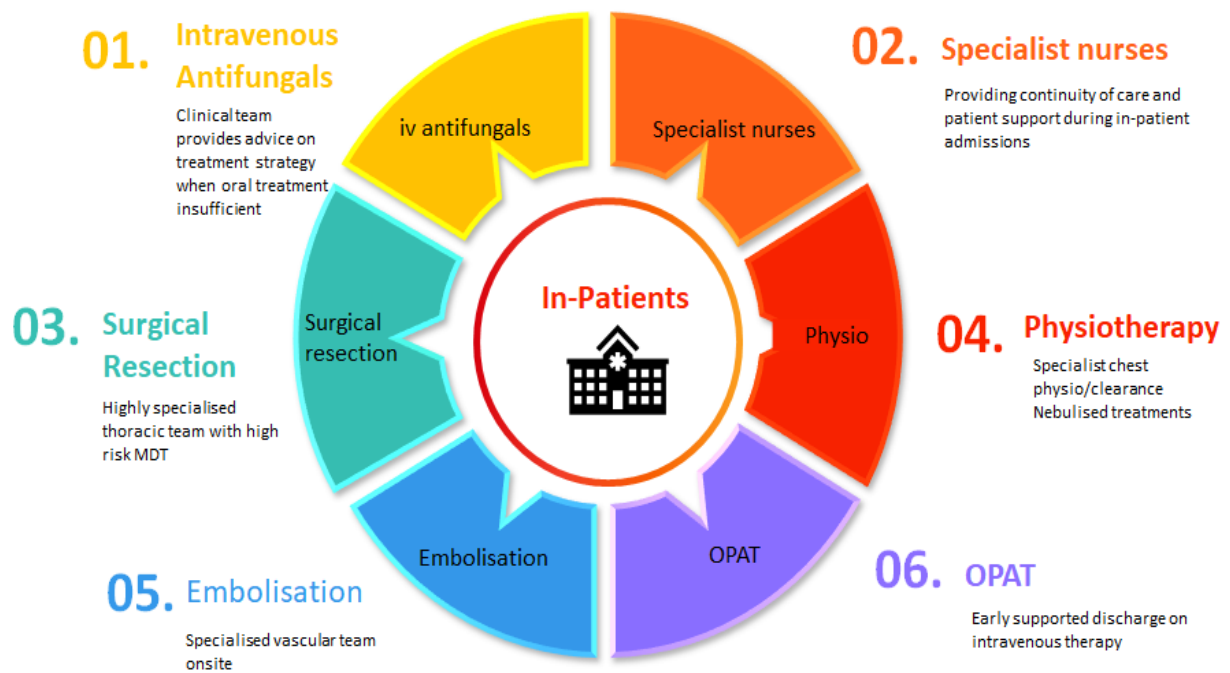
NEW PATIENT SERVICES



FOLLOW UP SERVICES



IN-PATIENT SERVICES



2.2 Workforce infrastructure and sustainability

Clinical and administrative personnel

The following clinical and administrative personnel provided support for the NAC in 2024/25:

Dr Chris Kosmidis, Consultant in Infectious Diseases and Clinical Lead (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 Prasun Chakravorty, Consultant in Infectious Diseases (1.5 PAs)
 Dr Tristan Banks, Consultant in Infectious Diseases (1.5 PAs)
 Dr Sarah Lawrence, Consultant in Infectious Diseases (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 (100%)
 Miss Niamh Duffy, Specialist Nurse (50%)
 Mrs Lincy Cyriac, Specialist Nurse (50%)
 Ms Claire Jones, 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%)
 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 2024/2025 compared to 2023/2024 are shown below:

2024/2025

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	
Referrals	17	33	14	14	19	28	23	36	32	25	28	28	297
New Patients Testing	10	10	4	6	11	15	9	23	12	12	9	8	129
New Patients Advice and guidance	2	3	6	5	6	2	11	6	3	6	5	11	66
New Patients MDT	4	13	6	8	9	7	10	3	3	3	9	13	88
Embolisations	0	0	1	0	0	1	0	0	0	0	0	0	2
Surgical Resection	0	0	0	0	0	1	0	0	0	0	0	0	1
Caseload - Band 1	79	81	80	90	90	94	101	105	107	104	101	105	104
Caseload - Band 2	219	209	205	213	209	203	202	201	202	200	198	194	200
Caseload - Band 3	7	7	7	10	11	11	11	11	10	10	10	10	10
Occupied Bed Days	0	0	14	0	0	22	0	0	0	0	0	0	36
Outpatient - Follow-Up Attendances	93	118	80	98	103	98	104	108	91	112	113	105	1223
IV Homecare (OPAT)	0	0	0	0	0	0	0	0	0	0	0	0	0
Inpatient Discharges	0	0	2	0	0	2	0	0	0	0	0	0	4
Discharged from Service	3	4	4	7	5	3	2	2	2	6	7	5	50
Patient Death	6	3	3	2	6	7	2	3	2	1	4	2	41

2023/2024

	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 2 shows the clinical definition of case bands

Referrals

There was a total of 297 referrals from England and Scotland during the year 2024 to 2025 (up from 209 in 23/24) that underwent clinic consultation by the service for all forms of Aspergillosis. 129 (43%) of these were investigated for CPA (up from 101 in 23/24). All new patients with a proposed CPA diagnosis 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

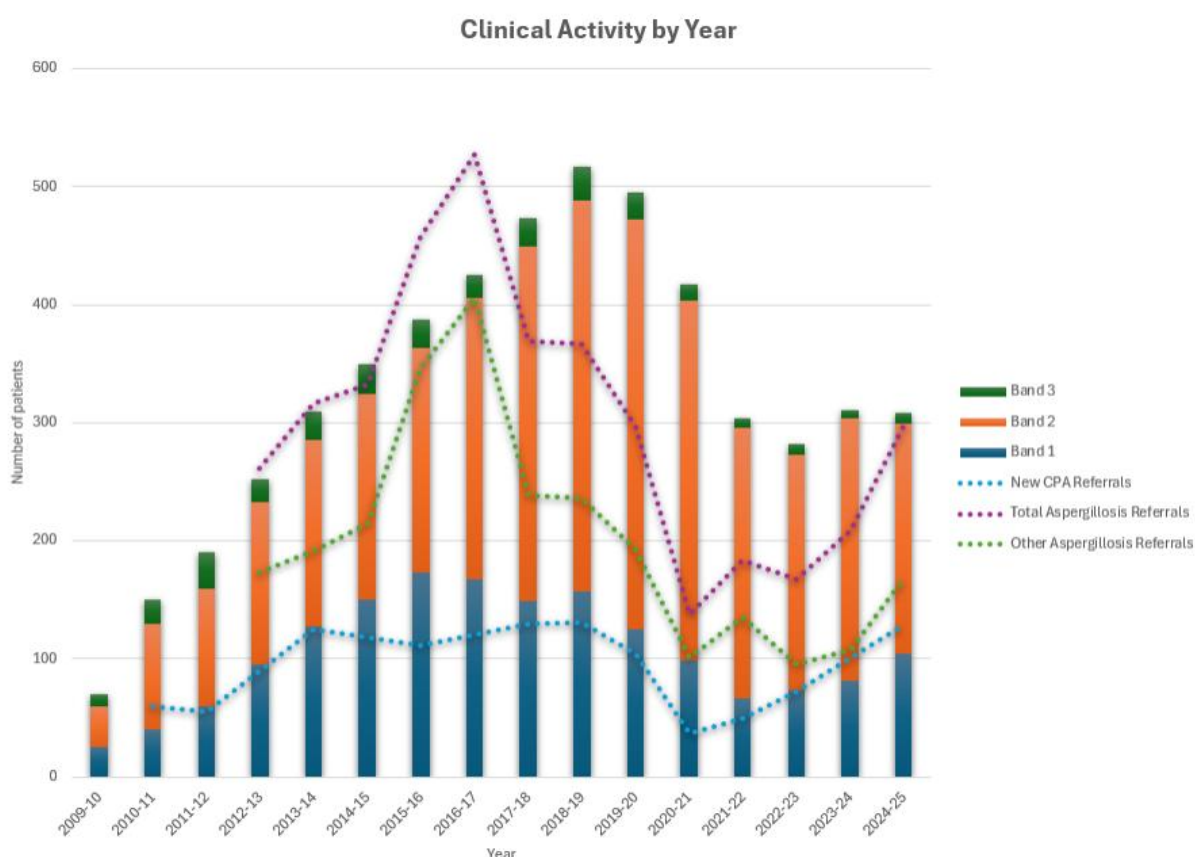
patients increased compared to 2023/2024; the proportion of referrals with a diagnosis of CPA remained stable this year. The number of new CPA patients has continued to increase following the significant reduction during the pandemic and has now reached pre-pandemic levels (we had 104 new CPA cases in 2019-2020).

Our National MDT forum, established in September 2021, gives the opportunity to external consultants to access NAC expertise. We discussed 88 such external cases in the MDT in 2023/2024 (up from 71 in 23/24). 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 66 cases (up from 56 in 23/24). 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 2025



Out-patient waiting times

The mean time from referral to clinic consultation was 42 days (down from 54.6 days in 23/24).

Geographical location

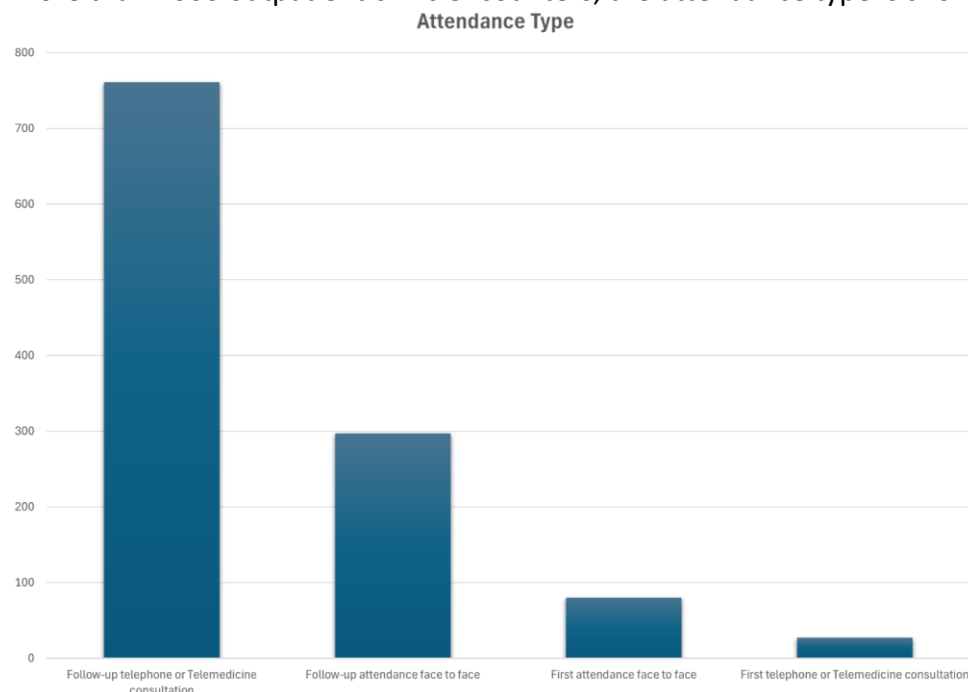
Appendix 3 displays maps of the geographical locations (postcode areas) of the new patient referrals and all patients on service. Historically more patients from the North-West of England were seen in the service. However, with the recent expansion of our National MDT and Advice and Guidance, more patients with CPA are discussed with local treating physicians: the number of patients outside of the NW has significantly increased (Appendix 3, Graph 2) compared to 2023 (Appendix 3, Graph 1).

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. 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, 309 patients from England and Scotland were on service (down from 311 in March 2023). Patients with CPA are banded according to disease severity, impact on functional ability and presence of antifungal resistance (Appendix 2).

