NHS Manchester University NHS Foundation Trust

National Aspergillosis Centre

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

NHS National Commissioning Group - Highly Specialised Services

Chronic Pulmonary Aspergillosis National Service

The National Aspergillosis Centre

Annual Report 2022-2023

Contents

1. Annual Service Overview and Highlights

This report covers the fifteenth 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).

As we have emerged from the pandemic, we have adapted our work in several ways taking advantage of the available opportunities such as the evolution of remote consultations and the new paperless electronic patient records system in our Trust. We have had to embrace changes and ensure we are able to deliver continued excellence in patient care and experience. Our team has continued to show remarkable teamwork adaptability and innovation throughout the year.

From the 1st of August 2023 MFT established an Infectious Diseases Managed Single Service (ID MSS). The MSS consists of Infectious Diseases NMGH, Infectious Diseases WTWA, The NAC, GUM NMGH & OPAT WTWA. The aim of the ID MSS was to create a single service with further dedicated support, this has led to the creation of a new MSS Clinical Director post & a newly established & dedicated operational management structure, consisting of a Directorate Manager, Assistant Directorate Manager & Support Managers. This has given the services within the MSS direct access to a management team who are actively working on the wider evolution of the MSS & all services within the MSS.

The ethos of MSSs within MFT is that the joining together of University Hospitals South Manchester (UHSM), North Manchester General Hospital (NMGH) and Central Manchester University Hospitals Foundation Trust (CMFT) into Manchester University Hospitals Foundation Trust (MFT) has provided the canvas for creating Managed Single Services across relevant specialties. This way, patients from any MFT locality can expect to have services that are consistent, available, and equitable across different locations and best practice is shared across the MFT Group. There are many services across MFT that are separately managed and provided. Part of the benefit to bringing different hospitals together under the MFT banner is to combine best practice across specialties under MSSs. Different hospitals in the MFT group are taking leadership for various Managed Single Services. For Infectious Diseases, the Managed Single Service means bringing together the two current Infectious Diseases teams at North Manchester General Hospital (NMGH) and Wythenshawe Hospital (WTWA), into one single team with a single management structure and line of accountability under NMGH.

Following the completion of the process of creation of a Managed Single Service (MSS) for Infectious Diseases for Manchester University NHS Foundation Trust (MFT), the NAC will remain part of the Infectious Diseases service, which has delivered this work since establishment of the NAC in 2009, and will be under the governance structure of the ID MSS. Dr Caroline Baxter has stepped down from the role of Clinical Director and Dr Chris Kosmidis has been appointed as interim Clinical Director.

A total of 72 new patients from England and Scotland (plus a further 3 patients from Wales) were assessed at the NAC and diagnosed with CPA between 1st April 2022 and 31st March 2023. This was an increase from 49 in 2021-2022. A total of 167 new patients were referred and assessed for all forms of aspergillosis. The numbers of new CPA cases have increased likely due to a gradual increase in clinical activity in primary and secondary care post-pandemic. We are on track to return to numbers pre-pandemic (we had 104 new CPA patients in 2019/2020).

At the end of March 2023, we had 282 patients from England and Scotland on service. Thirty-three 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 44 deaths, a number similar to 2021-2022.

We have maintained our out-patient follow up activity using an evolving hybrid of video consultations, telephone consultations and face to face appointments. The number of face-to-face appointments has gradually increased: we saw 39% of patients face to face in July 2023 compared to 27% in February 2022. We aim to further increase the proportion of patients attending face-to-face, taking into account patient safety and satisfaction.

The main patient outcome we monitor is response after 6 months of antifungal treatment. We monitor this by assessing clinical response, radiological response on a chest CT scan, Aspergillus serology and a Quality-of-Life score (St George's Respiratory Questionnaire). We performed 40 such assessments: of these, 72% had a successful trial and they continued the antifungal. Seven (17%) had to stop therapy early due to side effects, four (10%) failed the trial and alternative treatment plans were put in place, and one (2%) died during the six-month trial. The proportion of use of various antifungals (itraconazole, voriconazole, posaconazole, isavuconazole, micafungin, amphotericin B) has remained stable.

Average waiting time for a new patient appointment was 7.0 weeks (range, 0-13 weeks). 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.

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

Our CARES team (Community, Awareness, Research, Education, Support) continues to support our patients as we emerge from the pandemic. The team have provided support to patients via several platforms including telegram group communication, monthly educational meetings, weekly social support meetings, health and wellbeing meetings and our quarterly newsletter. The team have moved from Zoom to Teams meetings in 2023. We have continued to seek patient feedback. We continue to see significant activity through our social media channels (Facebook, Twitter and LinkedIn). We additionally have taken a new focus on our patient and carers website which is growing in usage. In order to support patients better, the CARES team utilises MyMFT, an integral part of our Trust's new electronic patient record 'Hive' powered by Epic. MyMFT is the patient portal giving access to their own health records, appointments, and telehealth. We have continued to raise public awareness and educational outreach via World Aspergillosis Day 2022, social media, attending international conferences, clinician education throughout the UK and the development of a new MIMS primary care module.

The NHS Mycology Reference Centre Manchester (MRCM) provides the high-level diagnostic mycology service that is essential for the long-term management of patients with complicated fungal disease such as CPA. The MRCM has UKAS accreditation and both the MRCM and the NAC have European Confederation of Medical Mycology centre of excellence diamond award status. The laboratory is the largest mycology laboratory in Europe with a strong performance in turnaround time, critical results reporting in 1-hour, clinical audits, publications, and international representation. The MRCM has been at the forefront of diagnostic developments for Aspergillosis in the last decade, with pyrosequencing to determine azole resistance, high volume fungal sputum culture (a technique that increases the likelihood of detection of aspergillus is 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 16 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). The team delivers educational lectures and seminars nationally and internationally.

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

2. Clinical Service

2.1 Clinical Service Overview

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

Our face-to-face appointment ratio is increasing: 39% in 2023 vs 27% in February 2022, vs 16% in February 2021. 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.

On-going long-term management continues to include:

- evaluation of symptoms, quality of life impact and response to medication

- monitoring of antifungal drug levels and side effects

-establishing homecare medication delivery direct to the patient every 2 months

- withdrawing medication when there is no effectiveness as per our agreed clinical pathways

- liaison with the referring local team and GP to treat co-morbidities and organise necessary tests and delivery of treatment close to home whenever possible

- referral to thoracic surgery or interventional radiology as needed

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

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

Initial clinical assessment includes a full clinical and medication history, Aspergillus blood and sputum tests, lung function, radiological imaging, and an assessment of immune status. Baseline quality of life assessments, weight and MRC breathlessness scores are documented. Patients are provided with written information about their disease, the support available and contacts details of the team. When indicated, patients are also seen by a dedicated specialist physiotherapist for chest clearance and breathing control and at patient request, further tailored information such as exercise programmes. We follow a clear diagnostic algorithm to ensure consistent quality of care for all patients. All new CPA diagnoses are discussed and ratified in our weekly MDT meeting.

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

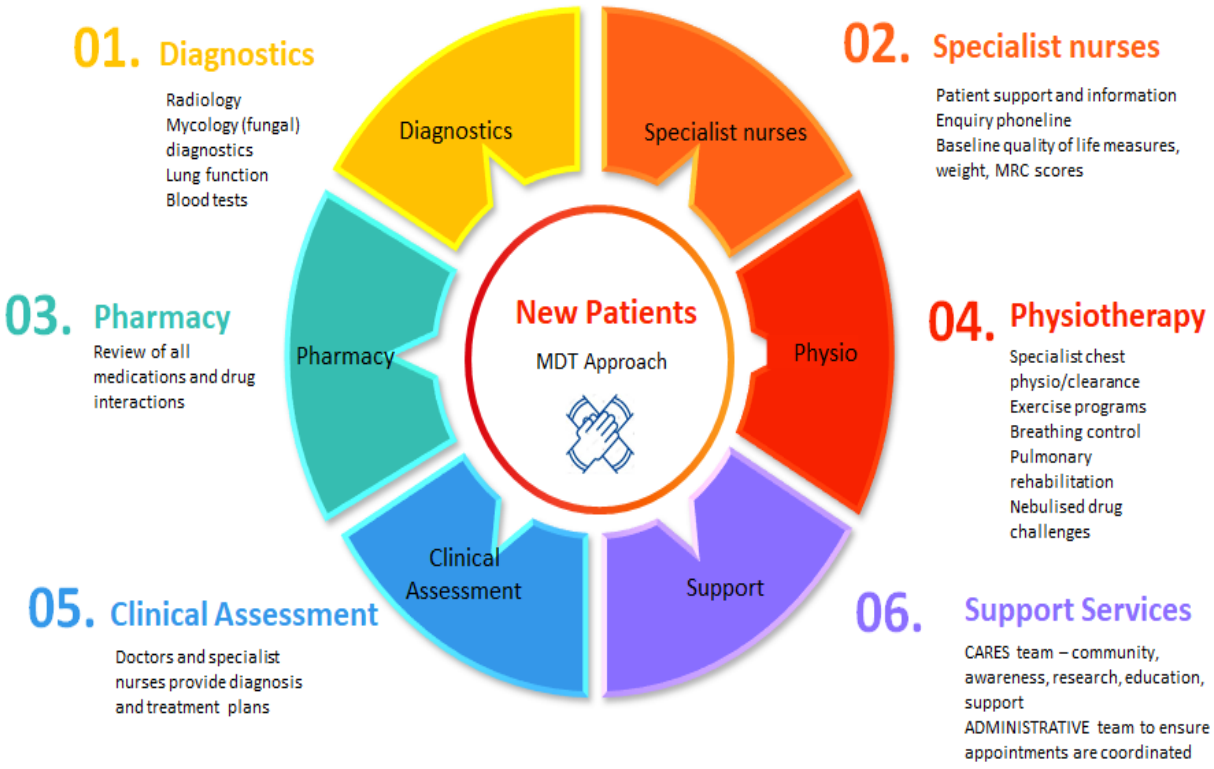
the years our OPAT team has accumulated significant experience in the administration of antifungals in the community.

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

This report details the outcomes over the time period 1st April 2022 to 31st March 2023.