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:

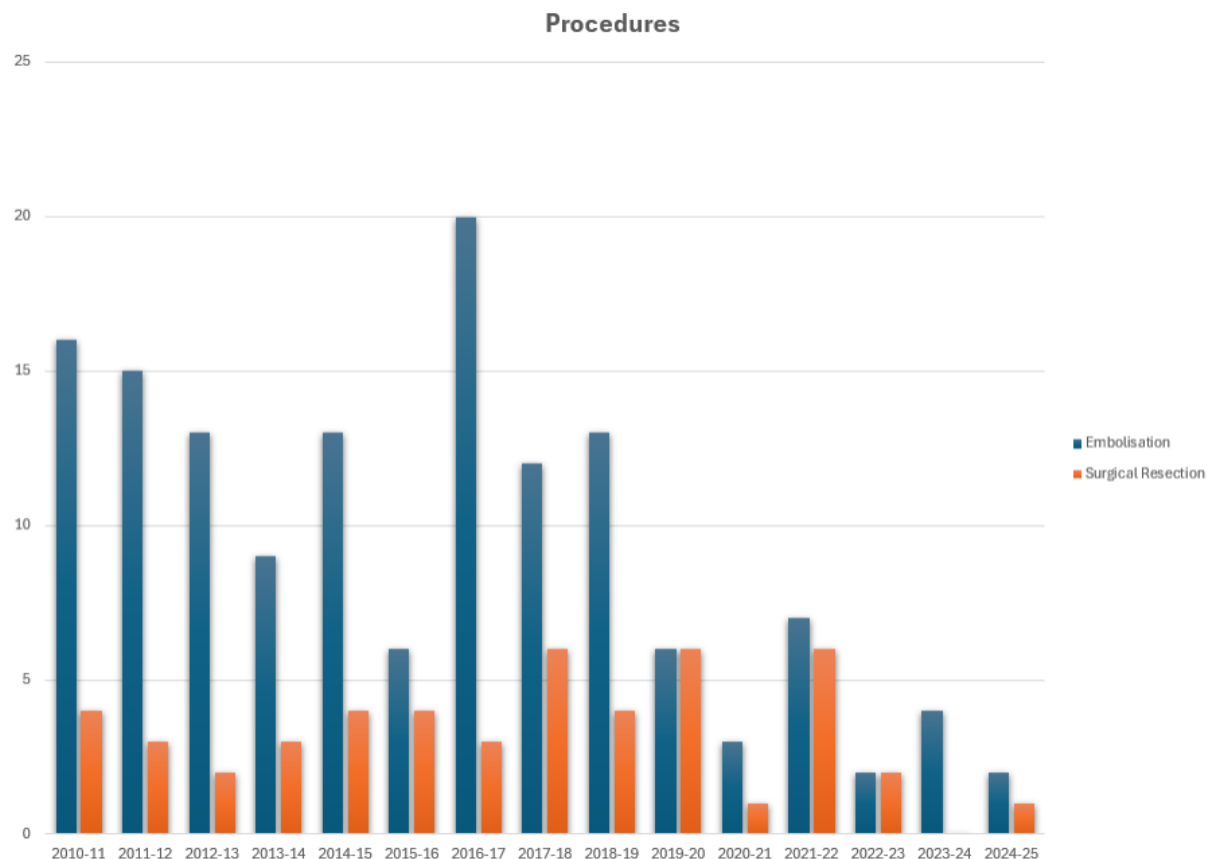


We currently see 42 patients in our weekly CPA clinic. There are at least 2 consultants at any time in the clinic, along with trainee doctors, Specialist Nurses, a Healthcare Assistant and a Physiotherapist.

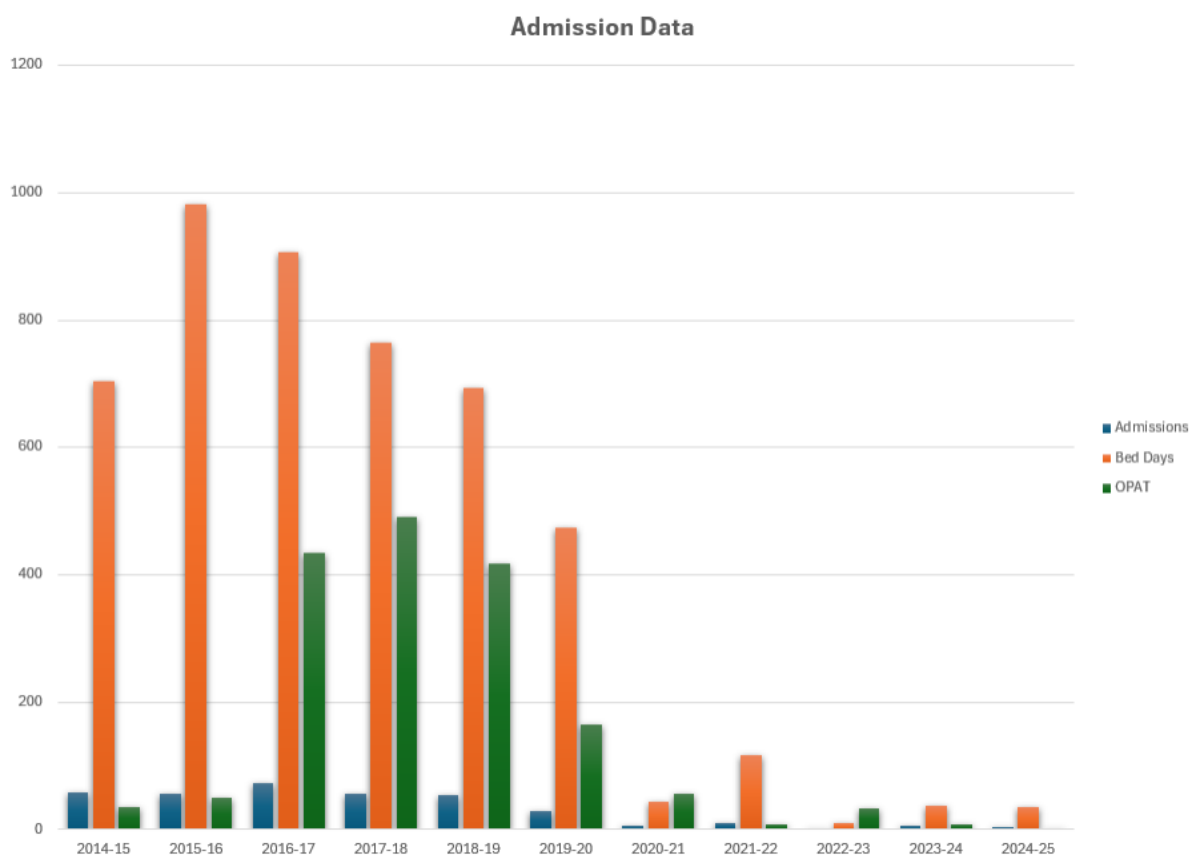
Our weekly CPA MDT lasts for 2 hours to accommodate discussion of all new CPA cases, 6-month drug trials, complicated cases and cases brought by external consultants. There are up to 15 patients discussed each week, with 3-4 external cases. There was an increase in the number of external consultants bringing cases, with representation from throughout the UK. (Appendix 4).

In-Patient Hospital Activity

We have seen a reduction in in-patient activity this year to 36 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. Two patients had embolization and one had surgical resection. The numbers of patients who underwent embolization and surgical resection in the NAC 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 58%. Failure of treatment, defined as lack of clinical improvement and/or adverse events of the medications, was documented in 25%. Ten percents died during the course of treatment. The outcomes for this year and the previous 2 years are shown in the tables below.

Trials of posaconazole/isavuconazole/voriconazole 2024-2025								
Outcomes	Posaconazole		Isavuconazole		Voriconazole		overall	
	%							
Success	15	54	10	83	9	47	34	58
Failure/ADR	5	18	1	8	9	47	15	25
Death	8	29	1	8	1	5	10	17
Total	28		12		19		59	
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			

2.5 Intravenous antifungal therapy

Intravenous antifungal therapy is most often used when azole therapy has failed, resistance has developed or around surgical resection. Six patients received intravenous antifungals via their local OPAT service. Four received caspofungin, one micafungin and one rezafungin.

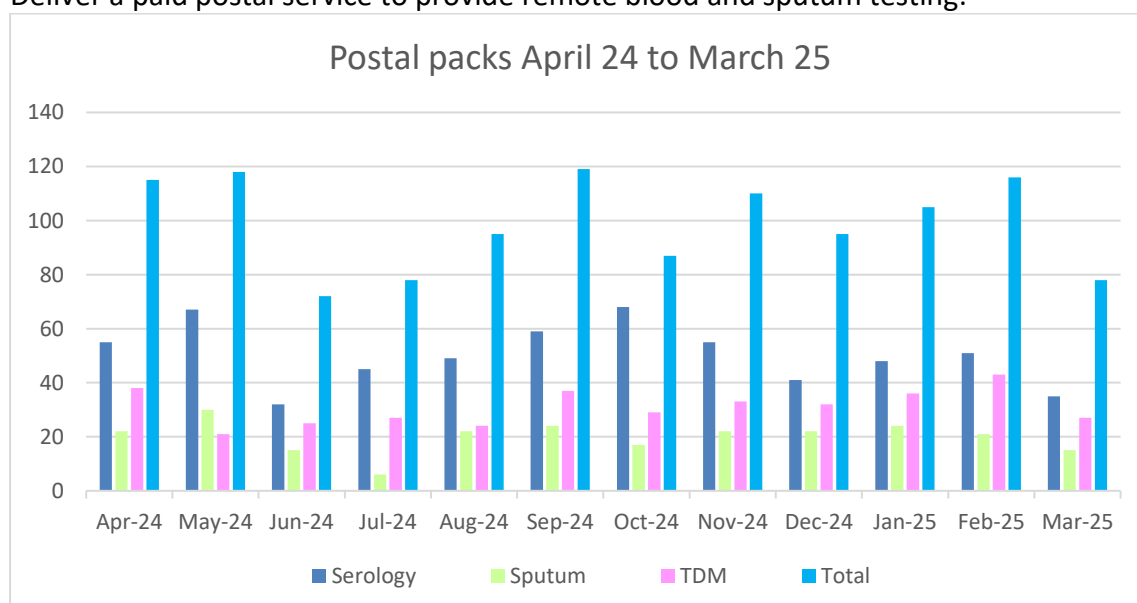
2.6 Antifungal prescribing and expenditure

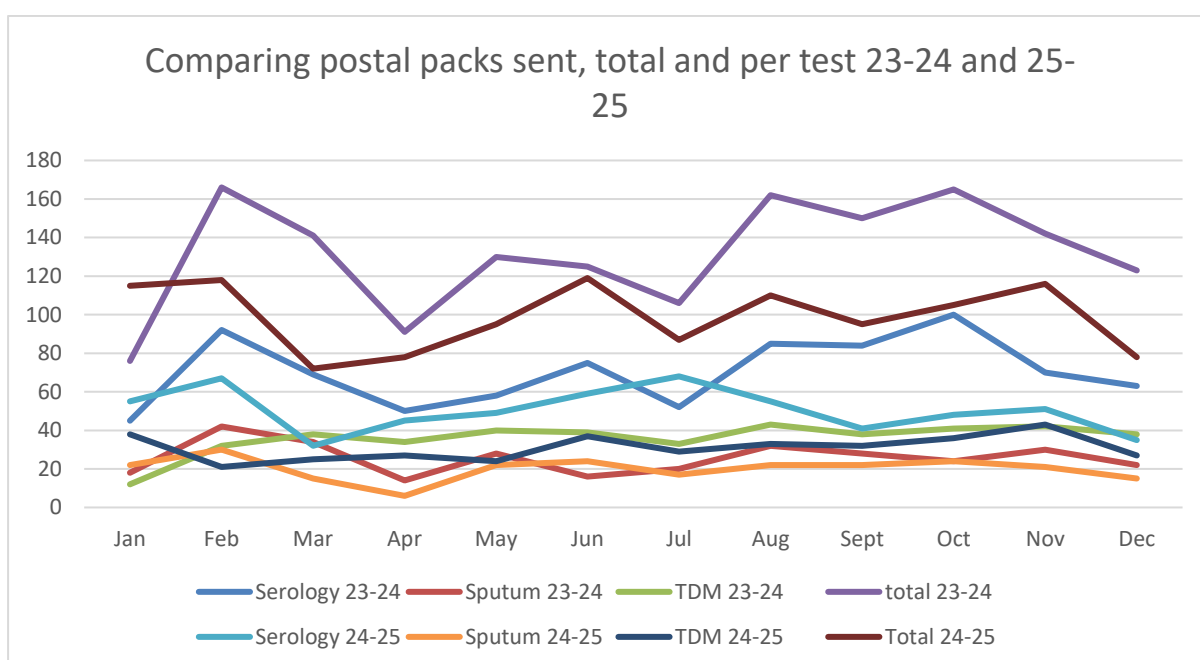
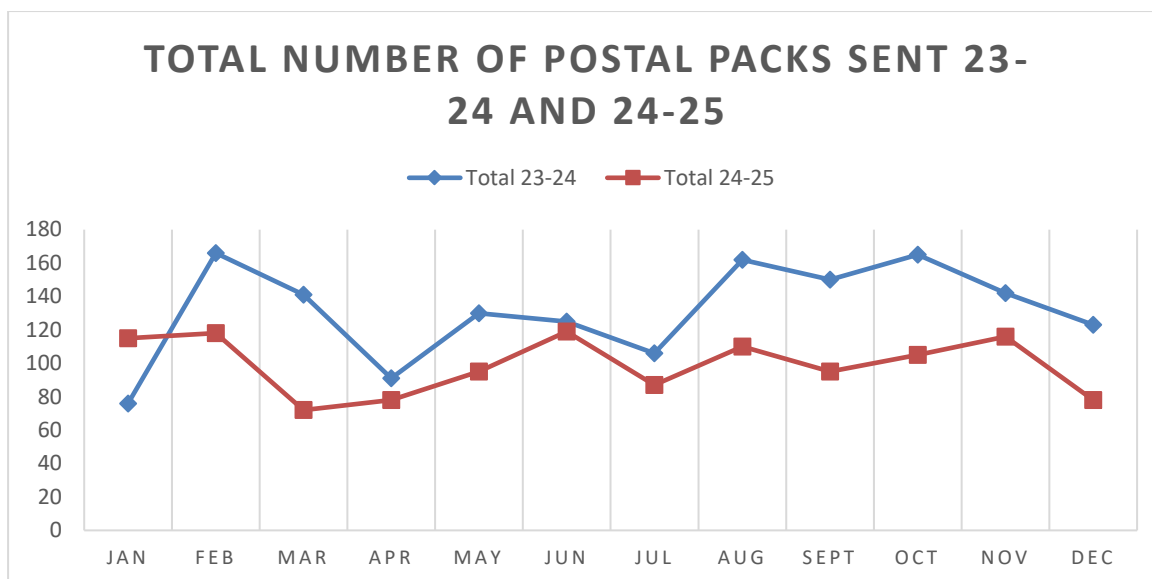
Antifungal expenditure has fallen significantly since Posaconazole came off patent and generic brands become more widely available in 2021. This is similar to 2017 when voriconazole came off patent. Isavuconazole costs have remained stable since the introduction into our commissioning pathway in 2016 (see Section 13). Itraconazole is the only aspergillosis treatment prescribed in primary care. Intravenous antifungals (micafungin, amphotericin B) continue to be given as salvage therapy.

3. Specialist Nurse Service

The NAC has a team of highly specialised and dedicated nurses. The service currently has 3 clinical specialist nurses (CNS) (2 WTE) 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:





- Lead CNS continues to independently prescribe treatment.
- Lead CNS worked collaboratively with a project and design company to complete an e-learning module on aspergillus disease, aimed at nurses and AHPs. However, as this is a highly specialised area the e-learning module will be included in resident doctor induction also.

Infectious diseases learning programme

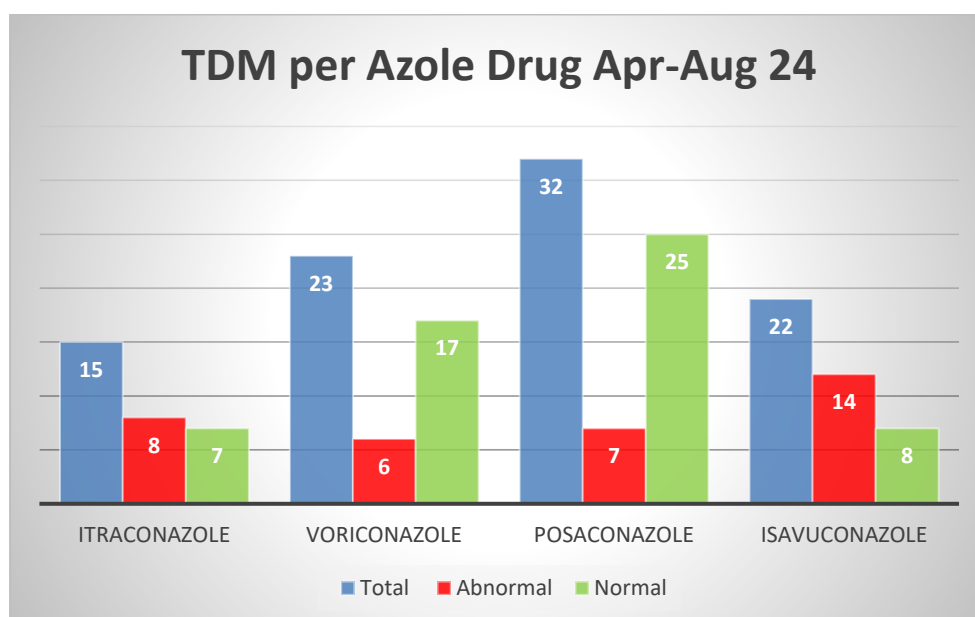
Unit 9: Aspergillosis

NHS
Manchester University
NHS Foundation Trust

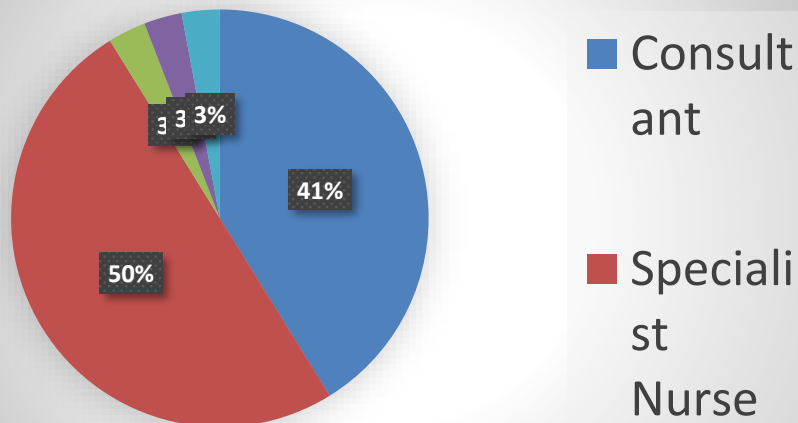
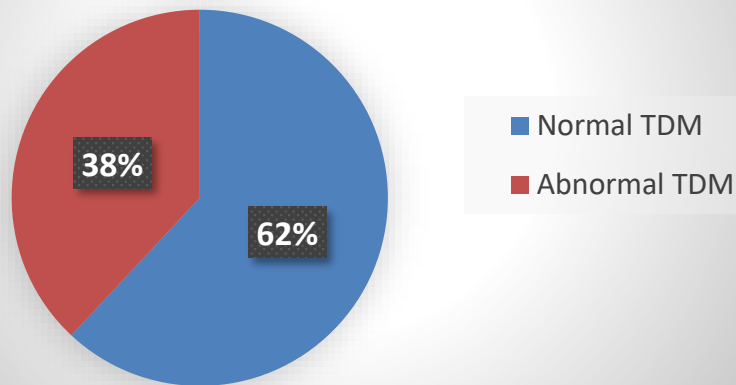
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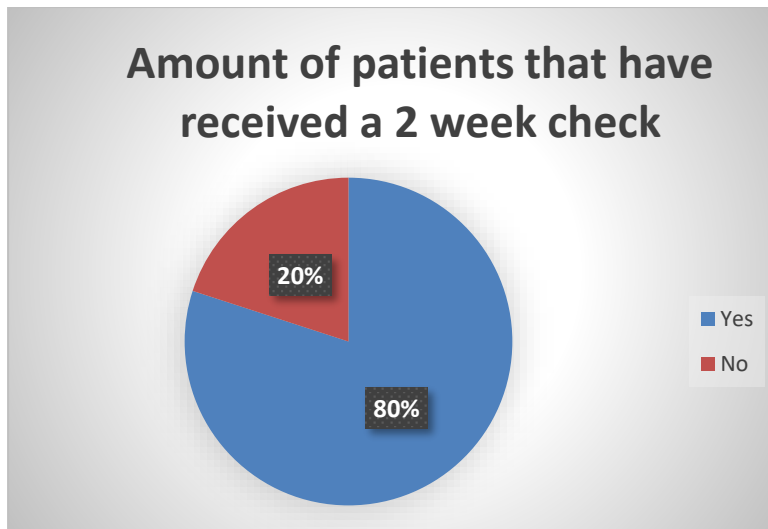
- Lead CNS has been involved in the development of BTS clinical statement.
- Lead CNS completed a patient safety audit on azole therapeutic drug monitoring (TDM). Results: Over a 3-month period out of a total of 91 TDM samples, 35 samples were out of range. 5 samples of the out-of-range results were not actioned within the target time of 5 days. This did not result in any harm. Actions: The results were presented to the team and team reminded of the policy, clinical impact and that the NAC nurses will action the TDM results, to ease medics workload. NAC CNS's currently action 50% of the abnormal TDM results:



Normal/Abnormal TDM Apr- Aug 24



- Patient safety audit completed. Following historic incidents identifying missed opportunities to check patients after commencing azole therapy and struggling to review patients in clinic appointments. The NAC nurse team implemented a week phone call check for all patients that commenced a newly prescribed azole treatment. 25 patients audited, 20 patients had a 2 week check 5 did not, due to the prescribing clinician not informing the nursing team, results below. Actions: Send a reminder to all clinicians in clinic to inform the NAC nurse team of newly prescribed azole therapy. Plan to re-audit.



The NAC nursing service challenges in 2024-2025:

- 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 2025-2026:

- With the implementation of the new electronic system continue to explore data collection and analysis, with an aim to complete further audits
- Explore research opportunities
- Recruit and train a newly recruited senior HCSW
- Support changes to patient quality of life questionnaire, to assess patient treatment outcomes

4. Physiotherapy Service

The physiotherapy service is delivered by 1.5 WTE specialist physiotherapists with extensive respiratory experience. The service had 156 new referrals this year of which 114 were first assessed face to face (73%). We have said goodbye to Mairead Hughes our Band 7 physio in December 2024 but welcomed Fiona Chambers to replace her in June 2025.

This year 35 patients were provided with oscillatory positive expiratory pressure (OPEP) devices to enhance their mucus clearance. We have secured improved access to these devices directly from clinic. There can be hesitancy using positive pressure devices with patients with cavitating lung disease and/ or haemoptysis so we have done some teaching locally about how these devices can be used safely in our Aspergillus cohort. We have switched 2 patients from nebulising Fungizone to the liposomal form of Amphotericin- Ambisome, a drug we hadn't previously nebulised in our trust.

We continue to promote our physiotherapy role and the role of the National Aspergillus Centre. This year we have delivered a lecture to postgraduate Scientist Training Practitioners

and coincidentally this year their professional exam had a question about Aspergillus lung disease. We've also delivered a session to those on the local NHS practitioner training programme as well as teaching locally in our trust and at national network meetings (NTM and ID physio networks).

As respiratory services nationally have grown their outpatient physiotherapy offer we are increasingly using our skills for optimisation of existing therapy. For example we managed to reduce a patient's nebulisation and airway clearance treatment burden from taking 2.5 hours to 70 mins a day with no reduction in efficacy apparent at 3 month follow up.

We are looking at ways to improve physiotherapy support to those who don't travel to Wythenshawe as these patients may well not be accessing services local to them like pulmonary rehabilitation/ respiratory physiotherapy outpatient services. Next year we plan to investigate what our patients think of the physiotherapy service and how we can improve. Small tweaks often have massive impact on patients' daily experiences of treatments and our feedback is consistently positive. We acknowledge the daily burden of treatment many of our patients live with and seek to help lessen the impact of living with their long term conditions.

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 provide general support to patients, prospective patients and external healthcare professionals. This includes handling queries, managing referrals, supporting follow-up processes and preparing clinic correspondence.

They also provide administrative support to the weekly MDT, maintain the Patient Tracking List and assist with audits. The team play a key role in ensuring the smooth running of the service and supporting its ongoing development.

7. Mycology Reference Centre Manchester

Departmental Introduction

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 a second time, for another four years in January 2025.

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

The MRCM also contributes to the development of UK Standards for Microbiology Investigations (UK SMI) and has representation on the EUCAST Antifungal Susceptibility Testing Subcommittee, the Education Committee of the European Society for Clinical Microbiology and Infectious Diseases, the Committee of the European Fungal Infection Study Group of ESCMID, 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 the Hospital Infection Society Prevention and Control of Aspergillosis in Healthcare, and Cystic Fibrosis Infection Prevention guidelines.

The MRCM team comprises a total of 26 staff including a Consultant Medical Mycologist, a Consultant Clinical Scientist, three Clinical Scientists, scientific and technical staff, and clerical support. The MRCM laboratories are well equipped with a full range of analytical and automated platforms and enjoy the support of infectious diseases and respiratory clinical teams.

The laboratory is an integral part of the University of Manchester Fungal Infection Group (MFIG) which brings the MFT NHS services and University of Manchester research and teaching functions together and creates one of the leading centres for medical mycology in Europe. The Manchester Fungal Infection network is made up of over 100 NHS doctors, Clinical Scientists, nurses, and University of Manchester researchers and has a combined aim to understand and reduce the burden of human fungal disease.

The MRCM is involved in several collaborative global initiatives to promote education and raise awareness of fungal diseases, and to inspire and support the next generation of laboratory staff.