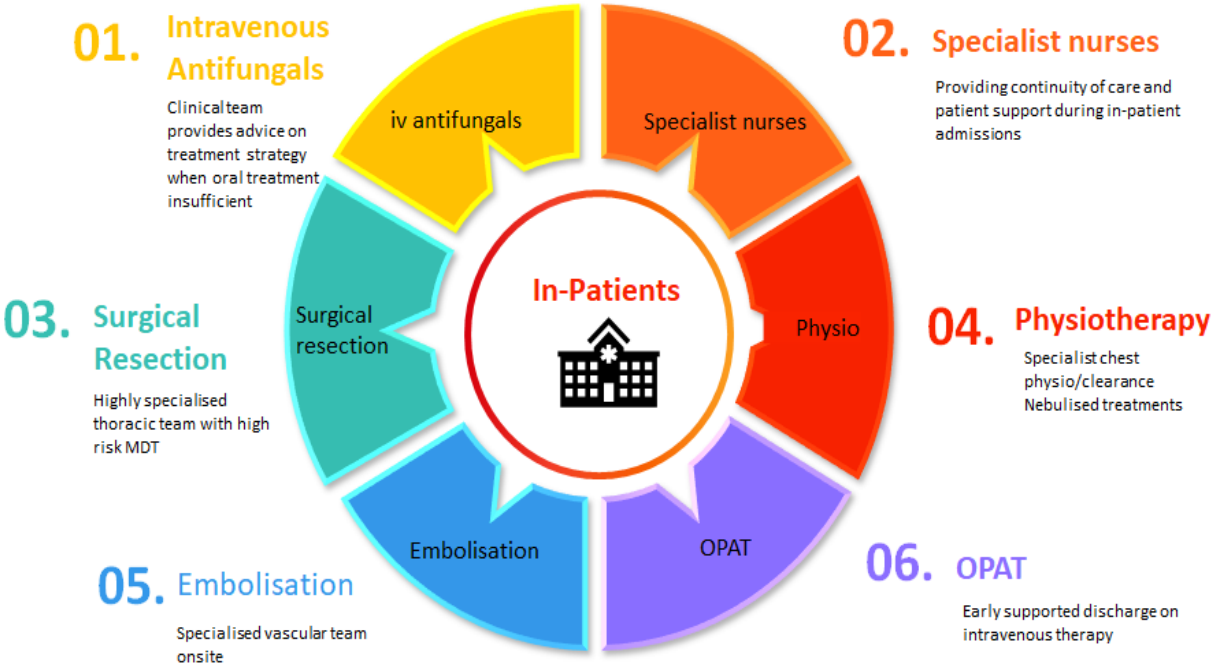
Schematic diagrams of NAC services

NEW PATIENT SERVICES



FOLLOW UP SERVICES

IN-PATIENT SERVICES



2.2 Workforce infrastructure and sustainability

Clinical and administrative personnel

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

Dr Chris Kosmidis, Consultant in Infectious Diseases (3 PAs)
Dr Gianluca Grana, Consultant in Infectious Diseases (2.5 PAs)
Dr Rohit Bazaz, Consultant in Infectious Diseases (2.5 PAs)
Dr Giorgio Calisti, Consultant in Infectious Diseases (2.5 PAs)
Dr Manuela Barrera, Consultant in Infectious Diseases (2.5 PAs)
Dr Nico Janssen, Consultant in Infectious Diseases (3 PAs)
Dr Chris Eades, Consultant in Infectious Diseases (2.5 PAs)
Dr Riina Richardson, Honorary Consultant in Mycology
Mrs Christine Harris, NAC manager (100%)
Mrs Jenny White, Lead Specialist Nurse (85%)
Miss Niamh Duffy, Specialist Nurse (50%)
Mrs Lincy Cyriac, Specialist Nurse (50%)
Ms Deborah Kennedy, Specialist Nurse (10%)
Miss Rochelle Baron, Specialist Nurse (10%)
Mrs Smitha James, Specialist Nurse (10%)
Ms Lindsey Caudwell, Band 3 HCA (100%)
Mr Philip Langridge, Senior Specialist Physiotherapist (100%)
Ms Mairead Hughes, Specialist Physiotherapist (50%)
Dr Admire Murongazvombo, Clinical Fellow (30%)
Dr Burak Berke Su, Clinical Fellow (30%)
Dr Mahmoud Achira, Clinical Fellow (30%)
Dr Eleri Jackson, Clinical Education Fellow (30%)
Dr Neetu Adhikaree, 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, Senior Information Technology Architect and Patient engagement (100%)
Mrs Lauren Amphlett, Communications Specialist (100%)
Dr Elizabeth Bradshaw, Medical Writer and Web Manager (100%)
Ms Carmel Marshall, B5 Infectious Diseases and NAC Directorate Support Manager (50%)
Ms Anna Mikolajczak, B3 Waiting List Clerk (50%)
Ms Letitia Blake B3 Administration and secretarial support (50%)
Vacant (from 29th May 2023) B2 Administration and secretarial support (50%)
Ms 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 2022/2023 are shown below:

Activity Measure	M01	M02	M03	M04	M05	M06	M07	M08	M09	M10	M11	M12	YTD
	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	
Referrals	13	13	16	21	10	18	10	17	9	14	11	15	167
New Patients Testing	6	6	6	8	4	8	2	6	6	6	4	10	72
Outpatient Follow up attendances	92	102	103	117	82	64	59	66	68	51	84	128	1016
Caseload - Band 1	68	68	70	69	69	68	70	69	70	77	75	74	74
Caseload - Band 2	227	226	220	216	213	211	206	202	202	198	198	199	199
Caseload - Band 3	8	8	8	9	9	9	9	9	10	10	10	9	9
Occupied Bed Days	0	0	0	0	0	0	0	0	0	0	0	10	10
Inpatient Discharges	0	0	0	0	0	0	0	0	0	0	0	1	1
iv Homecare	0	20	0	0	0	0	0	14	0	0	0	0	34
Surgical Resection	0	0	1	0	0	0	0	0	0	0	1	0	2
Embolisations	0	0	0	0	0	0	0	0	0	0	1	1	2
Patient Death	6	1	3	4	2	4	5	6	2	2	4	5	44
Discharge from service	2	1	5	3	4	2	2	1	1	5	3	4	33

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

Referrals

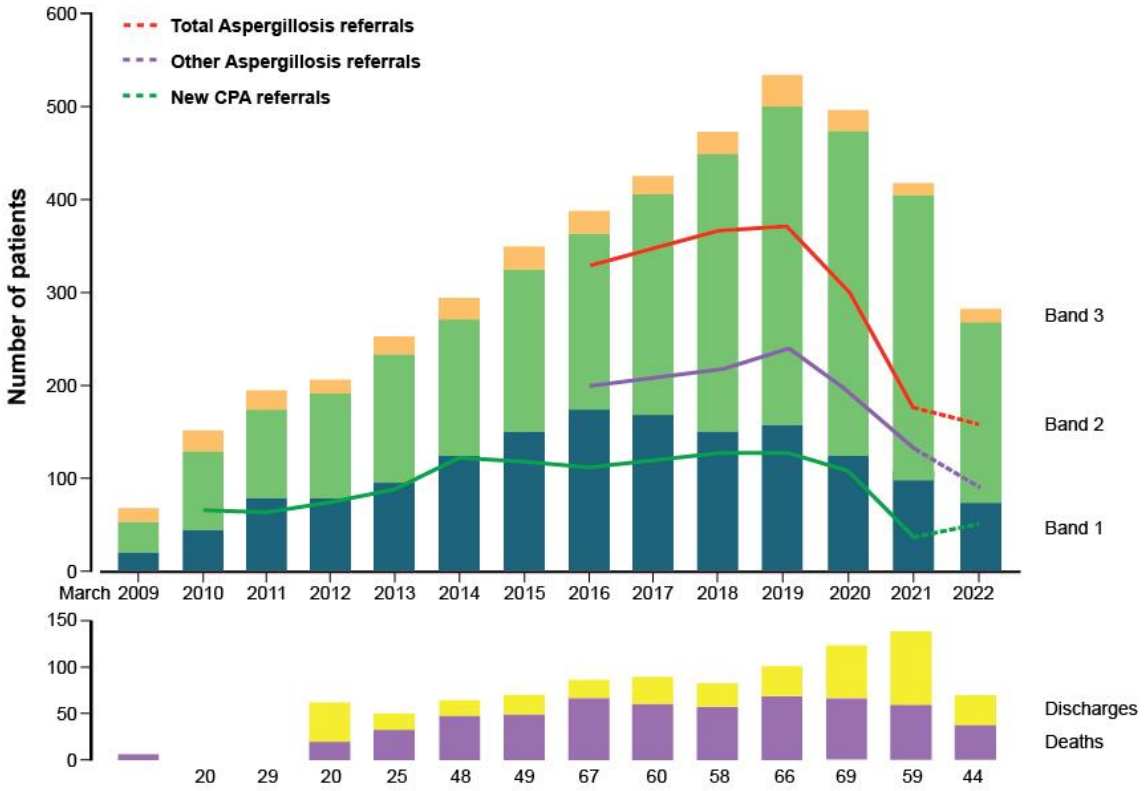
There was a total of 167 referrals from England and Scotland during the year 2022 to 2023 that underwent clinic consultation by the service for all forms of Aspergillosis. 72 (43%) of these received a confirmed diagnosis of CPA. There were a further 6 patients from Wales of which 3 were confirmed with CPA. All new patients are discussed at our weekly MDT to ensure a unified agreed diagnosis and management plan. The number of new CPA patients has increased compared to 2021/2022 (from 49 to 72); in addition, the proportion of referrals with a diagnosis of CPA increased this year from 27% to 43%. The number of new CPA patients referred has increased year-on-year for the first time since the pandemic. Therefore, we are gradually seeing a return to 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 51 such external cases in the MDT in 2022/2023. 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 52 cases. This is down from 55 in 2022/2021. 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 have started reporting our MDT and written advice and guidance data in our monthly NHSE data.

NAC Referrals and Caseload 2009 to 2022



Out-patient waiting times

The mean time from referral to clinic consultation was 7.0 weeks (range 0-13 weeks) (Appendix 2). The mean time from referral to clinic was higher (8.3 weeks) for the 3 months after the implementation of our new paperless EPR, from September to December 2022, indicating possible issues with appointments being booked or sent on time, but was reduced to 6.8 weeks thereafter (see Appendix 2).

Geographical location

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

Patient Caseload

At the end of March 2023, 282 patients from England and Scotland were on service with an additional 10 patients from Wales, 2 from Northern Ireland, 2 from the Isle of Man and 1 from overseas. Patients with CPA are banded according to disease severity, impact on functional ability and presence of antifungal resistance (Appendix 1).

During 2022/23 there was a reduction in patient numbers. (See NAC referrals and caseload, above). This reduction is due to increased rates of discharge from service the previous years. Death rates have not increased. The increased rates of discharge are due to regular assessment of the ongoing need for follow up; patients with no active CPA who are not benefitting from our further input are discharged from service. However, many remain under the care of our team but outside the commissioned service. As the relapse rate of CPA is around 20%, some patients may re-enter the service.

There were 44 patient deaths which is a stable proportion compared to previous years: 14% of patients died in 2022-23, 11% in 2021-22, 12% in 2020-21 and 13% in 2019-20. There were 33 discharges from service which is lower than the 3 previous years (75 in 2021/22, 61 in 2002/21, 56 in 2019/20). The number of patients discharged from service has been increasing due to robust MDT discussions about the need for on-going care of patients stable off therapy as well as a clinical move away from lifelong medication.

Out-patient face-to-face appointments are increasing as we emerge from the pandemic. Proportions of face-to-face, video and telephone consultations in selected intervals in the last 3 years are shown below:

	Face-to-face	Video	telephone
February 2021	**25 (16%)**	60	83
February 2022	**33 (27%)**	18	73
July 2023	**42 (39%)**	12	54

There was a reduction in the clinic capacities across the Trust during the initial implementation of the new paperless EPR but full capacity was restored after a few weeks. We currently see 42 patients in our weekly CPA clinic. There are at least 2 consultants at any time in the clinic, along with trainee doctors, Specialist Nurses, a Healthcare Assistant and a Physiotherapist.

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

<u>In-Patient Hospital Activity</u>

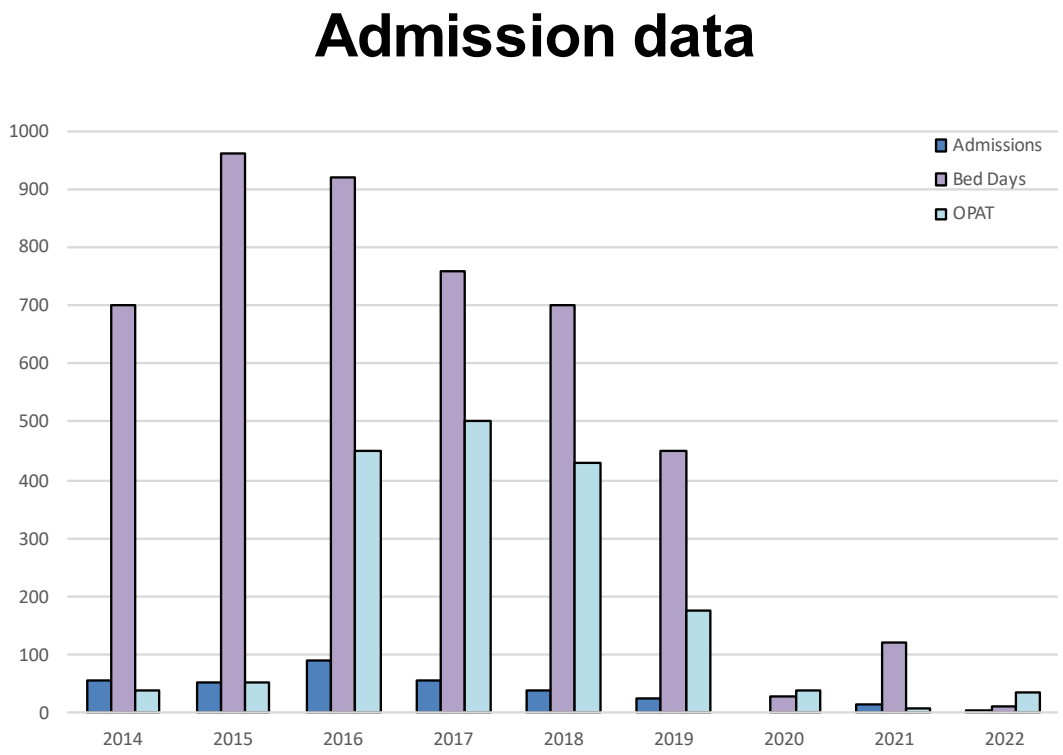
We have seen a reduction in in-patient activity this year to 10 bed days. However, there were 11 patients who were admitted in their local hospitals for CPA-related issues. The reduction in in-patient activity is the result of coordination with our OPAT service to enable IV antifungals in the community, 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. Of these patients, three had embolization and one had surgery, and 7 had intravenous antifungals. The numbers of patients who underwent embolization and surgical resection in the NAC is shown below.

	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21	2021-22	2022-23
Embolisation	16	15	13	9	13	6	20	12	13	6	3	7	2
Surgical resection	4	3	2	3	4	4	3	6	4	6	1	6	2

OPAT Activity

The outpatient parenteral antimicrobial therapy (OPAT) team provides intravenous therapy and clinical monitoring for patients deemed suitable to receive their therapy in the community, avoiding a hospital in-patient admission. During the financial year 2022/23 we had a total of 34 OPAT patient days, an increase over the previous year (see below). One patient had Amphotericin B (20 days) and one patient had micafungin (14 days). Our team has also managed to coordinate and advise on IV therapy at distant hospitals for 7 patients; 3 had caspofungin, 3 had micafungin and one had amphotericin B.