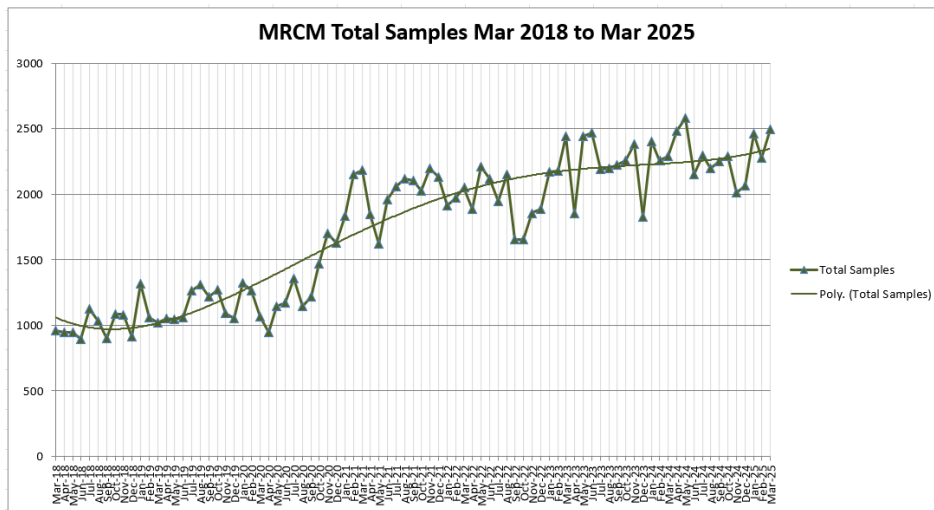
The MRCM acts as a training and research centre in medical mycology, and it is an integral part of the UK Clinical Mycology Network. Furthermore, the MRCM provides undergraduate (University of Manchester Medical School and School of Biological Sciences) and post-graduate (PhD programmes in Medical Mycology) level education for the University of Manchester, and the European Society for Clinical Microbiology and Infectious Diseases. It also provides placements and training for Clinical Scientists, biomedical scientists, registrars, and clinical fellows in infection training (Microbiology, Infectious Diseases, Respiratory Medicine).

Overview of 2024/2025

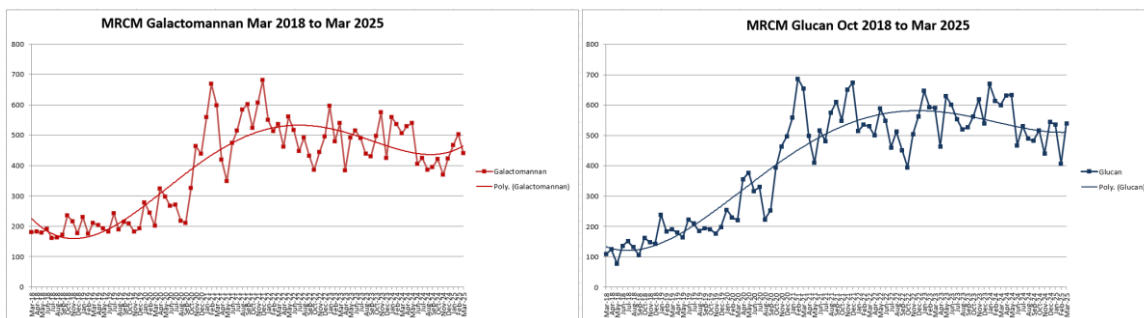
The MRCM, in its current form, has completed its 15th year of operations. There have been numerous developments, initiatives, and continued growth in its portfolio of tests and activities.

MRCM total activity for 2024/25 was more than 27,500 specimens – a 3% increase from 2022/23 and a 14% increase since 2022/23.

Over the last five years, our activity has increased by 97% outstripping our increase in staffing over the same period.



The activity of fungal biomarkers testing, both galactomannan and glucan, remained high. Overall, test volume of galactomannan and glucan has increased by ~110% and ~156%, respectively compared with pre-Covid-19 activity (2019/20).



Discussions with clinical colleagues throughout the Northwest region confirmed the appreciation of the excellent turnaround time and, hence, usefulness of these tests. It appears that the change to requesting practices initiated by the Covid-19 pandemic has now been embedded, benefitting the care of our sickest patients.

Throughout 2024/25, we have seen an increase in requests to review histopathological sections of tissue from biopsy and post-mortem specimens. 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 Master's level on-line modules in collaboration with the British Society for Medical Mycology and the University of Exeter.

The Mycology Reference Centre is home to the Manchester University NHS Foundation Trust (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 assist MFT Infection Prevention and Control (IPC) teams in the investigation and remediation of hospital buildings following catastrophic flooding events and ongoing demolition and renovation works. MFT hospitals have employed an antifungal stewardship programme, based on best available evidence and adapted to the local context, which includes an understanding of interventions that include environmental sampling to inform about the level of airborne contamination, in particular *Aspergillus*. The MRCM team are co-authors of the MFT Aspergillus Policy so are well positioned to provide a high level and responsive service and are contributing to the Healthcare Infection Society in collaboration with European partners in writing guidelines on mould surveillance in healthcare setting. Multiple authorities provide guidelines to facilitate early and sustained coordinated planning between IPC teams, building and engineering teams, and other relevant ancillary teams and strongly encourage hospitals to keep up to date with current best practice. 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 and Liverpool Police Services and the respective Coroners in investigating the possible role of allergenic and pathogenic moulds.

Key Achievements

- Successfully maintained UKAS accreditation to ISO15189: 2012 in February 2024, with no quality management system findings.
- Successfully transitioned to ISO 15189:2022 standard with no quality management system 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.
- Continued successful optimisation of the 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.
- 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.

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.

Publications

- 17 in 2024/25, including *Nature Reviews Microbiology*, *Lancet Infectious Diseases*, *Emerging Microbes and Infections*, *Journal of Infection*, *Journal of Antimicrobial Chemotherapy*, *Clinical Infectious Diseases*, *PLOS One*, and *BMC Microbiology*.
- Numerous clinical and laboratory R&D projects and audits presented at national and international meetings and written up as publications and international guidelines including but not limited to:
 - Weaver D, **Novak-Frazer L**, Palmer M, **Richardson M**, Bromley M, Bowyer P. Development of a novel mycobiome diagnostic for fungal infection. *BMC Microbiol.* 2024;24:63.
 - Maertens J, Slavin M, Hoenigl M, Thompson GR 3rd, **Richardson M**, Lass-Flörl C. Breaking the mould: challenging the status quo of clinical trial response definitions for invasive fungal diseases-a debate. *J Antimicrob Chemother.* 2024;79:1786-1793.
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- Ramage G, Kean R, **Rautemaa-Richardson R**, Williams C, Lopez-Ribot JL. Fungal biofilms in human health and disease. *Nat Rev Microbiol.* 2025.
- Cornely OA, Dupont H, Mikulska M, **Rautemaa-Richardson R**, Garcia-Vidal C, Thompson GR 3rd, Hoenigl M. Rezafungin in special populations with candidaemia and/or invasive candidiasis. *J Infect.* 2025;90:10643
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Strategic Objectives for 2025/2026

- Continue to provide an exemplary NHS mycology reference service for the UK and beyond - delivering a service, which is comprehensive, interpretative, timely, accredited and appropriate to user needs
- Maintain international, national, and local leadership in medical mycology

diagnostic services, and training

- Maintain UKAS ISO 15189 accreditation and European Centre of Excellence Diamond status
- Maintain good working relationships with other departments within MFT, and colleagues in other hospitals, universities, and institutions
- Ensure 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)
- To develop and implement Staff Survey action plan to improve staff experience to ultimately provide a supportive, caring, safe, appropriate and comfortable working environment which is inspirational and motivating that empowers the team
- Focus on staff development, career progression and quality CPD opportunities.
- 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
- Maintain an excellent and close working relationship with the 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 work with MMMP on the development of novel genomic testing methodologies
- To continue to select, evaluate and validate new mycological tests
- Continue to develop our Environmental Mould Surveillance Service and support of MFT IPC.
- 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
- To continue to improve resilience for consultant clinical advice
- Focus on 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 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 medical mycology teaching at the University of Manchester and Masters level programmes.
- Supporting Patient and Public Engagement activities delivered by the MFT Aspergillosis Communications Team.
- Continue to support with HIVE updates and optimisation.
- 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 are vital for patient pathway changes.

Staffing, Quality and IT aims

Staffing

- Create an IT Lead role – there is a need for a permanent IT trained staff member to support HIVE Beaker and other IT systems, and 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, often urgent, workload from MFT IPC/Estates, the police and the coroner.
- Continue to utilise the CPD Tracker to ensure equal opportunities across the department.

Quality

- The MRCM has maintained their UKAS ISO 15189:2012 accreditation status following successful surveillance visits between November 2024 – January 2025.
- MRCM expect to transition to ISO 15189:2022 in 2025 after successful transition assessments between November 2024- January 2025.
- 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 the QMS monthly overview working spreadsheet. Monitoring monthly ensures that we keep on schedule with our quality requirements and 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 X (formerly Twitter).
- Provide user education via the MRCM website, MRCM X (formerly 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 to free clinical scientist time for laboratory and quality tasks: The discussion of an IT Lead for MRCM was not successful.

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, EU 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, including the MSc in Medical Mycology run jointly between BSMM and the University of Exeter
- International reputation for medical mycology training including ESCMID observerships
- 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
- A 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 WTTA 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
- Scientific and clinical staff using their time to do IT and struggle to do what they should do
- No full-specification Category III containment facility within the laboratory (there is on site)
- Limited resilience in staff numbers, especially in senior roles, given persistently high activity
- Limited resilience and lack of contingency plans in case of any space issues.
- Limited resilience re Mould Surveillance Service – significant increased need with limited staffing

Opportunities

- To continue to become an integral part of the MFT Infection Strategy
- To continue collaboration with MMMP on diagnostic pathways and evaluating feasibility of having shared posts for generic roles not requiring specialty expertise (eg IT, clerical).
- 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: • NGS for fungal diagnostics and molecular resistance testing • <i>Aspergillus</i> IgG/IgM LFD • <i>Aspergillus</i> galactomannan LFA as POC test • Introduction of <i>Aspergillus</i> PCR on blood specimens • Mucorales PCR • Re-introduction of <i>Pneumocystis</i> PCR on saliva and respiratory specimens • PCP resistance testing • Investigate the development of an in-house <i>Aspergillus fumigatus</i> specific probe	• This is a long-term plan over the next five years. • 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	• 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	• 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	• Analyses of TAT and workflow, resolving any barriers found
Improve access to and use of fungal diagnostic tests to support reduction of unnecessary empiric use of antifungals	• Continue to engage with users via user surveys.
Retention of experienced and dedicated staff	• This is a rolling departmental goal. MRCM have 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	• This is achieved by communications to external establishments via the MRCM X (formerly Twitter), LinkedIn, MRCM website and the hospital and GP newsletters. Additionally, staff

	attending conferences and courses will be able to promote our services.
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Summary

Over the last five years, our activity has increased by 97%, outstripping our increase in staffing over the same period. In addition, there has been a significant increase in environmental, and police/coronial workload. We continue to grow and innovate, embracing further opportunities to develop and expand our unique service: increasing staffing to sustain growth, and investment in state-of-the-art IT solutions and technologies. Realising these opportunities will be the focus of our strategic plan; this aligns with DLM, and ultimately, MFT vision.

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

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 2024-2025

8.5 High impact learning assessment (HILA)

One HILA was carried out in 24/25. Patient on antifungals and inhaled steroids developed adrenal insufficiency. This was due to the interaction not recognised few years ago. Actions were:

- Audit of all patients for this interaction. Patients found to be on combinations were switched (see section 9).

- Trust guideline produced on management of this interaction

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.

Main audits in 24/25:

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.

Quality improvement project on the use of patient reported outcome measures to assess antifungal treatment in CPA.

Background: the St George's QoL questionnaire was used pre-pandemic in CPA to assess response to antifungal treatment, however it is a complex questionnaire with >50 questions. As a result it was not easy to complete, especially for patients attending remotely. We are evaluating the use of the CAT score:

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy 0 ☒ 2 3 4 5 I am very sad

			SCORE
I never cough	0 1 2 3 4 5	I cough all the time	
I have no phlegm (mucus) in my chest at all	0 1 2 3 4 5	My chest is completely full of phlegm (mucus)	
My chest does not feel tight at all	0 1 2 3 4 5	My chest feels very tight	
When I walk up a hill or one flight of stairs I am not breathless	0 1 2 3 4 5	When I walk up a hill or one flight of stairs I am very breathless	
I am not limited doing any activities at home	0 1 2 3 4 5	I am very limited doing activities at home	
I am confident leaving my home despite my lung condition	0 1 2 3 4 5	I am not at all confident leaving my home because of my lung condition	
I sleep soundly	0 1 2 3 4 5	I don't sleep soundly because of my lung condition	
I have lots of energy	0 1 2 3 4 5	I have no energy at all	
TOTAL SCORE			

This score is validated in CPA and bronchiectasis, which are comorbidities present in many CPA patients. The score is incorporated into the electronic medical records and patients can fill out in the hospital app on their phones.

Methods: We initiated completion of the CAT score at 0,4 and 6 months of antifungal treatment. The score is available for clinicians during the clinic visit.

Results:

- 22 patients had the score at baseline and at 6 months
- Mean age 67 years, mean weight 54 kg
- Comorbidities:
 - COPD 65%
 - Bronchiectasis 26%
 - TB 9%
 - NTM 9%

QoL score compared to the current outcome measures:

QoL score	CT scan	Serology
Improved: 12	Improved: 6	Improved: 20
Stable: 6	Stable: 12	Worse: 2
Worse: 4	Worse: 1	

Conclusion:

- The imaging was most often stable at 6 months
- The QoL score may provide more information early on about response rates

In the next phase we will assess a larger number of participants and identify factors affecting the clinical response (comorbidities, demographics etc).