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. We collect quality of life data (St George's respiratory questionnaire) at the beginning of the drug trial and at 6 months. We aim to incorporate quality of life assessment in our new EPR to enhance clinical decisions and patient experience. Details of antifungal trials and their clinical outcome data this year can be found in Appendix 6. In summary:

- 11 patients completed a 6-month trial of voriconazole during 2022/23. Eight benefited from treatment and continued treatment. Two stopped due to side effects and one died two months after starting treatment. An additional 12 patients have been started on voriconazole but the 6-month assessment is pending.
- 17 patients completed a 6-month trial of posaconazole during 2022/23. Ten benefited from treatment. Of these, 8 continued posaconazole whereas 2 completed the therapy at 6 months. Five stopped due to side effects and two did not benefit from treatment and posaconazole was stopped. An additional 4 patients have been started on posaconazole but the 6-month assessment is pending.
- 13 patients completed a 6-month trial of isavuconazole during 2022/23. Eleven benefited from treatment. Of these 10 continued isavuconazole whereas one patient completed the treatment at 6 months. Two patients did not benefit from treatment and isavuconazole was stopped. An additional 2 patients have been started on isavuconazole but the 6-month assessment is pending.

Overall success of antifungal therapy was 72%, up from 60% in 2021/22. Overall, 17% had to stop therapy early due to side effects, 10% failed the trial and alternative treatment plans were put in place, and one patient (2%) died during the six-month trial.
All antifungal trial outcomes are discussed within our MDT. The outcomes for this year and the previous 2 years are shown in the tables below.

Trials of posaconazole/isavuconazole/voriconazole 2022-2023

Outcomes	Posaconazole		Isavuconazole		Voriconazole	
		%		%		%
Success	10	58	11	85	8	73
Failure	2	11	2	15	0	0
Death/ADR	5	29	0	0	3	27
Total	**17**		**13**		**11**	
Pending	**4**		**2**		**12**	

Trials of posaconazole/isavuconazole/voriconazole 2021-2022

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

Trials of posaconazole/isavuconazole/voriconazole 2020-2021

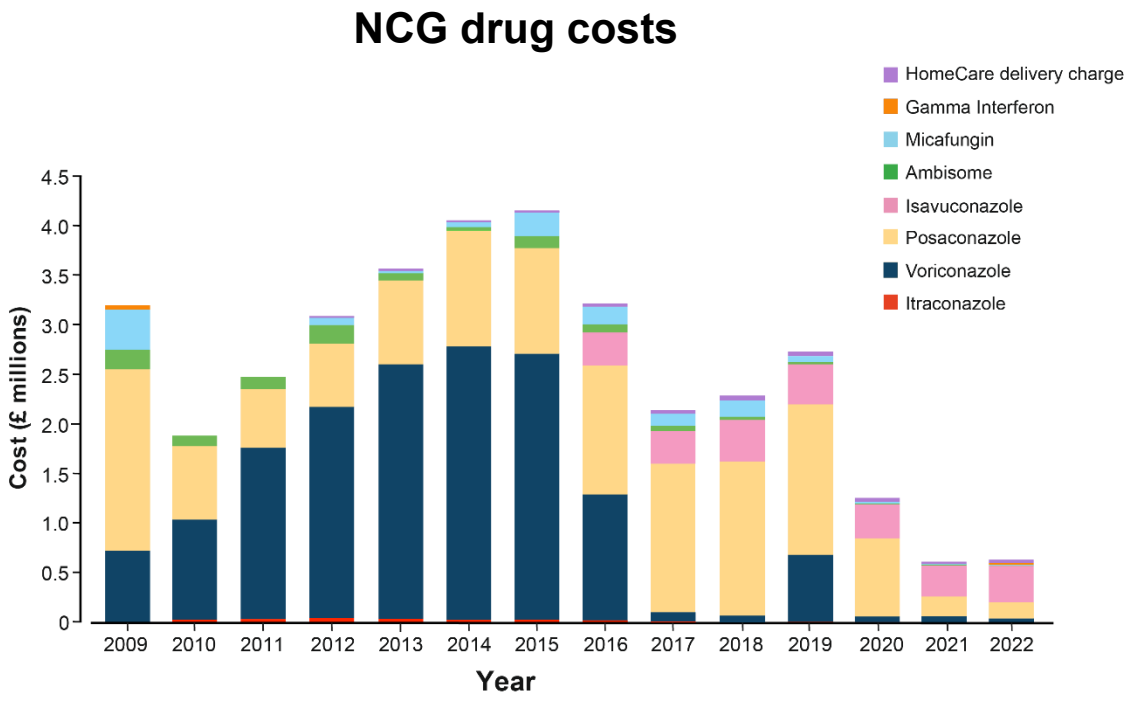
Outcomes	Posaconazole		Isavuconazole		Voriconazole	
		%		%		%
Success	9	64	5	71	7	88
Failure	5	36	2	29	0	0
Death	0		0		1	12
Total	14		7		8	
Pending	**5**		**2**		**6**	

2.5 Intravenous antifungal therapy

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

2.6 Antifungal prescribing and expenditure

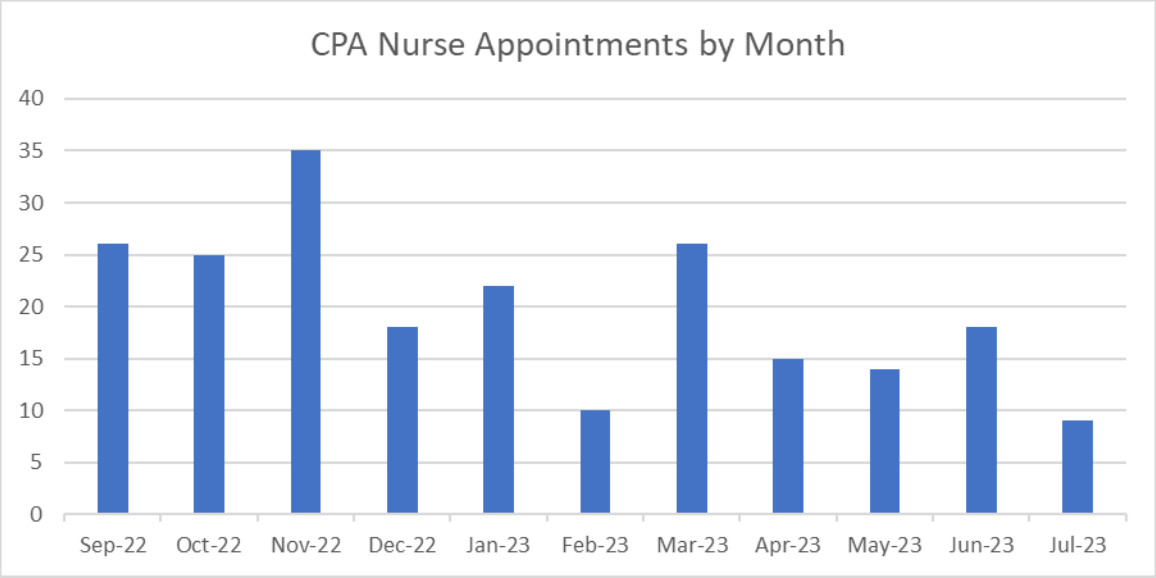
Antifungal expenditure has fallen significantly since Posaconazole came off patent and generic brands become more widely available in 2021. This is similar to 2017 when voriconazole came off patent. Isavuconazole costs have remained stable since the introduction into our commissioning pathway in 2016. As can be seen below, drug costs have remained comparable to 2021/22.



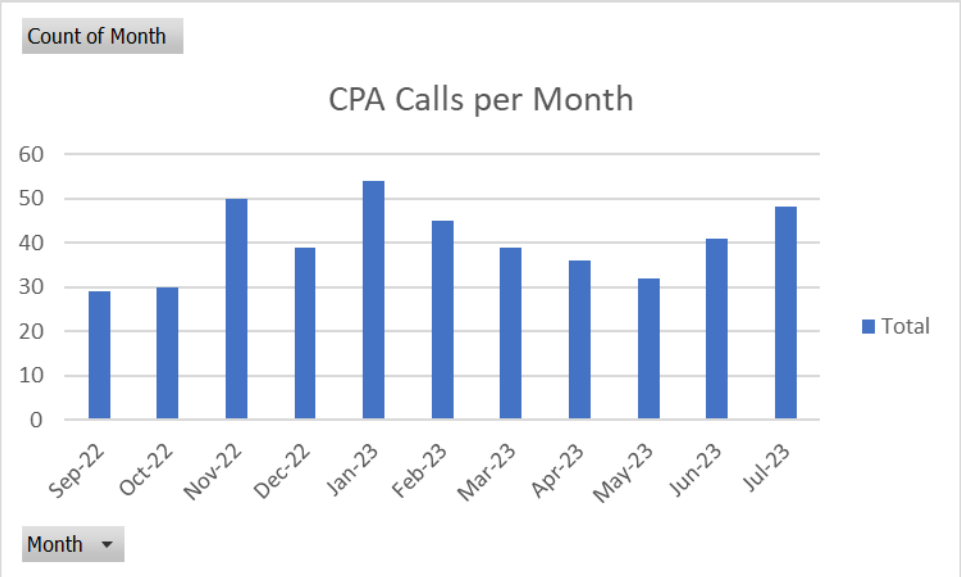
3. Specialist Nurse Service

The NAC has a team of highly specialised and dedicated nurses. The service currently has 3 specialist nurses who provide a wide range of clinical and patient support services. During the last year the service has continued to:

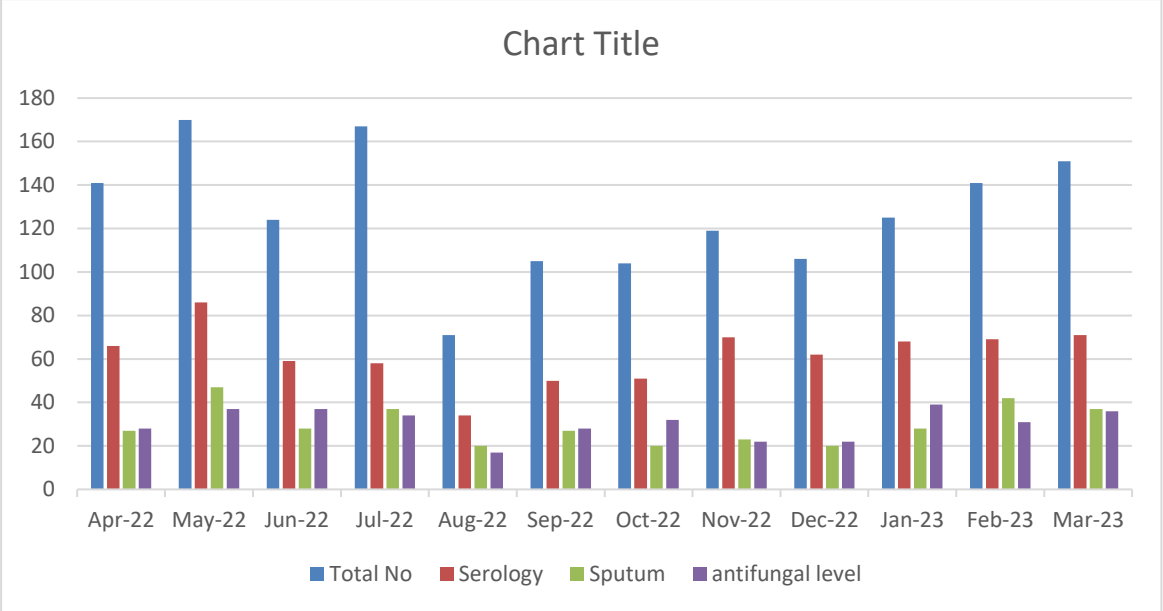
- Independently review patients in outpatient clinics via telephone, video and face-to-face appointments. Numbers of patients who had nurse consultations below:



- Answer patient enquiries and provide support via a patient phone line available 5 days a week. Number of phone calls on CPA related issues below:



- 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. More than 100 samples per month are collected, processed and interpreted in this way (see below):



- Senior nurse continues to independently prescribe treatment.
- All the nurses have completed an advanced communication course.
- Senior Healthcare Support Worker (HCSW) supports patients in the outpatient clinic appointments, in particular new patient appointments.
- Senior HCSW completes quality of life questionnaire (St George's score) with patients over the telephone.
- The nursing team have received very positive feedback from the surveys sent out post clinic consultations, the team will aim to maintain this standard, feedback included below:

My consultation with (Nurse) Jenny was very uplifting & informative and had a "light touch" about it, so I felt very much that my contribution to the discussion was welcomed. I'm very grateful for the excellent care I continue to receive from the NAC clinicians, via Wythenshawe Hospital.

Excellent consultation, very thorough and really listened.