10. Research and Publications

NAC has been increasing its research participation this year and is now participating in several exciting clinical trials that we hope will make new treatment options available to aspergillosis patients.

We use a variety of channels to make sure our research findings are seen by clinicians so that they can inform their clinical practice. This year our staff were authors on 25 papers, including several in high-impact journals – please see appendix 5 for full bibliography and links. They also shared their findings in the form of posters and talks at international conferences and regional meetings, which were promoted via social media and our professional email newsletter.

New antifungals are the research topic of greatest interest to our patients, but most new antifungals are initially approved for invasive infections. NAC's large patient cohort allows us to play a key role in generating evidence for expanding their use to chronic forms of aspergillosis.

- Rezafungin is a new IV echinocandin that is given only once per week, which would be much easier for patients and OPAT than caspofungin/micafungin, which need to be infused daily). It was approved in 2024 for invasive candida infections and Dr Rautemaa-Richardson recently contributed to a review article about whether dose adjustments are needed for patients with liver/kidney problems or older/critically ill people (Cornely *et al*, 2025). NAC has also been appr Phase2 clinical trial to test whether Rezafungin is safe and effective for CPA (recruitment begins summer 2025).
- Dr Bazaz participated in an FDA workshop about improving clinical trials of inhaled antifungals that was published in Clinical Infectious Diseases (Jjingo *et al*, 2024).
- Dr Rautemaa-Richardson contributed to a large European study of isavuconazole for treating *Aspergillus* infections in the brains of haematology and transplant patients (Serris *et al*, 2024)
- Saarah Niazi-Ali co-authored an overview of the most important drug interactions to consider when prescribing azole antifungals (Lewis *et al*, 2024).

Long-term CPA data is collected from our patients in order to guide treatment and monitoring of CPA patients.

- CPA patients unfortunately often relapse after completing antifungal therapy, so we analysed health records to help predict which patients will relapse and how long this typically takes. This won the poster prize at the Fungal Update conference (see figure below).
- Dr Kosmidis contributed to a systematic review combining mortality data from 8778 CPA patients (Sengupta *et al*, 2025), which will be useful for tailoring treatments to patients with different characteristics (e.g. CPA comorbid with either post-TB vs COPD)

- Health records of NAC patients were used to calculate the mortality rates of patients who had developed CPA after undergoing surgery for lung cancer (Whittaker *et al*, 2024)
- We collaborated with Imperial University on their CAPSULE study, which is validating a new quality of life tool that measures factors such as sleep and mood. We recruited 30 patients and are now collecting data. We hope to use this tool in our CPA clinic to gain a better overall picture of how each patient's health progression and needs

Subtle immunological defects can help to explain why some patients with risk factors (e.g. COPD, prior TB) develop CPA, while others do not. This is a cutting-edge area of research that could bring about more treatment options for CPA patients who have not responded adequately to antifungals

- Dr Kosmidis worked with researchers at MFT and the University of Manchester to look at different types of white blood cells in CPA patients versus bronchiectasis patients (Colombo *et al*, 2025). Dendritic cells normally mature and produce cytokines in response to the presence of a pathogen. CPA patients had fewer of a key dendritic cell type (cDC1) and these were less able to mature and produce a cytokine (IL-12p40) in response to a fungal protein (ZYM). This could result in less signalling to produce interferon gamma and therefore a weaker immune response to fungi.
- We were delighted to start recruiting for the INCAS trial, a Phase2 RCT (NCT05653193) testing whether interferon gamma injections could help boost the immune system of CPA patients when given alongside standard antifungal treatment.
- Dr Kosmidis and Dr Callisti were authors on a study about survival rates of patients with STAT3 hyper-IgE syndrome, which is a rare genetic disorder that causes skin and respiratory problems including aspergillosis and bronchiectasis (Tsilifis *et al*, 2025)

Dr Rautemaa-Richardson (director of MRCM) has been active in publishing on **fungal diagnostics**, particularly in molecular testing (PCR) to diagnose *Pneumocystis* pneumonia and invasive mucormycosis, which are rare fungal infections that are occasionally seen in the NHS

- A high-profile paper was published in Clinical Infectious Diseases describing a meta-analysis of data from 7835 patients about using PCR (a DNA-based test) to diagnose *Pneumocystis* pneumonia (Brown *et al*, 2024a). This work generated great interest when presented at the xx? Conference and was discussed in the journal (Brown *et al*, 2024b). The same group of authors also wrote an expert review of the strengths and weaknesses of this type of test (Brown *et al*, 2024c).
- A systematic review was published with performance data about PCR testing for mucormycosis, a severe mould infection similar to invasive aspergillosis (Brown *et al*, 2025d).

- Case study: *Cladophialophora* infection in a kidney transplant recipient (Mackrill *et al*, 2025)
- Case study: histoplasmosis in a returning traveller (Zafar *et al*, 2024)

NAC and MRCM staff also publish on **other fungal infections** such as *Candida* (yeast)

- Dr Rautemaa-Richardson was part of ECMM III, a multinational study looking at risk factors and mortality rates among hospital patients with bloodstream infections caused by different species of *Candida* (Salmanton-García *et al*, 2024)
- Effect of *Candida* colonisation on gene expression in oral cancer (Rusanen *et al*, 2024)
- Invasive mould infection in combat wounds (Roberds *et al*, 2024)

Our staff contribute their considerable experience to **guidelines and recommendations**

- Dr Kosmidis and several former NAC staff were authors on the new ISHAM guidelines for diagnosing and treating ABPA (Agarwal *et al*, 2025). Dr Ellis gave a talk at WAD2025 to explain the impact of these guidelines for a lay audience, which was very well received
- Dr Rautemaa-Richardson represented the UK in a workshop on the impact of the Fungal Priority Pathogen List on mycology in European countries (Arendrup *et al*, 2024)
- Prof Richardson co-authored a paper summarising a debate conducted as part of the Trends in Medical Mycology conference. They discussed whether it is time to update the standardised definitions of response to treatment that are currently used in clinical trials on severe mould infections (Maertens *et al*, 2024).
- A letter was sent to the editor highlighting the considerable comorbidity rate between CPA and non-tuberculous mycobacterium infections (Denning & Kosmidis, 2025)
- Dr Rautemaa-Richardson was part of the group who published new comprehensive guidelines for all types of candidiasis in the Lancet (Cornely *et al*, 2025)

11. Patient and public engagement

NAC CARES Team Overview

The NAC CARES team (Community, Awareness, Research, Education, Support) comprises:

- **Graham Atherton** – Team Lead
- **Beth Bradshaw** – Medical Writer (Mycology)

Previously, **Lauren Amphlett** managed patient communities and social media; she has now moved to another role within NAC.

The CARES team focuses on five core aims:

1. **Expert Support** – Providing reliable guidance to patients, carers, and healthcare professionals, especially those newly encountering aspergillosis, both nationally and internationally.
2. **Community Building** – Fostering mutual support to reduce isolation and improve wellbeing in people with rare diseases.
3. **Raising Awareness** – Promoting recognition of aspergillosis across the UK and globally to improve early diagnosis and outcomes.
4. **Research Communication** – Acting as a bridge between researchers and patients, ensuring two-way information flow and feedback.
5. **Educational Access** – Offering up-to-date resources for patients and professionals via online platforms, meetings, and partnerships.

Expert Support

Why	Non-Clinical	Expertise	Matters
For people living with chronic aspergillosis—or seeking a diagnosis—non-clinical expert support is often as vital as medical care. Navigating an unfamiliar and complex illness can be overwhelming, particularly when symptoms are misunderstood or diagnosis delayed.			

Non-clinical experts:

- Help patients understand the disease and prepare for appointments.
- Offer emotional and practical support.
- Provide reliable information and signposting to trusted resources.
- Build patients' confidence to advocate for tests, referrals, and treatment options.

These networks benefit not only patients and carers but also busy GPs, nurses, and non-specialist hospital teams who need quick access to guidance and referral pathways.

Reach	Through	Social	Media
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Patient engagement is driven through dedicated support communities:

- **Facebook:** Private, closed group with more than 3,000 members; 1,306 were active in the past week. Discussion topics are wide-ranging (see **Fig. 1**).
- **Telegram:** Confidential group for day-to-day, real-time support.

Posts ⓘ		Top posts ▼	By all ▼
The posts with the most activity in the last 28 days.			
Date	Post	Reach	Engagement
7/24/2025 1:19 PM	 Hi All I would just like to share some wonderful news with you about our Son Jordan who has ABPA, Secondary... Posted by Jackie Burrows	555	95
7/8/2025 1:45 PM	 High IgE (7000+) – Do I Have Asthma or Just Allergies? What Test Can Confirm? I recently found out my IgE levels... Posted by Laxman Laxman	205	31
7/28/2025 4:51 PM	 Afternoon. Just a quick follow-up from my earlier post. My GP prescribed antibiotics, plus confirmed I have aspergillu... Posted by Andrea Hennessy	348	55
7/15/2025 6:01 AM	 □ DIY Flutter for Mucus Clearing – Need Advice! □ Hey everyone! I'm planning to make a DIY flutter device at... Posted by Laxman Laxman	222	27
7/26/2025 5:59 AM	 Morning. Im bringing more mucus up than normal I'm not sure if it's aspergillus or my asthma. I've had this thought... Posted by Andrea Hennessy	261	31
7/8/2025 12:06 PM	 Biofilms - the 'goo' that many microbes exude and live in - is increasingly becoming an important topic for doctors... Posted by National Aspergillosis Centre	221	27
7/14/2025 9:51 AM	 Morning. I have no idea if the pain/stinging feeling in my right breast area & occasionally in my back upper right si... Posted by Andrea Hennessy	268	19
7/11/2025 9:06 AM	 Need a face mask so can anyone advise asperilligus spore size and perhaps pollen size? TIA Posted by Ian May	486	18
7/29/2025 6:25 PM	We have a patient meeting this Friday, 1st August. This is your opportunity to ask us to address any specific topics... Posted by National Aspergillosis Centre	123	18
7/9/2025 12:37 PM	 I was diagnosed yesterday with ABPA following a short hospital stay and am concerned that this is a chronic... Posted by Ian May	327	18

Fig. 1 – The variety of topics posted in our Facebook group shows the breadth of patient interest and need.

While most members are UK-based, many are from overseas (see **Fig. 2**). Their contributions often add valuable perspectives.

Top countries		Top towns/cities	
United Kingdom	1,179	London	65
United States	1,041	Sydney, NSW, Australia	29
Australia	166	Melbourne, VIC, Australia	28
India	73	Manchester	26
Canada	59	Birmingham	22

Fig. 2 – Global membership spread, with strong UK core and active international participation.

Discussions from these groups often inspire new articles on **aspergillosis.org** (640+ posts to date, updated most days). **Fig. 3** shows recent articles; **Fig. 4** highlights the most-read posts as of 1 August 2025.

News archive

Hide filters

- Air pollution
- Allergy or Intolerance
- Antifungals in development
- Antimicrobial resistance
- COVID-19
- Climate change
- Diagnostics
- Events
- Fundraising
- GP Guidance
- General interest
- How do I...?
- Information and Learning
- Latest research news
- Lifestyle
- Lifestyle and Coping Skills
- Living with Aspergillosis
- NAC announcements
- NHS
- News archive
- Palliative care
- Patient and Carer Blog

Dupilumab for ABPA: What You Need to Know Now the Trial Is Complete

August 1, 2025

READ MORE

Why It's Important Not to Share Your Clinical Trial Experience – Until It's Over

August 1, 2025

READ MORE

Rezafungin: A New Antifungal Being Trialled for CPA

August 1, 2025

READ MORE

Cyber Safety for Aspergillosis Patients: Supplement to UK NCSC Advice

July 31, 2025

READ MORE

Is It an ABPA Flare or a Bronchiectasis Flare? How to Tell

Asthma & Lung: 5 tips to

Fig. 3 – Recent posts on aspergillosis.org reflect real-world questions and issues raised by patients.

Plot rows		Search...		Rows per page: 10		Go to: 1		1-10 of 1241	
Page title and screen class		Views	Active users	Views per active user	Average engagement time per active user	Event count All events	Key events All events	Total revenue	
Total		7,592 100% of total	5,251 100% of total	1.45 Avg 0%	35s Avg 0%	22,606 100% of total	0.00	£0.00	
1 Home - Aspergillosis Patients & Carers Support		749 (9.87%)	458 (8.72%)	1.64	45s	2,349 (10.39%)	0.00 (-)	£0.00 (-)	
2 Aspergillosis Awareness: Conversation with Marcela Candeias - European Lung Foundation - Aspergillosis Patients & Carers Support		288 (3.79%)	286 (5.45%)	1.01	1s	858 (3.8%)	0.00 (-)	£0.00 (-)	
3 Understanding Your Risk: Aspergillosis, Steroids, and the Immune System - Aspergillosis Patients & Carers Support		224 (2.95%)	222 (4.23%)	1.01	5s	667 (2.95%)	0.00 (-)	£0.00 (-)	
4 Living with Asthma and Aspergillosis: Understanding the Overlap, the Immune System, and the Right Treatment - Aspergillosis Patients & Carers Support		207 (2.73%)	207 (3.94%)	1.00	1s	621 (2.75%)	0.00 (-)	£0.00 (-)	
5 General Strategies to Reduce Antimicrobial Resistance in Clinical Practice - Aspergillosis Patients & Carers Support		190 (2.5%)	190 (3.62%)	1.00	0s	569 (2.52%)	0.00 (-)	£0.00 (-)	
6 Airway Clearance in Aspergillosis: A Patient Guide - Aspergillosis Patients & Carers Support		188 (2.48%)	178 (3.39%)	1.06	6s	541 (2.39%)	0.00 (-)	£0.00 (-)	
7 Understanding Bronchiectasis, COPD, and Aspergillosis: What Patients Need to Know - Aspergillosis Patients & Carers Support		170 (2.24%)	127 (2.42%)	1.34	25s	440 (1.95%)	0.00 (-)	£0.00 (-)	
8 Dad and the Sneaky Spores - Aspergillosis Patients & Carers Support		146 (1.92%)	139 (2.65%)	1.05	3s	430 (1.9%)	0.00 (-)	£0.00 (-)	
9 Aspergillus Bronchitis: A Patient Guide - Aspergillosis Patients & Carers Support		127 (1.67%)	75 (1.43%)	1.69	33s	321 (1.42%)	0.00 (-)	£0.00 (-)	
10 Biologics and Long Term Side Effects - Aspergillosis Patients & Carers Support		110 (1.45%)	103 (1.96%)	1.07	13s	313 (1.38%)	0.00 (-)	£0.00 (-)	

Fig. 4 – Top ten most-read posts in 2025, showing where interest and engagement are highest.

aspergillosis.org also includes a **healthcare professionals** section with CPA and ABPA guidelines (BTS, ISHAM, ERS) and practical resources for GPs and non-specialists.

Community

Why It Matters

Chronic aspergillosis is rare and often misunderstood. Many patients never meet another person with the condition. Community provides:

- Emotional reassurance and understanding.
- Shared experiences and coping strategies.
- Empowerment to manage care and treatment.

Weekly Support Meetings

We run two informal **Microsoft Teams** meetings each week, with no set agenda — providing a safe space for open conversation. Typically:

- Around 10 regular attendees join most weeks.
- 35 others have joined at least one meeting in 2025.

Newcomers often arrive distressed but leave calmer and more reassured.

Ongoing Support via Telegram

Our 49-member Telegram group offers 24/7 peer support. Many members also attend weekly Teams meetings. Over time, strong bonds have formed, sometimes leading to in-person meet-ups.

When members' health deteriorates, the group responds with compassion. When someone dies, shared grief and memories provide comfort.

Advocacy and Mediation

The CARES team can step in when patients experience difficulties communicating with healthcare teams, helping to restore trust and ensure needs are met.

Awareness

Why Awareness is Key

Chronic pulmonary aspergillosis (CPA) is underdiagnosed and often mismanaged, partly due to symptom overlap with TB, COPD, or bacterial pneumonia. Without clinical suspicion, fungal testing (Aspergillus IgG, culture, or galactomannan) may be overlooked.

Impact of NAC Awareness Work

- **aspergillosis.org**: 106,000 active users from 201 countries between Aug 2024 and Aug 2025 (**Fig. 5**).

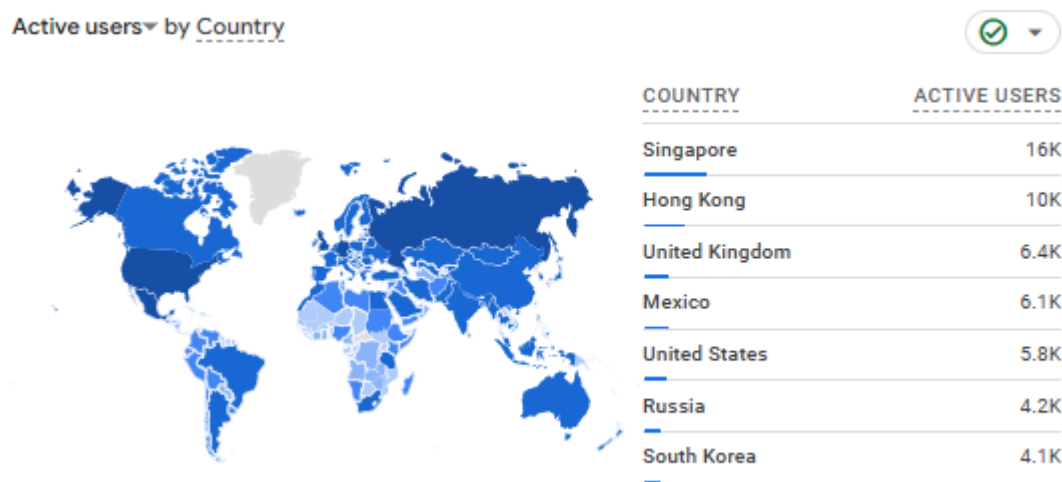


Fig. 5 – Global reach of aspergillosis.org, showing NAC’s worldwide educational influence. NHS England ICD-10 data show a sharp rise in outpatient episodes coded B44.1 (“Other Pulmonary Aspergillosis”) — from ~30 in 2009 to >2,300 in 2023 (**Fig. 6**).

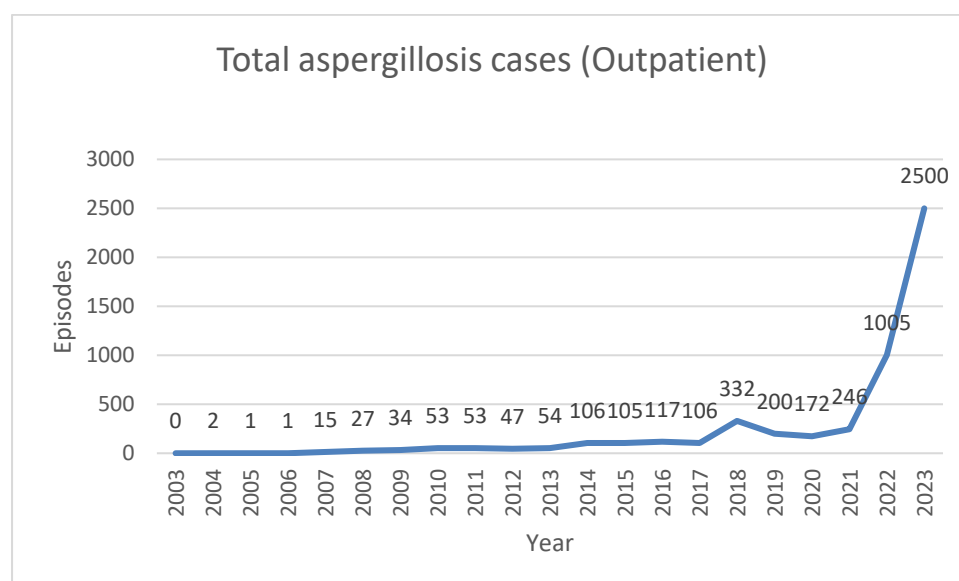


Fig. 6 – B44.1-coded outpatient episodes have risen 75-fold since 2009, reflecting increased diagnosis and awareness.
Referrals to NAC have expanded geographically (see Appendix 3)

Research

Partnership Approach

Progress in rare diseases depends on collaboration between researchers, clinicians, and patients. CARES supports this by:

- Educating patients about research and trials.
- Encouraging participation.
- Ensuring researchers share updates and results with patient communities.

Current Trials Recruiting

- OPERA-T (Opelconazole + other antifungals for refractory IPA)
- Olorofim Aspergillus Infection Study
- INCAS (Interferon-gamma in CPA)
- CAPSULE (CPA impact on health/well-being)
- Rezafungin for CPA with limited treatment options

Education

For Patients and Carers

Knowledge enables patients to:

- Recognise symptom changes.
- Stick to treatment plans.
- Communicate effectively with clinicians.

Monthly Educational Talks

Topics range from biologics to microbiomes. Recordings are available on aspergillosis.org, with 3,884 views in the past year.

For Non-Specialist Clinicians

Educating GPs, nurses, and allied professionals improves:

- Early recognition and diagnosis.
- Timely referrals.
- Patient experience and trust.
- Cost-efficient care by reducing delays and misdiagnoses.

Professional Engagement

- Annual BTS meeting
- Newsletter

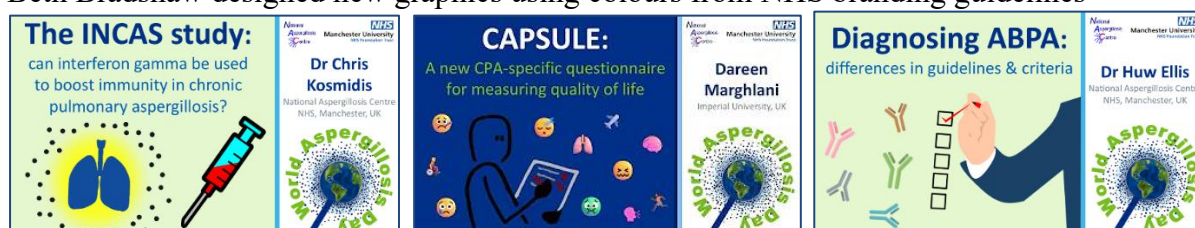
- *Filling the Gaps* – dedicated resource hub for healthcare professionals

12 Raising public awareness and educational outreach

This year's WAD meeting was held on 1st Feb via Microsoft Teams. Talks were based around two themes of key interest in our support groups (see tables below). Recordings are available to watch on-demand on our YouTube channel:

<https://www.youtube.com/@nationalaspergillosiscentr4264/videos>

Beth Bradshaw designed new graphics using colours from NHS branding guidelines



Why did I get CPA?	
Every person breathes in thousands of <i>Aspergillus</i> spores every day, but only those with risk factors such as COPD or subtle immune deficiencies develop CPA.	
Chris Kosmidis (NAC)	The INCAS trial: IFN γ for CPA
Margherita Bertuzzi (MFIG)	How does COPD weaken lungs against <i>Aspergillus</i> ?
Beth Bradshaw (NAC)	Storming the castle: why don't <i>Aspergillus</i> spores infect everyone?
Rita Oladele (U of Lagos)	Experiences from a resource-limited setting

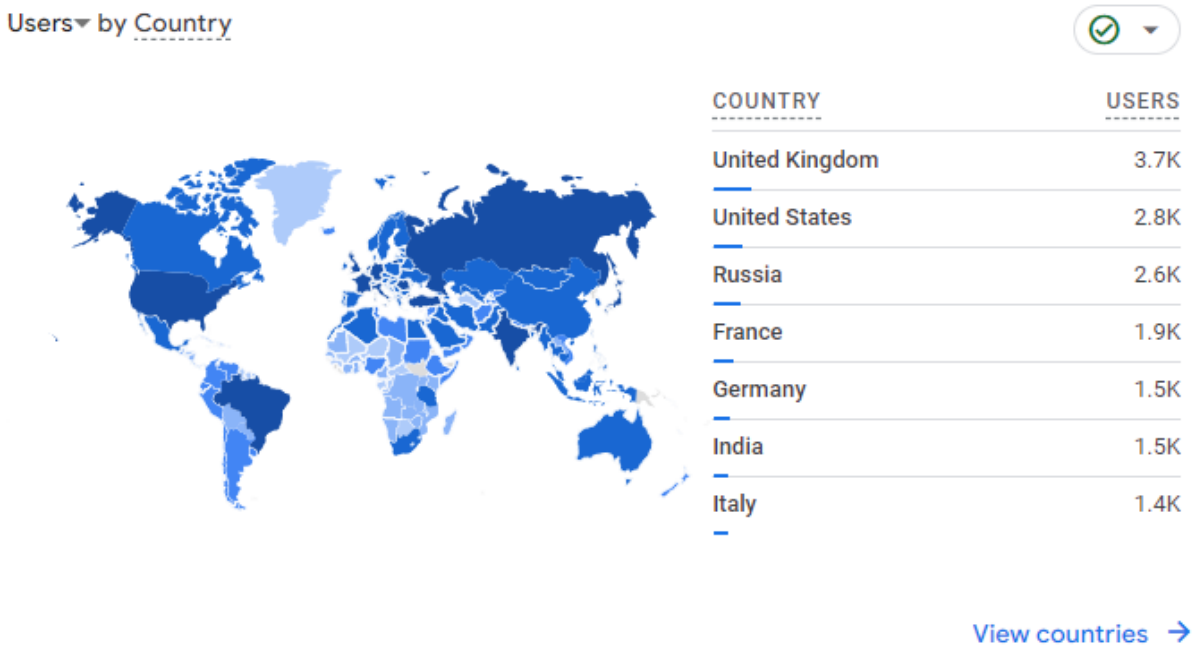
Quality of life (QoL)	
For many chronic patients, QoL factors are at least as important to their experience as the results of scans and blood tests.	
Dareen Marghlani (Imperial)	CAPSULE: a new CPA-specific QoL tool
Graham Atherton (NAC)	Why QoL matters & what NAC provides
Lisa McNeill (Aspergillosis Trust)	Who are the Aspergillosis Trust & what do they do?
Huw Ellis (NAC)	Diagnosing ABPA: differences in guidelines & criteria
Patient story: Mick	CPA
Patient story: Marcella	ABPA

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.