She did a good job in explaining and reassured me what the next steps will be thank you.

I thank the nurse for being very friendly and helpful.

I was so impressed with my consultation, Jenny was so welcoming, asked all the right questions and listened carefully to my replies. I never felt hurried and also felt that my concerns about certain medications were taken on board and understood. I left the hospital with a great sense of positivity and feeling very strongly that I'm in safe hands at the NAC.

Very grateful to Jenny and all the team at Wythenshawe. Dedicated staff, I feel in good hands. Please pass on thanks to her and to Dr Caroline Baxter. I always feel that I have been listened to and that we are jointly trying to keep me in as good health as possible. We are lucky to have such a good resource in the North West.

Excellent consultation. Jenny had clearly read the history and the technology worked well.

Both Jenny and the supporting nurse, Carol were excellent. I wasn't rushed and they took a lot of care and attention to my case and the plan going forward.

Fantastic as always, thank you for your help.
Everyone always listens are very helpful, professional, friendly, all makes the world of difference. Thank you all xxxxx

No other than think ms L Cyriak was very thorough and very caring, hope I get her next visit.

Very grateful for the care of all staff, it means such a lot . always at other end of phone when needed, helpful, friendly and professional. I am at last doing ok , thanks to help of you all. thank you all so much.
I feel that Lincy, listened to our every concern we had with father and advised all the way. Outstanding compassion and care.

I can but thank the team for all of the care and support offered to not only my father but to us all as a family. Without them we would feel extremely alone. Well done.

The NAC nursing service challenges in 2022-2023:

- 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.
- Merging services with NMGH, with managerial and governance changes.

Developments for the nursing team 2023-2024:

- With the implementation of the new electronic system, we are collecting data regarding telephone calls the nurses receive and the nature of the calls, we are hoping this will show trends in enquiries and possibly show areas that we need to focus on or improve.
- Attend and engage with the highly specialised services national network for specialist nurses and AHPs.
- Aim for 2 of the nurses to commence Non-Medical Prescriber course.
- Work with NAC medical director to explore alternative patient symptom questionnaire to aid objective measures of effective antifungal treatment.
- Explore research opportunities.

4. Physiotherapy Service

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

Referrals to physio can come from the patients themselves, occur ad hoc from face-to-face clinic consultations, arise after clinics/ MDT discussion, or from physiotherapist triage of those attending clinics face to face.

In 2022/23 the physiotherapy service assessed 131 new patients (118 face to face, 12 by telephone, 1 by video). This is in the context of maternity leave from October 2022 that was not backfilled. Follow up mainly is via telephone.

Service development

We have secured additional long-term clinical space to enhance our in-clinic offer to patients.

We have taken a greater number of physiotherapy students this year for parts of their placement to help consolidate their respiratory skills and to promote the work of the National Aspergillosis Centre. Feedback from these students (BSc and MSc level) has been consistently positive.

Our new electronic patient record, Hive, has enabled us to communicate securely with patients in new ways. Sending patient information electronically regarding their physiotherapy advice is now open for all MFT care-givers to see. It also means that MyMFT users have a resource to call on whenever they need it, and should they lose access to their written advice it is easily sent again by MFT staff. It also has enabled patient initiated follow up for their physiotherapy which in part explains fewer follow up appointments routinely being offered.

The challenges ahead

We are still fathoming the opportunities that Hive presents as well as becoming part of the North Manchester-managed MFT ID service. Maintaining strong connection to our respiratory peers will be essential in the continued delivery of high-quality physiotherapy interventions.

The number of patients that the DNA (Did Not Attend for an outpatient appointment, or for treatment) rate for MyMFT app users is 4.4% compared to the wider MFT rate of 9.7%. This may signal a service equity challenge for those who can't use the app. Once patients are referred to physiotherapy, we are able to work round most barriers to consultation/ communication with our patients but our national catchment area remains a potential barrier to face to face physiotherapy input at Wythenshawe.

As a leader in the care of patients with Aspergillosis we continue to "set the standard" for physiotherapy care of these patients. With the heterogeneity of comorbidities the patients present with, the physiotherapy team have to be ready for anything that comes through our clinics. This is the challenge we strive to rise to and prepare diligently for by engaging with service users and continuing our professional development.

5. Administrative Team

The admin team is made up of a service manager who manages 4 admin staff whose roles are 0.5 FTE dedicated to NAC. The admin team provide support to patients, prospective

patients and other health care professionals. We receive about 40-50 calls a day; the calls vary in nature but cover the following:

- changing appointments
- advice on how to be referred into the service.
- queries on clinical letters or requesting copies.
- transport queries.
- notification from patients they have had local imaging to be imported.

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

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

6. Mycology Reference Centre Manchester

Background to the Mycology Reference Centre

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

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

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

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

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

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

ESCMID COLLABORATIVE CENTRE

European Confederation of Medical Mycology
ECMM
Center of Excellence in Clinical and Laboratory Mycology and Clinical Studies

MRCM MISSION

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

Role and functions

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

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

Service Strategy

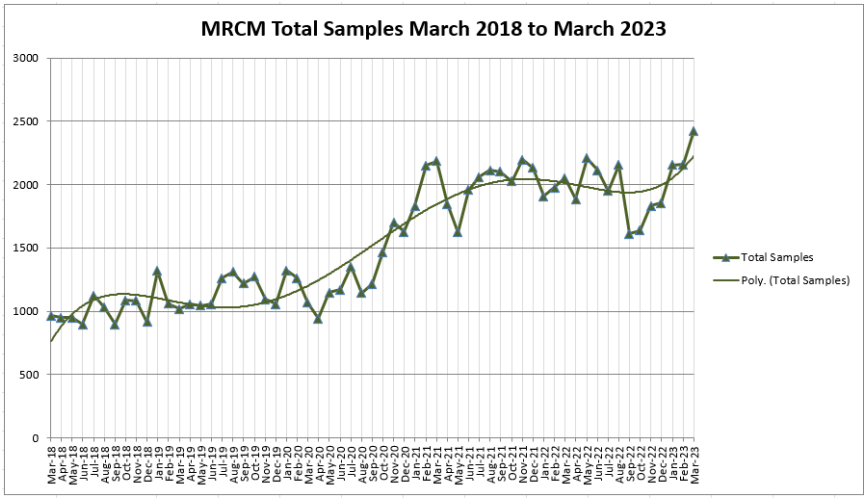
- The MRCM has expanded appropriately to meet the requirements of the National Aspergillosis Centre, with an emphasis on antifungal susceptibility testing and a range of molecular tools. Growth of the MRCM has provided much needed support for NHS research, including clinical trials of new antifungal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

Training, Research and Development

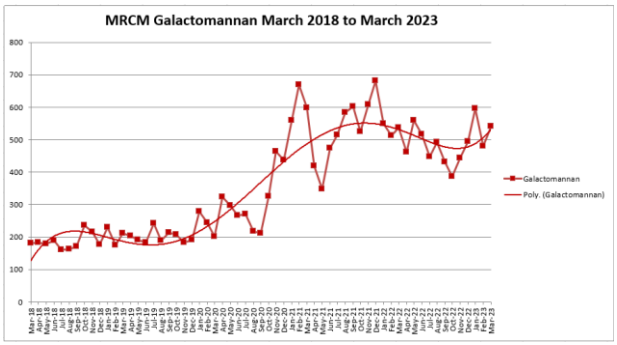
- Provision of clinical mycological training to medical and clinical scientist trainees.
- Contribution to external courses (Institute Pasteur, ESCMID, University of Manchester, University of Leeds, University of Dublin)
- Provision of undergraduate and post-graduate research training and supervision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

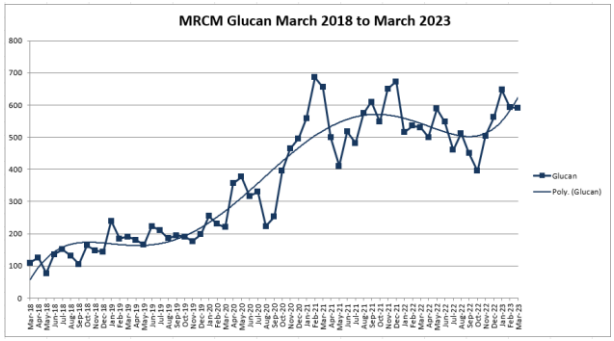
Summary of 2022/23

The MRCM, in its current form, has completed its 14th year of operations. 2022/23 was another challenging yet successful year. There have been numerous developments, initiatives, and continued growth in its portfolio of tests and activities. MRCM total activity for 2022/23 was approximately 24,000 specimens – maintaining the high activity levels seen in 2021/22.



The activity of fungal biomarker testing, both galactomannan and glucan, remained high. There was evidence of a decrease across the summer and early autumn months of 2022, with an increase again observed during winter. Overall, test volume of galactomannan and glucan increased by ~130% and ~160%, respectively compared with pre-Covid-19 activity (2019/20).





Over the last five years, our activity has increased by 103% whilst our staffing by 49%. The MRCM team comprises a total of 24 staff including a Consultant Medical Mycologist, a Consultant ClinicalScientist, three Clinical Scientists, scientific, quality 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.

In addition to the increase in the clinical sample workload, there has been a significant increase in the environmental mould surveillance workload from the police and the Coroner.

Key Achievements

- Successful in maintaining UKAS ISO 15189 accreditation. Confirmation of clearance of findings and maintaining accreditation in August 2022.
- Highly Commended in the Royal College of Pathologists Achievement Awards 2022
- Continued to consistently meet all KPIs.
- Continued to deliver a centralised fungal biomarker service - galactomannan and glucan testing - within Greater Manchester, with turnaround times consistently exceeded for both tests.
- Significant input into the development and successful implementation of the new HIVE Beaker LIMS system to meet the needs of MRCM and users.
- Successful implementation of a DLM wide QMS system.
- Increased staffing – appointed three new members of staff: one band 7 scientist, one band 4 technologist and one band 2 medical laboratory assistant.
- 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.
- Agreement reached with the Manchester Medical Microbiology Partnership (MMMP) for MRCM to become the mycology reference laboratory for MMMP from the beginning of April 2023.
- Improvement and modernisation of the laboratory infrastructure including successful implementation of MALDI-ToF, and a new extraction robot.
- Continued contribution to the International Fungal PCR Initiative to improve the sensitivity, specificity, and quality of fungal molecular testing, including publications.
- Continuation as a EUCAST testing laboratory for UK NEQAS for Microbiology Antifungal Susceptibility Scheme.
- Numerous clinical and laboratory audits presented at national and international meetings and written up as publications:
    - Aspergillosis in COVID19 patients studies in collaboration with the ECMM-CAPA Study Group (published in Clin Microb Infect, Microbiol Spectrum and J Clin Microbiol)
    - Novel molecular mechanisms for antifungal resistance in Aspergillus (published in Antimicrobiol Agents Chemother)
    - ESCMID multicentre audit on risk factors for intra-abdominal candidiasis in intensive care units (published in Infect Dis Ther)
    - ESCMM multicentre audit on candidaemia guideline adherence predicting survival of candidemia (published in Lancet)
    - Audit on incidence of candidaemia in prolonged venovenous extracorporeal membrane oxygenation (published in J Hosp Infect)
    - Audit on the impact of BASHH guidelines on recurrent vulvovaginal candidasis on patient outcomes (published in J Fungi).
- Successful funding for staff's further education including:
    - BTEC Level 4 Diploma in Healthcare Science Apprenticeship
    - Upskilling funding from Health Education England - grants awarded for degree assessments, top-up modules and IBMS registration portfolios.

    - Staff member successfully achieved BA(HONS) Business Management Professional in Health and Social Care
    - Two staff members successfully completed IBMS registration portfolios, achieving HCPC registration.
- Successfully implemented InGenius PCR platform and MALDI-TOF identification platform.
- Successful collaboration with histopathologists and pathologists re fungal diagnostics
- Continued promotion of fungal diagnostics nationwide, including continued expansion of pan-fungal PCR of blood and tissue specimens.

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.
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.