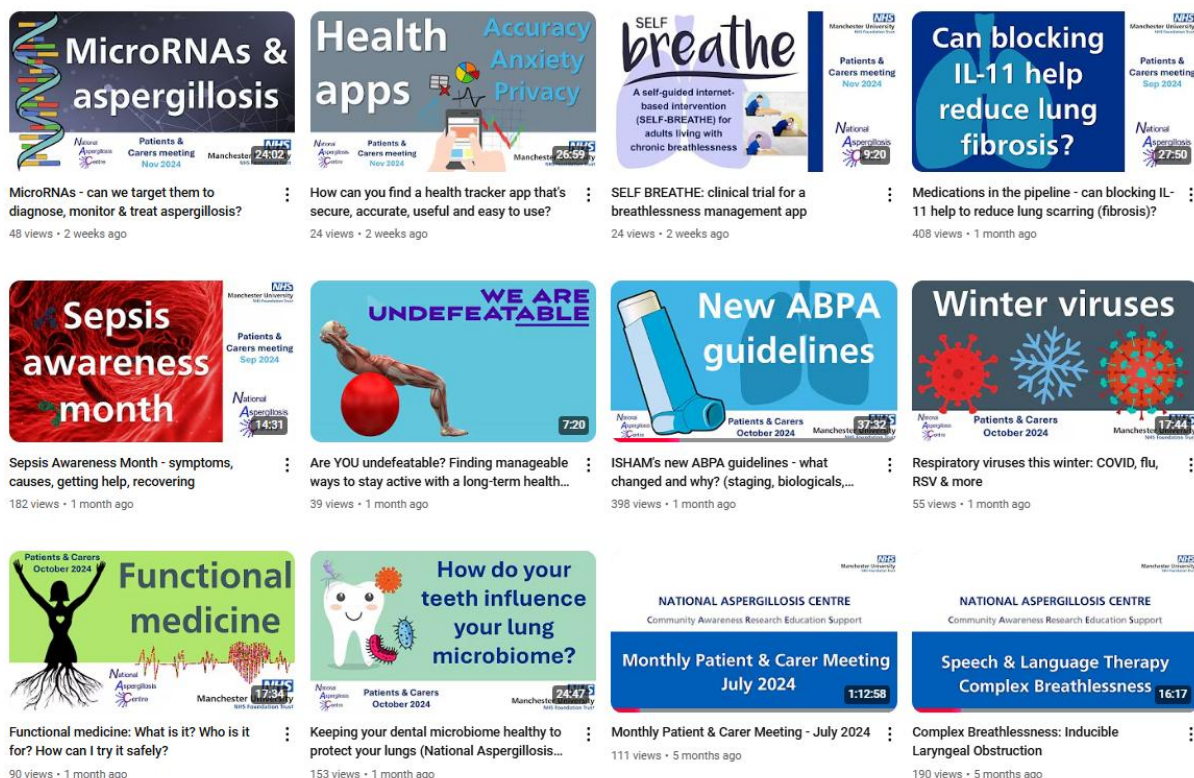
Map shows the numbers of people accessing aspergillosis.org over the last month (July 2024). The website is available in multiple languages. People from 191 countries have visited since July 2023.

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



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 and the content was updated in September 2025.

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.

NAC CARES – Impact at a Glance (2024–25)

Expert Support

- 3,000+ members in private Facebook support group; 1,306 active weekly.
- 49 members in 24/7 confidential Telegram group.
- 640+ articles published on aspergillosis.org; updated most days.

Community

- Two weekly online support meetings; ~10 regular attendees plus 35 occasional in 2025.
- Strong peer bonds formed; some members meet in person.
- CARES team mediates with NHS clinicians when needed.

Awareness

- aspergillosis.org – 106,000 active users from 201 countries (Aug 2024–Aug 2025).
- B44.1-coded outpatient episodes rose from ~30 in 2009 to >2,300 in 2023 (75-fold increase).
- Referrals to NAC increased from 131 (2018–19) to 631 (2024–25) with wider national reach.

Research

- 5 active clinical trials recruiting (including OPERA-T, Olorofim, INCAS, CAPSULE, Rezafungin).

- CARES connects patients to research opportunities and shares trial updates.

Education

- Monthly educational talks on topics from biologics to microbiomes; 3,884 views of recordings in past year.
- Resources for GPs, nurses, and allied health professionals via *Filling the Gaps* and annual BTS meeting.

14. Future Service Developments

The following developments are planned for 2025/2026:

- Improve equitable access to CPA treatment for all patients irrespective of their distance from the NAC.

Equitable access to the NAC for all patients with CPA in England and Scotland is the priority for the coming years. We have been working to raise awareness of CPA among clinicians and the public and have continuously sought to improve the service provided to external consultants via our national MDT. In the coming year we will further audit and enhance the quality of our National MDT discussions by expanding the specialist representation and by actively seeking feedback to improve this service.

- 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 outcome. 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.

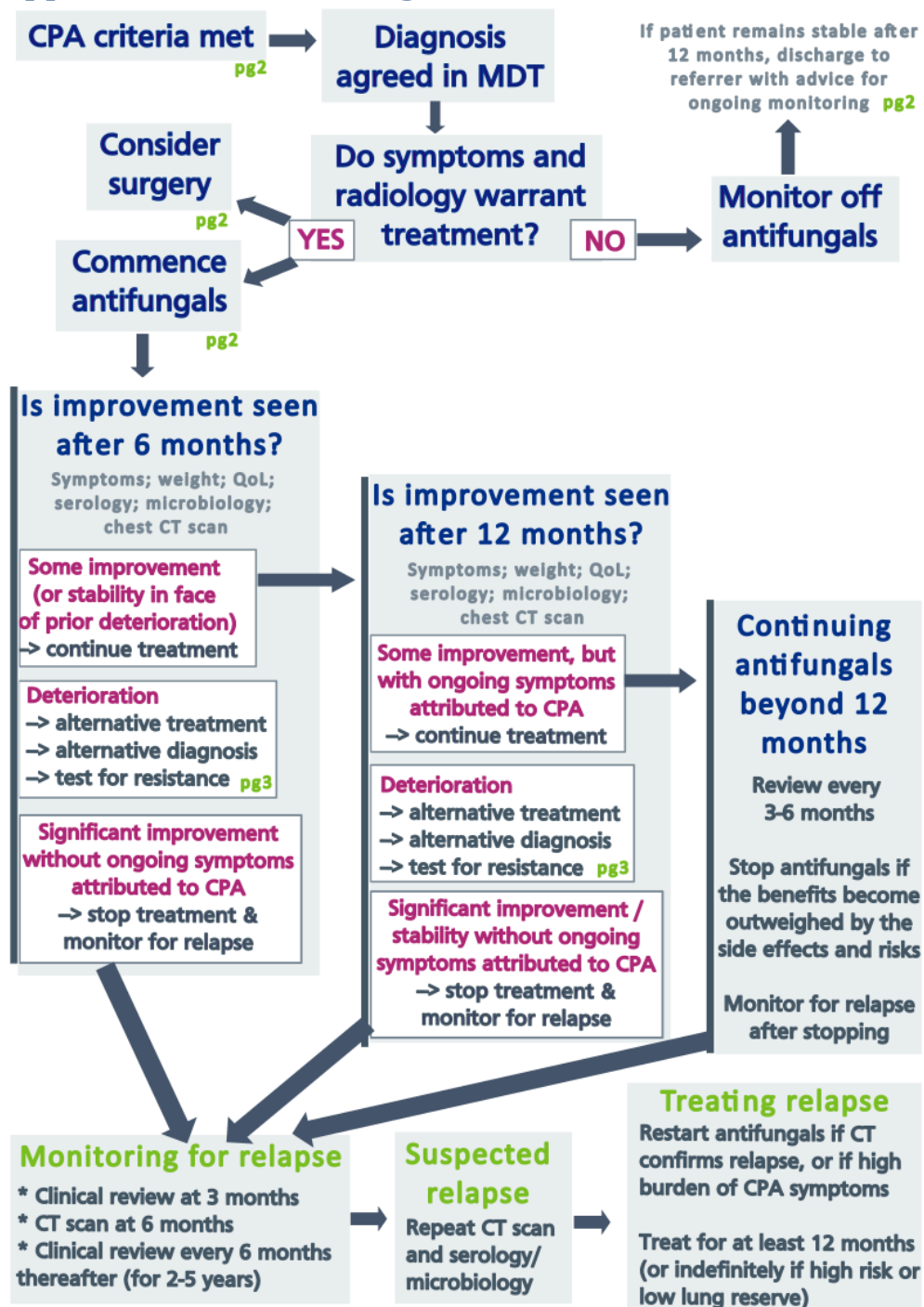
- Further audit and enhance the quality of our National MDT discussions by expanding specialist participation and improving user experience and educational opportunities

The demand for the National Aspergillosis MDT has increased significantly. We will ensure the increased demand will be met by continuous evaluation and auditing of the service, by formalising the terms of reference, by standardising the minutes and outcome process and by actively seeking feedback by participants.

- Continue to explore new treatment approaches in CPA via research while encouraging patient engagement.

The NAC hosts the only clinical trial of immunotherapy in CPA globally, and is the main site for the multicentre clinical trial of the novel antifungal rezafungin in CPA. We will continue to explore new avenues for improved treatments in CPA via clinical trial design of by collecting and analysing existing treatment outcome data.

Appendix 1 Treatment algorithm for CPA



Appendix 2 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

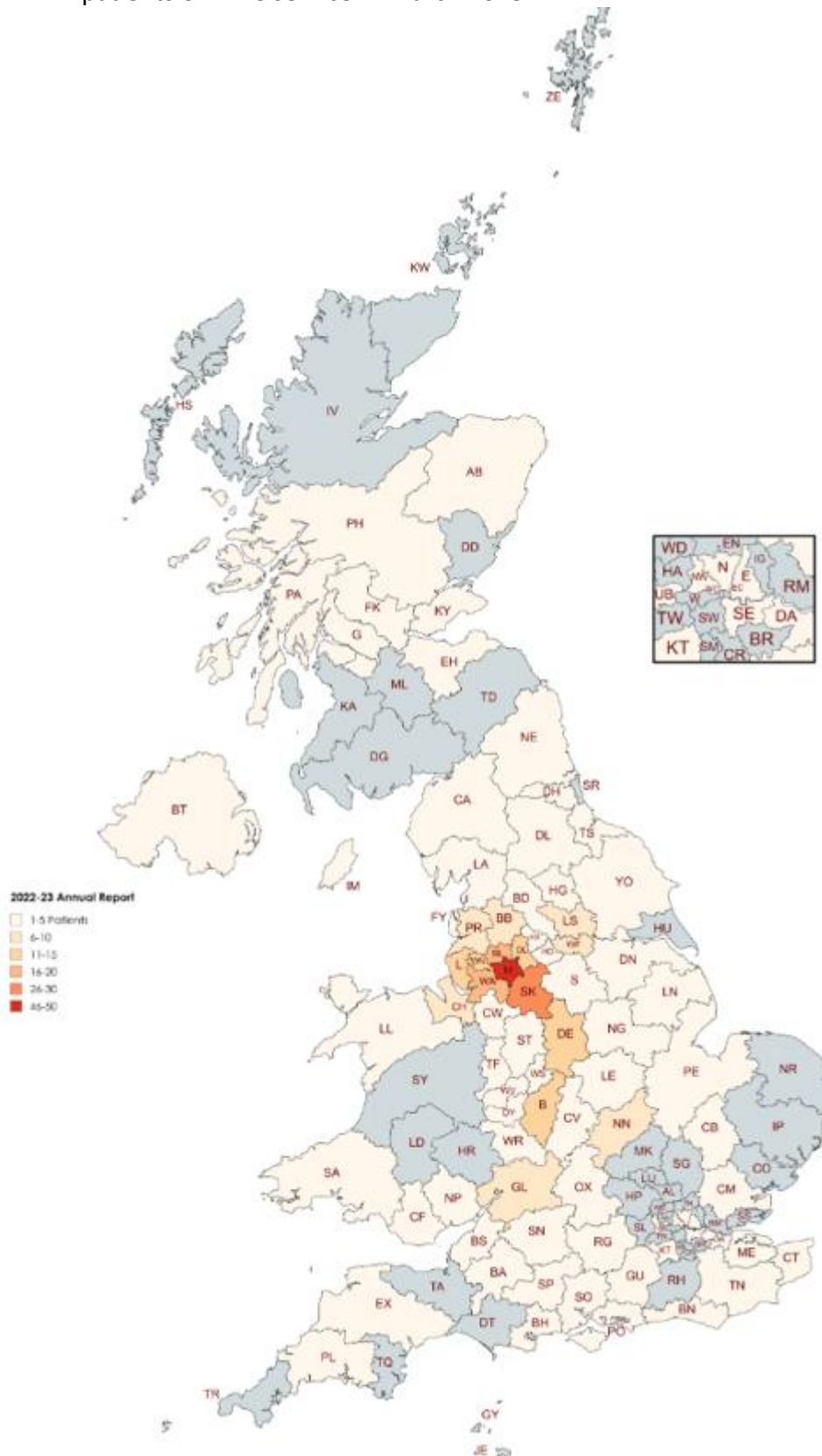
- Significant impairment of respiratory function, sufficient to impair activities of daily living, but ambulant and/or
- Concurrent anti-mycobacterial treatment and/or
- Failed or developed toxicity to itraconazole capsules and
- No evidence of azole antifungal resistance