Publishing Activities

- Reporting MRCM audit data on resistance and novel antifungal susceptibilities
- Participation to international audits on CAPA and candidaemia.
- Contributions to national and international guidelines
- Contributions to National Aspergillosis Centre and the Manchester Fungal Infection Group publication output

- RR and MDR are Editors for a number of peer reviewed journals (Journal of Fungi, Medical Mycology, Mycoses)
- Numerous clinical and laboratory audits presented at national and international meetings and written up as publications:
    - Prattes J, et al; ECMM-CAPA Study Group. Risk factors and outcome of pulmonary aspergillosis in critically ill coronavirus disease 2019 patients-a multinational observational study by the European Confederation of Medical Mycology. Clin Microbiol Infect. 2022 Apr;28(4):580-587.
    - White PL, et al; Fungal PCR Initiative. An overview of using fungal DNA for the diagnosis of invasive mycoses. Expert Rev Mol Diagn. 2022 Feb;22(2):169-184.
    - Setianingrum F, et al. A prospective longitudinal study of chronic pulmonary aspergillosis in pulmonary tuberculosis in Indonesia (APICAL). Thorax. 2022 Aug;77(8):821-828
    - Ocansey BK, et al. Improving awareness, diagnosis and management of invasive fungal infections in Ghana: establishment of the Ghana Medical Mycology Society. Med Mycol. 2022 Sep 29;60(9)
    - Cornely et al. The FURI Study: Patient Outcomes After Treatment with Oral Ibrexafungerp Based on Prior Antifungal Therapy and Patient Enrollment Criteria. ECCMID 2022
    - Alexander B et al. Oral Ibrexafungerp Outcomes by Fungal Disease in Patients from 4th Interim Analysis of a Phase 3 Open-label Study (FURI). ECCMID 2022
    - Eades CP et al. The performance of two point-of-care assays for the diagnosis of Aspergillus-associated pulmonary disease in patients undergoing broncho-alveolar lavage: A real-world evaluation. ECCMID 2022.

Strategic Objectives for 2023/2024

- Continuing to provide an exemplary NHS reference mycology service for the UK and beyond - delivering a service, which is comprehensive, interpretative, timely, accredited and appropriate to user needs
- Maintaining international, national, and local leadership in medical mycology diagnostic services, and training
- Maintaining UKAS ISO 15189 accreditation and the European Centre of Excellence Diamond status
- Maintaining good working relationships with other departments within the Trust, and colleagues in other hospitals, universities, and institutions
- Assuring that all MFT patients have access to the same high standard mycology diagnostics in a timely manner including provision of support for the diagnosis of COVID-19-associated systemic fungal infections (aspergillosis, candidosis, mucormycosis)
- Continue to contribute to MFT guidelines involving fungal infections and monitoring and managing environmental risk factors from mould exposure
- To continue the development and implementation of the MFT infection strategy
- Maintaining an excellent and close working relationship with MFT Infectious Diseases Department, the National Aspergillosis Centre and other MFT Infection Services and developing these further
- Focus on developing our collaboration with MMMP
- Continue to develop our Environmental Mould Surveillance Service and supporting MFT Infection Prevention and Control team.

- To provide a supportive, caring, safe, appropriate and comfortable working environment which is inspirational and motivating that empowers the team
- Reacting to emerging fungal infections (for example, *Candida auris* in the critical care setting)
- To continue to invest in leadership to ensure a strong management team and clinical leadership
- Focus on staff development, career progression and quality CPD opportunities
- Focus on the MFT research and innovation ambitions, in partnership with the University of Manchester and the European Confederation of Medical Mycology, and by collaborating on clinical trials with Pharmaceutical companies
- To initiate the first phase to introduce next generation sequencing into our diagnostic portfolio – development ongoing, NIHR Manchester Biomedical Research Centre funded, in collaboration with the Manchester Fungal Infection Group
- To maintain our existing arrangements with the University of Manchester. Currently MRCMstaff have either substantive or honorary contracts with the Manchester Fungal Infection Group, Division of Evolution, Infection and Genomics, University of Manchester (five staff members)
- Supporting Patient and Public Engagement activities delivered by the MFT Aspergillosis Communications Team
- Keeping the MRCM website (www.mrcm.org.uk) up to date and continue to be active on professional social media (LinkedIn).

Laboratory and Staff Objectives

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

Quality and IT Objectives

Objective	Achieved by:	How will we know we have succeeded?	How will this be monitored?	Comments
To encourage staff to take an active role within the QMS system, to allow us to remain on track with QMS and maintain our UKAS ISO 15189 accreditation.	• Implementing quality huddles • To provide training on how to undertake quality tasks, including documentation review and completing, addressing, and closing non-conformances	• Documentation review percentage is ≤10% • Non-conformances are addressed and closed within the timeframe documented in MRCM-PR-QU6	• This will be monitored in the laboratory's quarterly quality reports and on the QMS monthly overview working spreadsheet	Recruitment of Band 7 Quality Manager will have oversight of QMS, ensuring training and delegation of QMS tasks occurs
To improve the total (patient to patient) TAT for all MRCM tests within MFT	• Streamlining specimen transportation • Beaker/HIVE	• Audits	• Audits	
To continue to engage with the HIVE EPR programme to optimise Beaker.	• Working with the HIVE analysts to continue to develop a fit for purpose LIMS	• Beaker is functioning to the department's needs.	• This will be monitored by the laboratory's change control process	
Implementation of the new UKAS ISO 15189 2022 standard	• Attending DLM monthly task and finish groups • Attending courses and conferences regarding changes to the standard • Implementing departmental UKAS standard meetings with senior staff to discuss and implement any changes	• Successful accreditation against the new UKAS standard	• Successful accreditation against the new UKAS standard	

Financial Expectations for 2023/2024

- To maintain increased levels of activity and thus secure funding for additional staffing costs, particularly for clinical authorising and advice, and consumable costs:
    - due to increased clinician awareness and rapid TAT, demand for our fungal biomarker service remains high.
- To seek to increase external client income, both clinical and veterinary diagnostics, and environmental services. This is dependent on increased staffing and effective marketing.
- Further external income from providing centralised diagnostic services for clinical trials of new antifungal drugs – Pulmatrix and Pulmocide and other trials now restarted following Covid-19 pandemic.

Anticipated cost pressures

- Continued high activity, especially fungal biomarkers service, from MFT and external sources.
- Under-recovery of external income whilst P2P block payments are in place for Greater Manchester providers throughout 2023/24, and uncertainty over new financial arrangements of system funding.
- Superficial mycology service – negotiations with Integrated Care Boards re pricing tariff
- Inflationary price increases on consumables, kits, and maintenance costs, up to 10% in some cases
- Expected ask for contribution to NAC Communications team for maintaining MRCM website.
- Higher than expected Consultant recharges.

Deliverables for 2023/2024

Target	Milestones	Timelines	Comments
Optimisation of HIVE Beaker LIMS	Optimise software Input into BAU staff training	Ongoing	
Optimisation of Q-pulse	Seek further training to ensure all modules are being used effectively Use of asset module Use of supplier module	Ongoing	
Maintain UKAS ISO 15189 accreditation	QMS monitored via QMS monthly overview working spreadsheet	Ongoing	Full UKAS inspection expected May 2023
Implementation of the new UKAS ISO 15189 2022 standard.	Participate in the Task and Finish groups Perform Gap analysis between both standards	Ongoing Expected date of change 2025	Attend external courses and meetings to further understanding of change
Implementation of MALDI-ToF technology for mould identification	Validation of the test for mould identification	Validation by the end of 2023 Added as ETS to next UKAS assessment	
Introduction of *Aspergillus* qPCR for blood specimens	Submit new test application Validation of the assay Begin offering service	Dependent on New Test Application	Dependent on automated DNA extraction platform
Work towards introduction of Mucorales PCR	Evaluation of existing commercial kits Contribution to FPCRI EQA development	Ongoing	MRCM is a FPCRI member laboratory
Introduction of Evolis platform for the automation of biomarker testing	Start to develop a business case for funding Submit application for new tests Validation of platform and assays Begin offering service	By March 2024	Once funding for platform is secure, funding and application to introduce new mycology diagnostic tests can be submitted
Audit and manage MRCM test demands	Review internal guidelines and audit compliance with these Beaker/HIVE	Ongoing	
Isavuconazole TDM	No equipment required, assay to be performed by Biochemistry Dept, Wythenshawe Hospital Continue discussions with Biochemistry Department	Ongoing	Validation start date dependent on Biochemistry staff availability

Other Aims for 2023/2024

We consistently perform well in our current KPIs (biomarker TATs and rejected specimens), so we will look to add to our KPIs to monitor other aspects of our service

Staffing, Quality, IT

Staffing

- A business case for a containment level 3 responsible person is required to improve the preparedness of the service for next pandemics and to allow processing of all fungal pathogens safely.
- Create a joint IT lead role for the MRCM and other laboratory services – there is a need for a part time person 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.
- Strengthen the medical consultant support for the laboratory to cover the increased number of clinical enquiries.
- Complete the business case for the Environmental Mycology service to be able to respond to the increased workload from the police and the Coroner.
- Funding to be confirmed for a Band 6 Biomedical Scientist post and a Band 3 Medical Laboratory Assistant post.
- Funding to be confirmed for a Band 4 Associate Practitioner post attached to successful completion of Level 4 Healthcare Science apprenticeship.

Quality

- The MRCM has retained their UKAS ISO 15189 accreditation status following a successful surveillance visit in December 2021. We hope to continue to retain accreditation after the full UKAS inspection, which is expected to happen in October 2023.
- 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 our QMS monthly overview working spreadsheet. Monitoring monthly ensures that we maintain our UKAS ISO 15189 accreditation.
- All tests are registered with external quality assurance schemes where applicable and all performance is monitored. There are regular departmental quality meetings.
- There are multidisciplinary and technical/clinical meetings which help to create an informed dedicated team.
- We have structured training programmes and hold IBMS registration training status.
- The development and implementation of DLM wide Q-pulse system has allowed us to implement new ways of working. These new procedures have encouraged all staff to have an active role within the Quality Management System, including completing non-conformances and reviewing documentation.

Information Technology

- Maintain and update, when necessary, the MRCM website for external users, to continue to provide information of tests and guidelines.
- To continue to promote Mycology and MRCM via MRCM Twitter.
- Provide user education via the MRCM website, MRCM Twitter and the GP and hospital newsletters.
- Continue to be involved with the optimisation and development of HIVE Beaker LIMS.
- Continue to be involved with the optimisation and development of the DLM wide Q-pulse.
- To provide external users with electronic reports (NPEx)
- All this will require an IT trained and dedicated person: Create a joint IT lead role for the MRCM and other laboratory services with a need for a part time person to free clinical scientist time for laboratory and quality tasks

SWOT Analysis

Strengths:

- Strong scientific and clinical leadership
- Professional expertise, over 100 years of experience in the field of Medical Mycology, and skills mix of all staff.
- Close working relationship with the Infectious Diseases (ID) service
- Consultant cover for Clinical Lead annual leave in place
- Recognition throughout the UK and Europe, as reflected by UKAS ISO 15189 accreditation and the renewal of award as an ECMM Centre of Excellence in Clinical and Laboratory Mycology and Clinical Studies
- Informative website and marketing platform
- Approaches by UK and US pharma companies to service clinical trials of new antifungals.
- UK strategic influence: recognition by various NHS organisations as a centre of expertise as reflected by invitations to join various advisory group and committees.
- Relationships with wider public health and academic communities
- Providing link between hospital and community
- Partnership with the component departments of the Division of Laboratory Medicine (MFT)
- High quality accommodation with modern facilities and equipment
- Integral part of the Manchester Fungal Infections Group, University of Manchester, and access to a range of molecular platforms and biological imaging facilities
- Active Research and Innovation (R&I) programme
- Strong publication activities
- Molecular expertise
- National reputation for the provision of medical mycology training for all levels of non-medical and medical staff, including University teaching at numerous universities.
- Networking and communication across the global mycological community
- Molecular epidemiology: capacity and expertise to develop typing systems for *Candida* and *Aspergillus* isolates.

- Respected clinical liaison across the UK and globally, as evidenced by invitation to join the ECMM Expert Consultation Service for medical centres around the globe seeking advice when there is no fungal infection consultant available, and to join European-wide audits and clinical trials of new antifungal drugs.
- Multiple opportunities for income generation, with support from the DLM teams
- Good engagement with National Aspergillosis Centre Commissioners
- The EUCAST testing laboratory for UK NEQAS for Microbiology Antifungal Susceptibility Scheme
- The MRCM is the UK's EUCAST collaborative laboratory.
- Test centre for all Fungal PCR Initiative (FPCRI) schemes – fungal PCR for *Aspergillus, Candida, Pneumocystis,* Mucorales and tissue
- Access to the expertise of the National Aspergillosis Centre Communications team and their support with our website.

Weaknesses

- Staff/workload ratio does not allow enough focus on R&I or CPD.
- Scientific and clinical staff using their time to do IT tasks and struggle to do what they should do.
- No full-specification Category Ill containment facility
- Limited resilience in staff numbers, given persistently high activity.
- Limited resilience and lack of contingency plans in case of any space issues.
- Limited resilience re medical consultant time and input.

Opportunities

- Merger of WTWA Infectious Diseases service with the NMGH service: closer working relationships with all MFT ID specialists.
- To become an integral part of the MFT Infection Strategy
- Development of a near patient (point of care) portfolio with the commercial development and introduction of lateral flow devices for fungal antigens and antibodies
- Expansion of molecular services
- Marketing of services to a broader client base
- Evaluation of new diagnostic platforms
- Expansion of training programmes for UK and oversees trainees.
- HIVE electronic patient record system and Beaker LIMS for clearer and faster reporting as well as audit and demand management

Threats

- Lack of focus on R&I due to staff/workload ratio - not attractive to the highly educated and published members of staff.
- Lack of time to attend CPD due to staff/workload ratio - not attractive to the highly motivated and ambitious members of staff.
- Retraction of laboratory space by University of Manchester.
- Lack of dedicated IT Lead
- Challenges in maintaining a high quality fully established medical consultant workforce.

- Challenges in retaining highly dedicated staff with clear career progression.

Future Plan and Timelines

Key Target	Comments
Introduction of new assays including: • *Aspergillus* IgG/IgM LFD • *Aspergillus* galactomannan LFA as POC test • Introduction of *Aspergillus* PCR on blood specimens • Mucorales PCR • Re-introduction of Pneumocystis PCR on saliva and respiratory specimens • PCP resistance testing • Investigate the development of an in-house *Aspergillus fumigatus* 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 twitter, MRCM website and the hospital and GP newsletters. Additionally, staff attending conferences and courses will be able to promote our services.

Summary

Over the last five years, our activity has increased by 103%, and our staffing by 49%. In addition, there has been a significant increase in environmental 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.

7. Statutory reports

7.1 MRSA

No cases of MRSA were reported.

7.2 *C. difficile* and CPE infections

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

7.3 Serious Untoward Incidents (SUIs)

No SUI's were reported.

7.4 Complaints

There were no formal complaints in the Year 2022-2023

7.5 Hospital Incident Reporting System (HIRS) alerts

In 2022/23 there were no serious untoward incidents and no formal complaints. There were 4 incident forms reported:
-an excel database was missing from shared folder. IT was contacted but were unable to retrieve the file. An earlier version of the file was found and used.
-A CT scan had not been reported 3 months after the scan was performed. The patient attended clinic expecting to receive the result of the CT scan. Radiology were contacted the day before the patient's appointment. The report was produced only 4 days after the clinic appointment. The patient was subsequently informed via telephone. Since the incident we review CT scans in our MDT and escalate to a radiologist directly if concerns.
-A CT scan was not reported 5 months after it was performed. This showed progressive changes of CPA. The patient died 10 months after that report. The death was not related to the delay in reporting of the scan. Since the incident we review CT scans in our MDT and escalate to a radiologist directly if concerns.
-A patient called the service, explained they had been started on voriconazole 4 weeks prior and were about to run out of medication in 2 days. Checking the clinic letter, 4 weeks were

prescribed and clinic appointment had been requested for 4 weeks, but had not been booked yet. The patient was tolerating the drug and the blood level was in range. All prescribers have since been asked to prescribe at least 6 weeks of antifungals on first prescription. The numbers of SUIs, incidents and complaints over the last 10 years are shown below:

	SUI	HIRS	Complaints
2013-14	1	0	3
2014-15	0	0	1
2015-16	0	1	0
2016-17	0	0	1
2017-18	0	3	0
2018-19	0	1	0
2019-20	0	2	0
2020-21	0	1	1
2021-22	0	0	0
2022-23	0	4	0

8. Audit, Quality Improvement and Mortality Report

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

Audits in 22/23:

1. **Antifungals therapeutic drug monitoring audit (Fiona Lynch, Pharmacist)**

   Background: TDM is an integral part of NAC work as antifungal prescribing needs close monitoring to avoid toxicity (if levels too high) and suboptimal response (if levels too low).

   Aim: To review whether drug levels are requested appropriately and whether they are actioned.

   Audit standards:

   - Percentage of results acknowledged
   - Percentage of results with clearly documented action
   - Percentage of results actioned within 7 days
   - Percentage of high levels actioned within 3 days
   - Percentage of high levels requiring dose change actioned within 3 days
   - Percentage of low levels actioned within 7 days

Results:

- 98% or results acknowledged
- 86% with clear documented action
- Mean time to action of result: 4.9 days

Actions (presented to team in August 2023):

- Documentation
    - Need to document clearly when action is taken to adjust doses making it clear the date dose adjustments were communicated to the patient
    - If a level is only just out of range and no action is needed to document in the notes that no action needed
- Rotating Drs/new starters
    - Ensure any Drs rotating through clinic are aware to action their results or to put the consultant in charge of clinic as the authorising clinician
    - Inform new starters that they can forward results to the NAC nursing team to action
- Consultant inboxes during annual leave
    - To ensure someone is checking inboxes for colleagues that are on annual leave

2. Service evaluation of Nursing Team remote telephone advice (by NAC Nursing Team).

The NAC nursing team have collected data from HIVE (the Trusts EPR). The data has been collected by running a report that has identified patients with a CPA diagnosis and have a documented telephone encounter between September 2022 (HIVE go live date) and August 2023. The aim of collecting and analysing this data is to identify common themes and if the enquiry was resolved by the team. This will hopefully conclude that the nursing team are offering a high standard of care to the patients on the NAC service and help to identify if improvements are needed.

Aim:
To identify CPA patients telephone enquiry themes.

Method:
Report ran on HIVE-capturing patients with a CPA diagnosis and telephone encounter documented between September 2022 (month HIVE went live) to August 2023

Analysis:
Identify common themes such as medication enquiry, antifungal TDM, treatment side effects etc and then code the common themes. Analyse if the enquiry was resolved by the team.

Results:
Pending

Conclusion:
Pending

3. **Quality improvement project of obtaining sputum samples prior to the first clinic visit (Mairead Hughes, Physiotherapist)**

Patients seen for the first time in the CPA clinic need to provide a sputum sample fof microbiology. Many patients struggle to provide a sample during the appointment. Mairead is sending the patients a sputum pot in the post prior to the appointment so it can be obtained in the morning of the appointment and increase the yield of the culture.

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

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

In 2022/23, 46 patients who died were discussed. Some key issues identified, and indicative lessons learnt are presented below:

-A patient was diagnosed with skin cancer while taking voriconazole. Lesson learnt: Discontinue voriconazole if skin cancer is identified or suspected.

-there was lack of communication between the NAC and referring consultant as referring consultant was not copied in the clinic letter. This resulted in delay in obtaining a repeat CT scan. Lesson learnt: since implementation of the new EPR system, the process of copying referring consultants is different. All staff are familiar with the process.

-A patient was treated with itraconazole for 4 years, when a CT scan could have been performed sooner to assess whether itraconazole could be stopped. Lesson learnt: Perform CT scan after 6 months of treatment. This is now our standard approach.

9. Research and Publications

We were awarded a grant of £251,000 by the NIHR Research for Patient Benefit scheme to conduct a randomised controlled trial of immunotherapy in CPA.

NAC and MRCM staff were authors on 16 papers this year, which are listed in Appendix 5.

Papers on CPA

While our output of original research papers has been lower than usual this year, we have contributed to a number of important international papers that reflect our experience in CPA.

- Dr Kosmidis was the editor for a special issue on CPA in the Journal of Fungi (**Kosmidis** *et al*, 2022), which included contributions from around the world and will help to raise the profile of this rare disease.
- We contributed to the CPAnet consensus statement that defined treatment outcomes for CPA, which was published in the European Respiratory Journal (**Van Braeckel** *et al*, 2022). Experts and patients worked together to draw up a standardised definition, which will help researchers around the world to improve the design of clinical trials.
- EQUAL scores are a clinical self-assessment tool for doctors, which measure how closely they are following the diagnostic and treatment guidelines for various fungal diseases. This year NAC co-authored a new EQUAL tool for CPA (**Sprute** *et al*, 2022) that summarises the most important recommendations from ESCMID/ERS/ECMM guidelines for CPA, for example *Aspergillus* PCR and discussion at MDT. This 27-point checklist also includes several key antifungal stewardship measures including therapeutic drug monitoring and antifungal susceptibility testing, which are under-utilised in the UK.

Papers on COVID-associated pulmonary aspergillosis

Our expertise with fungal diagnostics has proven valuable during the pandemic because patients in critical care require screening for COVID-associated pulmonary aspergillosis (CAPA), a life-threatening invasive infection. We have been involved in research led by the ECMM-CAPA study group.

- At the start of the pandemic, it was not known whether *Aspergillus* strains causing CAPA were different from environmental strains or those causing other types of infection. Genomic analysis of CAPA strains from several European countries found that they were not closely related to each other, but all showed unusual responses to human immune cells, which may make them more invasive (**Mead** *et al*, 2023)
- CAPA is tricky to diagnose with certainty and more research is needed to show which combination of tests is most useful. This paper analysed mortality data from multiple centres and found that patients whose lungs test positive for both fungal cultures and galactomannan have a worse prognosis (**Giacobbe** *et al*, 2022)

Other papers

- Dr Rautemaa-Richardson co-authored two papers about *Candida* yeast, which is another important cause of fungal disease that is tested for by MRCM.
    - The EUCANDICU study looked at patients on ICU units who developed invasive *Candida* infections inside their abdomens, in order to identify the major risk factors and help future patients to receive antifungal therapy more promptly (**Bassetti** *et al*, 2022).
    - An audit of the recurrent vulvovaginal thrush clinic at MFT found that 82% of women achieved good control and 16% achieved partial control of their condition by following the recommendations in the 2019 update to the BASHH guidelines (**Brown** *et al*, 2022).

- Ibrexafungerp is a new antifungal that was recently approved for treating recurrent thrush and it is hoped that it may in future be used for aspergillosis. This review summarises data about its activity against *Aspergillus* and other mould infections (**Angulo** *et al*, 2022).

International research collaborations

We have also co-authored a variety of papers with overseas clinicians who have previously worked at NAC and returned to their home countries.

CPA is a widespread problem in Indonesia because there is a high rate of tuberculosis, which leaves behind lung cavities that become colonised by *Aspergillus*.

- The APICAL trial followed patients receiving treatment for tuberculosis and found that around 13% were also affected by CPA (**Setianingrum** *et al*, 2022). This paper should help to raise awareness of the problem and result in fewer missed diagnoses.
- Genetic analysis showed that around 1 in 4 post-TB CPA patients carried 'cryptic' *Aspergillus* species, which are often more resistant to antifungals than *Aspergillus fumigatus* (**Rozaliyana** *et al*, 2022).

Many regions of Africa have minimal laboratory capacity for performing fungal diagnostics, which makes it difficult to effectively treat patients and prevent the spread of antifungal resistance.

- A survey by ECMM and ISHAM found that antifungal susceptibility and fungal antigen testing were particularly lacking (**Driemeyer** *et al*, 2022).
- A review of studies spanning the last 20 years found azole-resistant Aspergillus in 17.1% of environmental samples and 1.3% of clinical samples, primarily with the TR34/L98H mutation in the *cyp51*A gene (**Amona** *et al*, 2022)

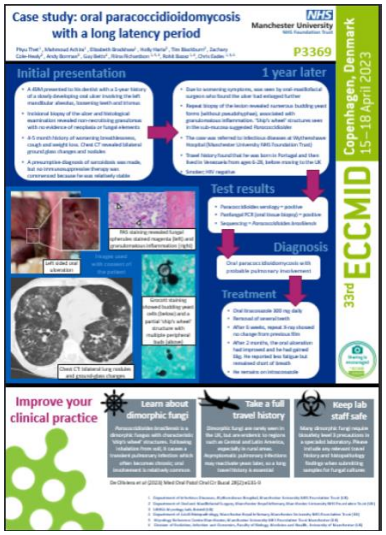
We co-authored 4 papers with a centre in Ghana, covering both invasive and chronic forms of aspergillosis:

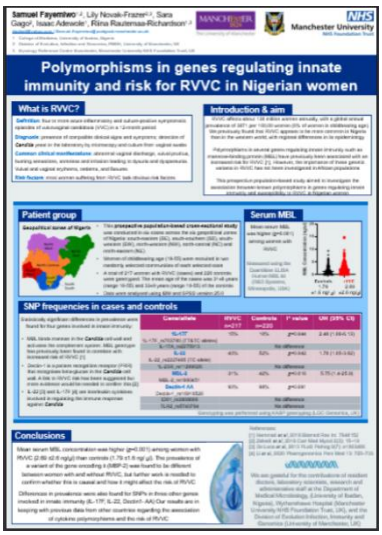
- CPA is common among patients with presumed tuberculosis relapse in Ghana (**Ocansey** *et al*, 2022)
- Cryptococcal and Histoplasma Antigen Screening Among People With Human Immunodeficiency Virus in Ghana and Comparative Analysis of OIDx Histoplasma Lateral Flow Assay and IMMY Histoplasma Enzyme Immunoassay (**Ocansey** *et al*, 2022)
- Importance of Aspergillus-Specific Antibody Screening for Diagnosis of CPA after Tuberculosis Treatment: A Prospective Follow-Up Study in Ghana (**Ocansey** *et al*, 2022)
- Invasive Aspergillosis among Haematological Malignancy Patients in Ghana: A Pilot Study on Prevalence and Antifungal Prophylaxis at the National Referral Hospital (**Ocansey** *et al*, 2023)

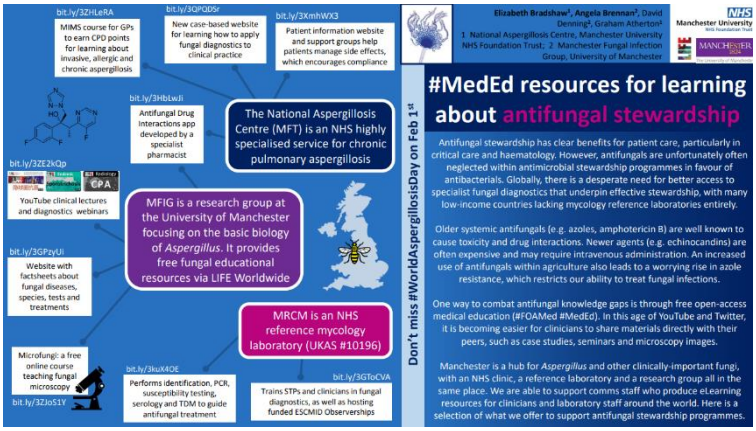
Conference posters and talks

NAC continues to present posters and talks at UK and international conference, which is a cost-effective and direct method of disseminating our experience among clinicians and

scientists. The figure shows conference posters presented by NAC at ECCMID (above) and BSAC (below).