Stage 3

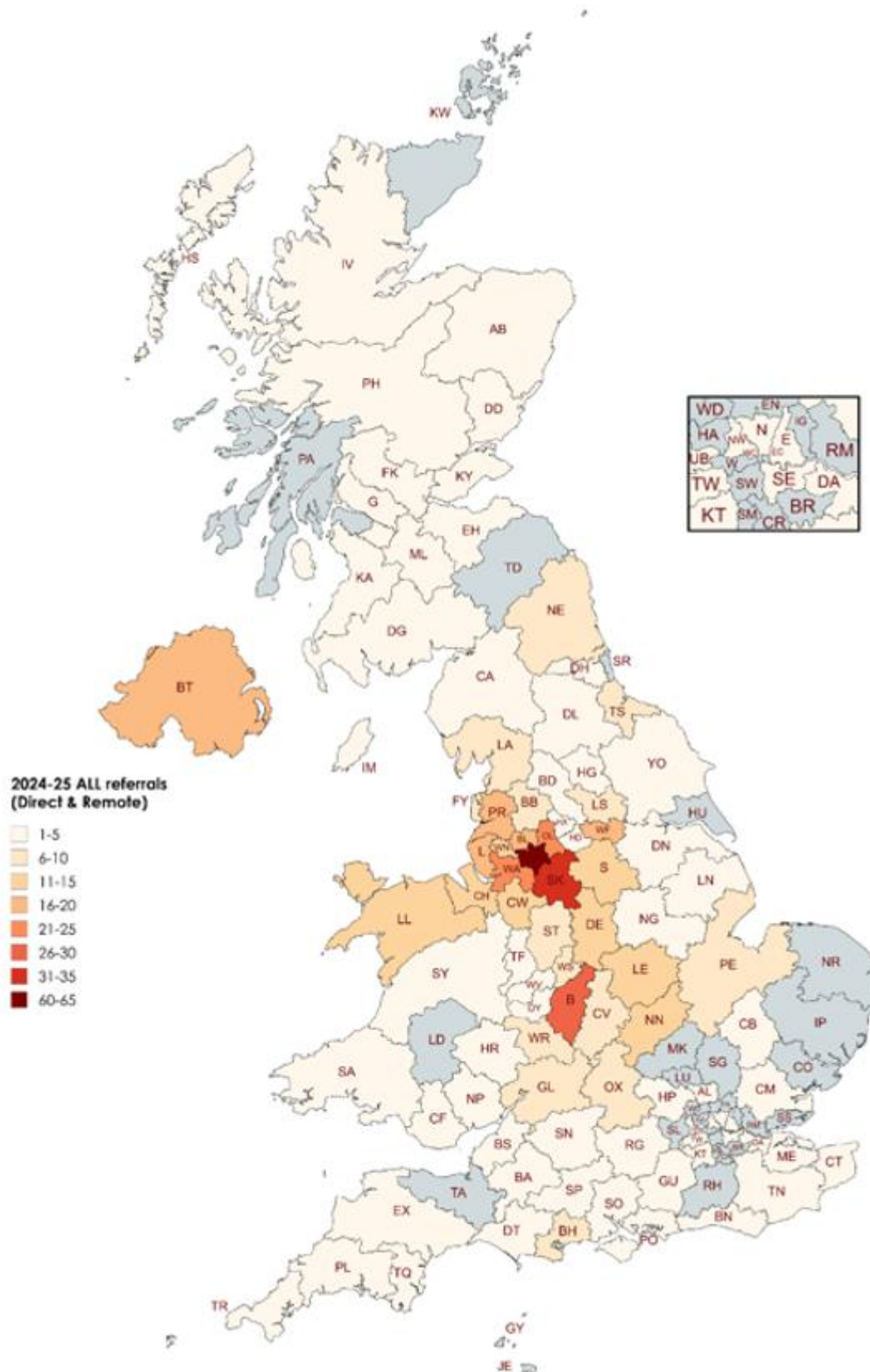
- Antifungal azole resistance documented and/or
- Long term nebulised or IV antibiotic treatment required (bronchiectasis, Pseudomonas colonisation) and/or
- Wheelchair bound and/or
- HIV infected and/or
- Severe hepatic or renal disease

Appendix 3 Geographical location of patients attending NAC

Graph 1. All patients on NAC service in March 2023



Graph 2. Patients seen at NAC and/or discussed via National MDT 2024/2025



Appendix 4. Clinicians discussed CPA cases in the National CPA MDT from the following regions in 24/25:

Row Labels	Count of Ceremonial County
Angus	1
Ayrshire	1
Buckinghamshire	1
Cambridgeshire	1
Cheshire	7
Cumbria	1
Denbighshire	5
Derbyshire	1
Devon	1
Dorset	1
Greater London	1
Greater Manchester	11
Hampshire	2
Herefordshire	1
Kent	2
Lanarkshire	1
Lancashire	5
Leicestershire	4
Northern Ireland	5
Oxfordshire	3
Perth and Kinross	1
Shropshire	2
South Yorkshire	5
Staffordshire	1
Surrey	1
Teesside	2
Tyne and Wear	3
Warwickshire	3
West Midlands	9
West Yorkshire	4
Wiltshire	1
Grand Total	87

Appendix 5. Publications

Clinical trials:

- INCAS: <https://clinicaltrials.gov/study/NCT05653193>
- CAPSULE: www.youtube.com/watch?v=9uqJgXmIbQQ

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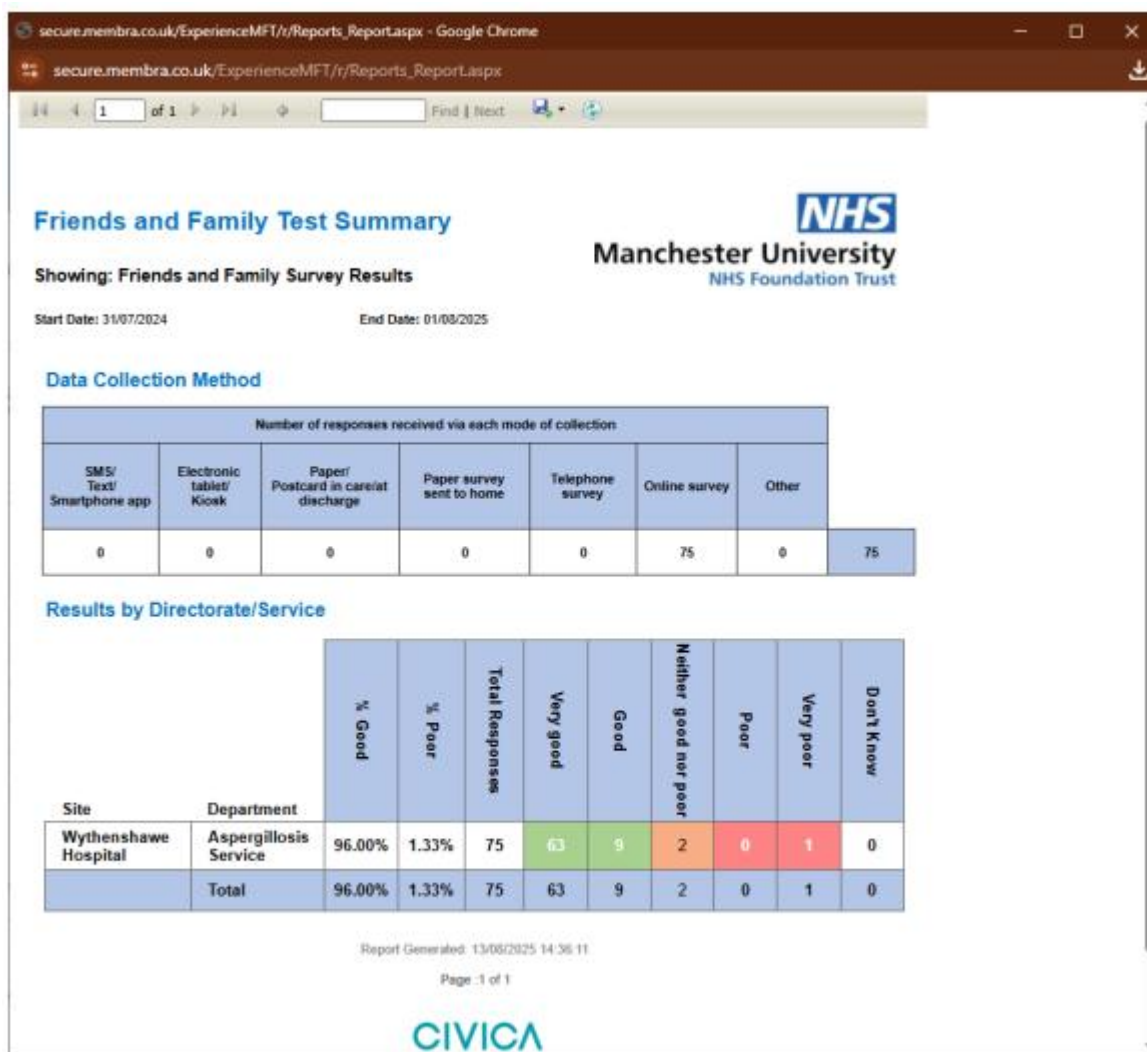
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Appendix 6. Patient Survey Results



AC FFT Q3 & Q4 – Summary of Themes and Example Quotes

This table summarises patient responses to: Q3: 'Please can you tell us why you gave your answer?' Q4: 'Please tell us about anything that we could have done better.' It groups responses into key themes with representative quotes.

Theme What is Working Well (Q3) What Could be Improved (Q4)

Staff professionalism & “Staff were polite, caring, mega informative... a — empathy fantastic asset to the team.” “Made me feel respected and cared for, never rushed.”

Efficiency & timeliness “Appointment was on time, sometimes even early.” “Seen before appointment time and dealt with quickly.” “Stick to agreed phone call times – earlier calls can disrupt patient schedules.”

Communication clarity “Everything explained in plain English.” “Clear plan to move forward left me reassured.” “Better updates on delays during clinics.” “Provide post-visit summaries to reduce stress.”

Continuity of care “Seeing the same doctor again made me feel fortunate and confident.” “Consistency in seeing the same consultant avoids repeating history and saves time.”

Access to results & follow-

up “MyMFT gives results fast – amazing service.” “Follow-up calls give reassurance.”
“Ensure lab results are included in letters.”

Coordination between

services — “Have shared medical record visible on screen between Trusts.” “Better liaison between NAC and local hospitals.”

Environment & patient

experience “Made me feel comfortable and at ease from start to finish.” “Friendly, smiley, lovely people.” “Parking is difficult.” “Clinic felt a bit disjointed – explain what’s happening.”

Use of technology “Video appointments worked well and were easy to connect to.” “Use clearer phone lines; avoid noisy environments.” “Video calls preferred over phone for complex discussions.”

NAC Annual Patient Survey 2025 – Insights Summary

Summary of key themes and findings from the 2025 NAC Annual Patient Survey, based on 55 patient responses. The feedback covers appointments, information, shared care, research, and overall experience.

Headline Stats

- 55 total responses
- Optional open-text feedback across 5 core areas
- Majority of comments were positive, highlighting professional, caring service

Key Strengths

- Professionalism, empathy, and expertise of NAC staff repeatedly praised.
- Specialist nurses and follow-up contact described as 'outstanding'.
- Patients value reassurance from follow-up calls and rapid responses.
- NAC communications seen as efficient and clear.
- Strong willingness to participate in research activities.
- Weekly peer support calls appreciated for reducing isolation and sharing experiences.

Areas for Improvement

- Some patients experienced delays of over 2 hours for scheduled phone calls.
- Desire for greater continuity – seeing the same doctor at each visit.
- Integration with local teams can be inconsistent; some patients feel abandoned locally.
- Slow exchange of results and scans between hospitals.
- Limited access to services for those far from Manchester.
- Need for non-digital information routes for digitally excluded patients.
- More detailed explanations of test results requested.

Recommendations

- Allocate patients to a consistent clinical team to improve continuity of care.
- Expand video MDT meetings with local services to improve joint care and result sharing.
- Introduce scheduled call time slots to reduce patient waiting frustrations.
- Provide alternative information formats for patients not online.
- Offer remote or regional participation in research to reduce travel barriers.
- Ensure all test results are explained clearly in patient-friendly language.