10. Patient and public engagement

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

Post COVID pandemic we are still seeing fewer patients face-to-face in clinic. Most patients (66%) seem to now prefer having the choice between a face-to-face meeting and phone or video meeting (NAC Annual Survey 2023). 100% were satisfied or better with our video or phone consultations.

As happened in 2021 & 22 this has necessitated us taking a new approach and texting every patient after each consultation with information on our support. In addition, we now have access to myMFT, a patient portal that is part of the new patient management system at Manchester University NHS Foundation Trust (MFT). Patients have to have a smartphone or other computer to use myMFT and also have to opt in to using the system so at first we could not reach many patients in this way but that number has now increased substantially and 65% (Sept 2023) of our patients are using myMFT. We can send patients messages and documents using myMFT.

Most of our resources still need internet access in order to access them. However, smartphone usage continues to rise with 69% of those ages over 65 having one in 2023 and 93% have access to a mobile phone. 98% of the UK population have access to the internet. That said, we promote an information phoneline and are finding a way to send out information by post in order to try to reach out to everyone.

10.1 Patient Support Services

Telegram

Telegram.com is a private and confidential NHS-approved individual/group communication App. There are three groups covering CPA/ABPA/General discussion populated by a total of 114 patients (Sept 2023 – some patients are part of more than one group) that are almost all NAC & NHS patients. We use Telegram to answer private & confidential questions.

Monthly NAC Zoom/Teams meetings

We have switched from using Zoom for these meetings as we now have access to Teams software that is free of charge. Teams meeting began in April 2023.
Apart from an opportunity to socialise, these meetings are intended to:

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

We record the content and publish links on https://aspergillosis.org to allow them to be watched at a later date. In 12 months up to Sept 2023 these videos had 9300 views (subtitled in multiple languages – mostly commonly Arabic) 12 months, 504 hrs watch time, 221 subscribers.

Weekly Zoom (Teams since April 2023) social support meetings

These meetings occur twice a week, at different times during the day to accommodate as many people as we can, and are attended by up to 12 people per meeting. This is mostly an opportunity for social interaction and is attended repeatedly by NAC patients who find it beneficial.
Patients and carers regularly comment that this community support has made a dramatic difference to their quality of life as they feel that only people who are living through the same

illness can really understand and furthermore, they can relax in their company. Aspergillosis can be a social embarrassment for some as the frequent coughing and expectoration, regularly having to cancel plans due to ill health and above all the fatigue caused by aspergillosis is disruptive of their relationships with others, including family members. A meeting with fellow patients is an occasion that they will be understood and offered empathy no matter what happens.
NAC CARES team stays in the background of these meetings, only commenting when asked or if help is needed. All questions are answered until the last person leaves.

Patient Health and Wellbeing

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

- Weekly meetings provide rapid, regular access to NAC CARES staff to provide information such as questions on keeping safe during the COVID pandemic, guidance to the correct information resources for to assess vulnerability, vaccination eligibility and many more.
- Monthly meetings provide a platform for NAC staff to give talks on a wider variety of subjects aimed at helping the 'whole person' including (given at an understandable level):
    - COVID pandemic and vaccines, variants
    - Living with COVID
    - Holiday travel
    - Heatwave warnings
    - Scientific advances in the understanding of Aspergillus, aspergillosis
    - Why does Aspergillus infect us and not others?
    - New antifungal drug targets
    - Biologic medication
    - Air pollution
    - Cellular therapy: repairing a pancreas
    - Adrenal insufficiency
    - Sitting exercises
- Aspergillosis.org often hosts articles that have resulted from a Zoom meeting discussion to provide detailed advice and guidance from reputable resources – this supports our talks and offers the information to a wider audience.

Quarterly/Monthly newsletter

We have remodelled the newsletter to concentrate more on patients' needs and interests, departing from the mainly technical and research newsletter of old. We have seen a large increase in the numbers of people opening the email since June 2023 Readership now stands at 6372 total contacts over the year and 37% (1723) opened in August 2023 (which was 7% in May 2023).

Facebook support groups

The National Aspergillosis Centre Support (UK) group is our largest with 2764 members (the year to 23rd Sept 2023) and 232 new members approved. 1621 members were active with 488 original posts, 6714 comments, 8031 reactions.

52.8% of our active audience are from the UK, 81.3% are women and 8/10 of the top cities that use the group are UK cities.

Date	Post	Reach	Engagem
29/08/2023 13:56	After some advice really. I am waking up in the night due to coughing? how can I help ease this please any tips? thank... Posted by	322	38
04/09/2023 21:40	 Not what I wanted to do today but got worse as the day went on. Keeping me in. Nebuliser hasn't worked. Increase... Posted by	767	110
11/09/2023 11:17	Hello. Since I have ABPA I have lost the ability to manage stress. In fact, I feel worse if I'm under stress. Does anyone... Posted by	283	40
19/09/2023 15:26	A couple of weeks ago I went away (not overseas) and fell ill to the extent it spoiled my break. Last week I went away... Posted by	620	60
07/09/2023 20:56	 BRING BACK THE GOOD OLD FASHIONED PILL BOTTLE. This ridiculous packaging poluting our lands. Not only will it... Posted by	200	53
12/09/2023 17:10	I have been diagnosed with abpa for the last 5 years. i have been off and on steroids for the last 60 years.I was tested... Posted by	163	33
10/09/2023 23:50	Totally fed up with this condition voriconazole seems to be making me cough even more... can't sleep at night !!!! left... Posted by	478	32
08/09/2023 17:27	Day 10 (5 days of 30mg no improvement, increased to 40mg - day 5 and very little improvement). Fed up. Would... Posted by	436	43
01/09/2023 15:50	This year is not being very kind to me. Seems I'm relapsing again well not even relapsing as I've not been back in... Posted by	556	44
23/08/2023 16:30	A few weeks ago I went to nurse practioner to say I was feeling unwell, more breathless, more tired etc no much l... Posted by	301	29

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

10.2 Patient Feedback

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

Weekly patient survey

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

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

Using this service over the last 12 months of operation 382 replies have been received and analysed.

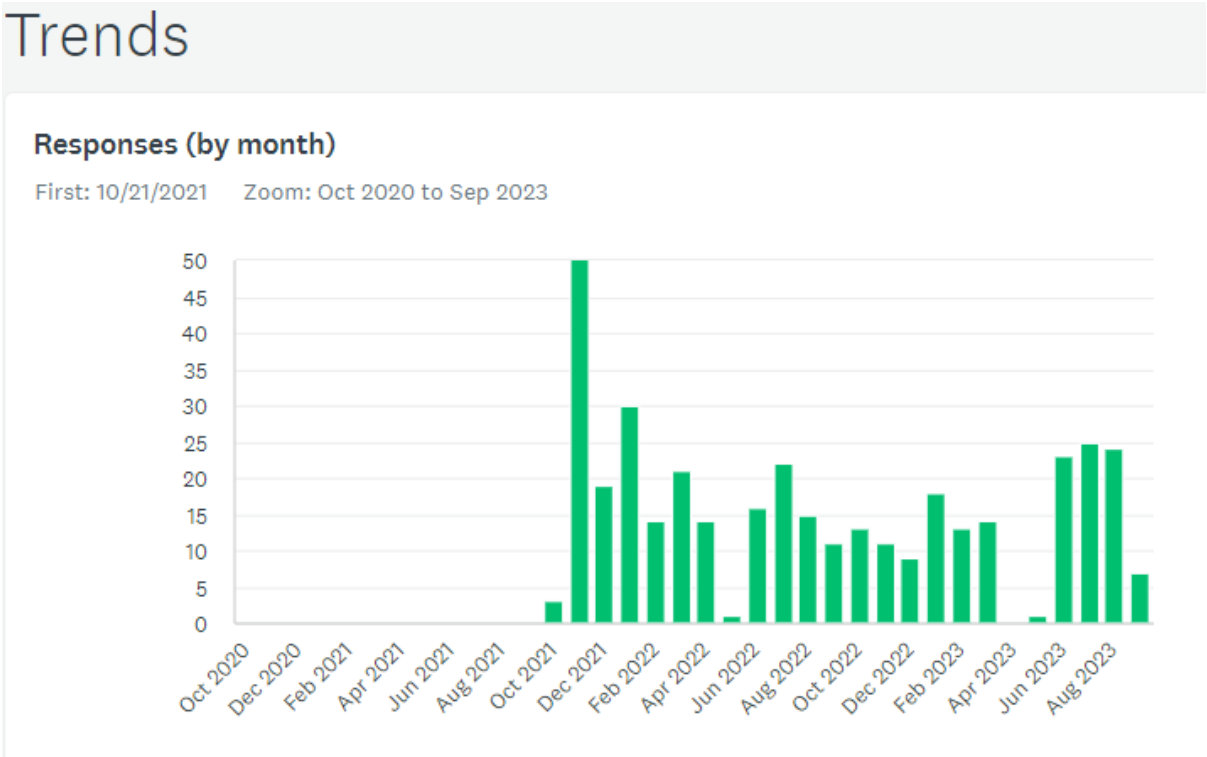


Fig 2. Monthly figures for consultation feedback

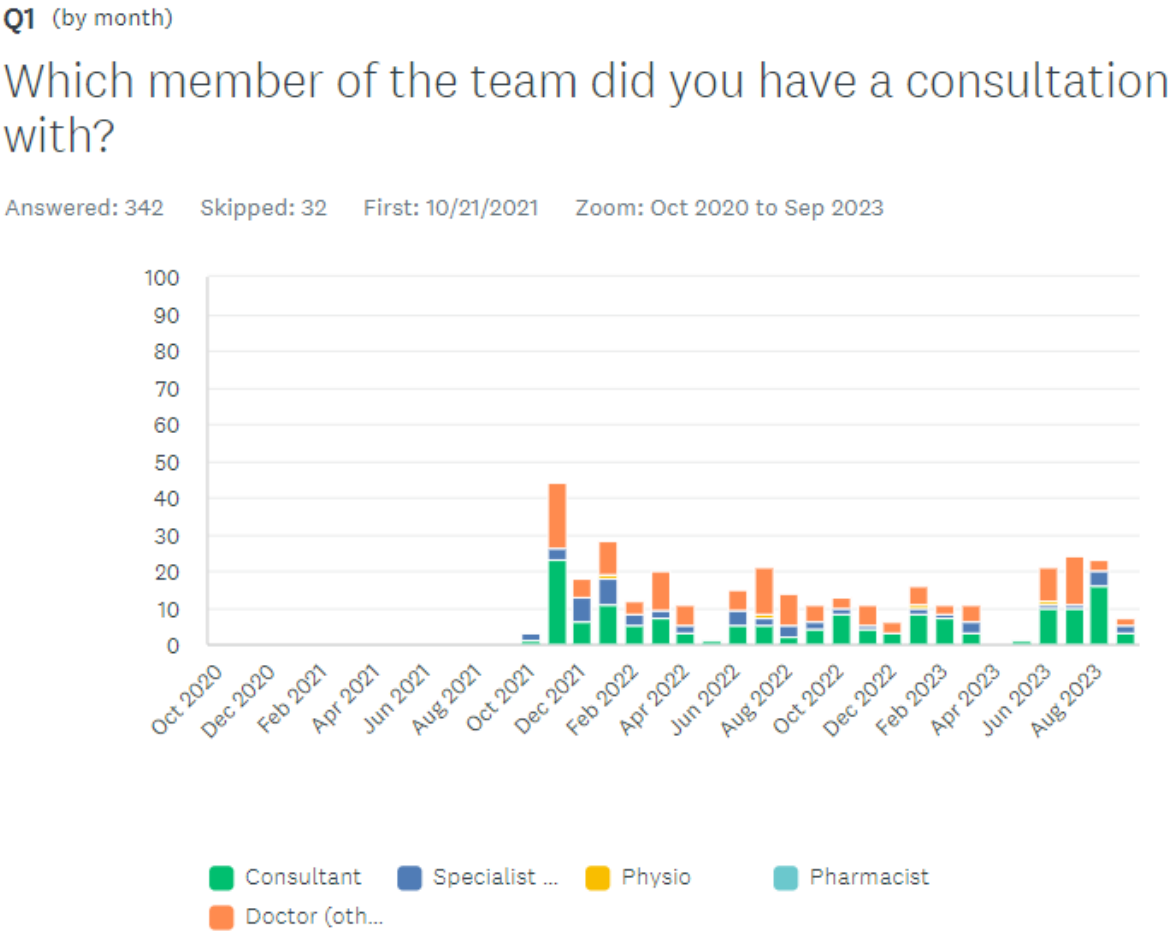


Fig 3. Monthly consultations broken down by team role

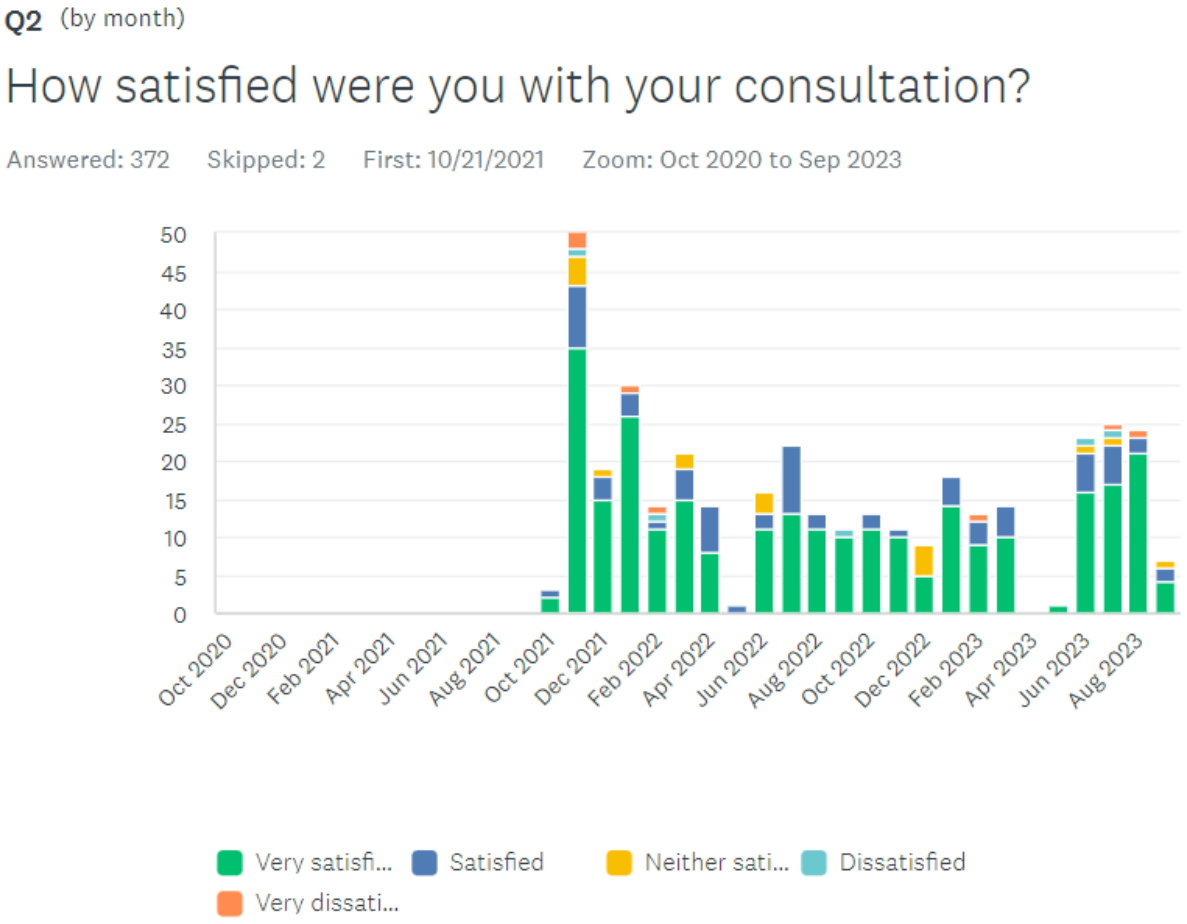


Fig 4. Patient satisfaction with consultation

Levels of expressed dissatisfaction are very low (4/168 (2%) overall) but where it is raised the relevant team lead is informed and a solution discussed. This survey also allows for comments that are often helpful. Of the four comments that expressed dissatisfaction, three related to difficulties in videoconferencing and one related to attending an appointment only to find no results were ready to be discussed. A further comment explained that the medical opinions offered by NAC were not the same as those offered by their local specialist.

Annual patient survey

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

In 2023 as NAC clinics remain only partially face-to-face, we have again offered this survey in a variety of ways to try and ensure that every patient is given an opportunity to complete it. We use Accurx internet services that allowed us to send all patients a text message offering the survey. In practice, more than 95% of all of our patients were able to receive text messages so we opted to use this method rather than attempting to send out paper copies to all patients as we did last year. We also used the new patient portal myMFT to send out requests to complete the survey.

The questionnaire was offered using a web application that allowed any patients with access to the internet via laptop/tablet/phone to complete it, and we offered to take entries over the phone for those with minimal web access.
The patient's survey was offered from March 29th to May 31st in 2023 (longer than usual) which resulted in a total of 468 patients being offered.

Of those, 29 patients (6.2%) responded and completed a survey.

Survey Highlights

Below is a summary of the main points for change 2022-2023. The full survey results can be seen in Appendix 8.

- All patients have expressed satisfaction with video consultation, which is a big improvement on 2022
- Patient preferences for the type of consultation have changed a little from face-to-face in clinic to mostly requesting a mixed approach (face-to-face and video) and telephone
- Approval of staff courtesy has risen to 100% for all staff groups in 2023
- Staff communication and care also improved with all but 2 teams showing increase in approval
- Communication about clinic appointments was markedly improved
- Fewer patients received information leaflets
- 100% (up from 90% 2022) were satisfied with information received
- Information about antifungal drug side effects was improved over 2022, but more improvement is needed
- 93% of patients found out answers to questions were understandable
- 43% had accessed physio online educational material, finding 'Useful content and guidance, very helpful'
- No patient had an in-patient stay 2022-23, presumably due to COVID precautions
- 94% would recommend Wythenshawe Hospital to family & friends
- Many more patients (66%) used the postal service this year, nearly twice as many as last year. This service enables care at NAC to reach patients in the remotest parts of the UK, without needing the patient to travel excessively.
- Medication was delivered to 28% of patients' homes, there was one complaint about poor services from the company employed to deliver.
- No patient used hospital transport in 2023
- 86% were happy to be contacted about research studies, and 100% of those were happy with procedures and consent
- 52% have seen the information leaflets available online at CARES website aspergillosis.org which is twice the previous year, and 100% thought them useful
- 31% visited aspergillosis.org website this year (40% in 2022). This website has been redeveloped and relaunched by the CARES team in 2023 and usage is rising. 100% are happy with the website
- Far more patients (21%) have attended a patient meeting online in 2023 compared with 2022 (7%), commenting 'excellent range of talks by staff', 'really

knowledgeable' and 'These are excellent with time to catch up with others and very interesting and useful talks'.

- Of those that had not attended a patient meeting, 73% did not feel that they needed this type of support (a reduction from 81% in 2022). 27% wanted to attend a meeting but could not due to lack of access to the internet (10%) or the meeting was at an inconvenient time (19% this was 11% in 2022).
- 21% were members of our support groups on Facebook (18% in 2022)
- 28% had heard of our twice-weekly social meetings
- 31% would like to hear more of our use of the Telegram private messaging App.

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

- I expect to hear from Dr. …… once he has the results of blood tests and my next CT scan.
- Excellent patient care and I'm extremely lucky to be under their care. Thank you.
- Thank you for all your support and treatment and advice
- Would welcome any opportunity to be actively involved in new NAC drug and / or therapeutic treatments to suppress condition or improve lung - breathing condition. I am an active person and any new treatments providing benefits would be welcome.
- Very professional, reassuring and friendly
- Superb care received, thank you !
- Nebulised Fungizone has freed me from harmful steroids and my condition is hugely improved.
- A big thank you to all the staff and doctors you're all appreciated keep up the great work you do
- keep up the great support. I really appreciate it
- not all people particularly senior citizens have smart phones and are not able to manipulate their way round websites which might seem simple to younger people !

<u>NAC response to the annual survey</u>
We are developing a series of actions in response to this survey:

******Action point A:*** *Patient comment: I am rarely told who is who and given their full names, so I'm not sure who I am commenting on so some ratings may not be correct. Everyone should give their full name and title so it is clear. It is also not made clear who I will be seeing and the purpose if the visit and what it will entail.*
Response: Issue reminder to all staff to introduce themselves when meeting a patient.

******Action point B:*** *34% of patients had received an information leaflet in 2023, which is significantly less than last year (47% 2022).*
Response: Issue reminder for clinicians to give patients information leaflets

******Action point C:*** *One patient asked for the option for information to be posted out rather than online.*
Response: Add an option to request an information leaflet by post to our patient messages ie. Accurx, myMFT, Newsletter, videoconference, in clinic.

***Action point D:** *52% of patients were informed about possible side effects of antifungal medication which is a small increase on 2022 (48%) but there is some way to go to get back to the numbers informed in 2021 (76%).*
Response: Issue reminder to give patients information of side effects.

***Action point E**: *No patient who completed a survey form had had an in-patient stay. This is a big drop from 2022 (30%).*
Response: Verify that this is a result of COVID restrictions on in-patient care for our patients.

***Action point F:** *Not satisfied, recently my prescription was over a fortnight overdue, did not receive the usual telephone call from them to re order and staff were unable to tell me what had gone wrong, not very helpful.*
Response: Review this with the company providing the service.

***Action point G**: *Can we arrange meetings at a better time?: 73% did not feel they needed this type of support (81% in 2022), but 27% expressed a wish to attend a meeting and the reason why they could not was lack of access to the internet (10% - this was 8% in 2022) or the meeting was put on at an inconvenient time for them (19% - this was 11% in 2022).*
Response: We have discussed this several times over the years we have been holding the meetings. Adjustments have been made from time to time but it is not possible to please everyone – we already runs meetings in the mornings and afternoons over 3 days of the week.

***Action point H:** *can we improve this? 28% had heard of our weekly meetings.*
Response: Almost everyone who attends a clinic appointment recieves texts from CARES team via Accurx containing links to information on how to attend meetings. We will review these.

***Action point I:** *31% would like to hear more of Telegram (40% in 2022).*
Response: Almost everyone who attends a clinic appointment recieves texts from CARES team via Accurx containing links to information on how to use Telegram. We will review these.

***Action point J:** *not all people particularly senior citizens have smart phones and are not able to manipulate their way round websites which might seem simple to younger people!*
Response: This is a very good point but it is less easy to solve. Patients who attend our clinics get some printed material and text messages reach those who have less modern phones. Our improved offer to post out printed material should help (Action point C)

11 Raising public awareness and educational outreach

Aspergillosis Patients and Carers Website (aspergillosis.org)

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

This website was completely redesigned over 2022-23 in order to become easier to use, easier for users to find what they want and it was relaunched in January 2023. These changes were patient-led as patient groups were consulted several times during the process. Since that date it has been viewed 185 000 times and had 167 000 users. These figures are 34% down on the previous year overall but it is normal to see that happening when a website is relaunched as all existing hyperlinks that are assessable via search engines are lost and it takes some time for the whole website to be reindexed. We are confident these numbers will rise.

In the Patients annual survey 2023 31% of all NAC patients had visited aspergillosis.org. 100% were satisfied or very satisfied with the website content.

Research

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

Communities

Lauren Amphlett (see 2023 Engagement and Impact Report attached) has worked tirelessly to develop relevant communities via social media that we can use as targeted audiences for awareness, education and to assist research and clinical staff.

- Linkedin

NAC has run a dedicated page in LinkedIn for the purpose of engaging professional audiences that we can reach out to, increasing awareness of aspergillosis and NAC throughout the medical and research communities in the UK and abroad. In 2022 – 23, 595 visitors view our NAC page 1619 times. 51% of these visitors had a job function related to healthcare, research or education. There are 2544 followers of the NAC page in Linkedin, of which 679 joined over the last 12 months.

The Mycology Reference Centre Manchester (mrcm.org) LinkedIn page is also supported by the CARES team and again we see great engagement of professional groups within research,

healthcare and education (43% in total). The MRCM LinkedIn page has 2860 followers of which 896 joined in the last 12 months.

- Twitter

Twitter followers of NAC's twitter page have increased to 3940 over the last 12 months, an increase of 19% (see 2023 Engagement and Impact Report attached).

Education

The CARES team and NAC fellows with NAC consultant Chris Kosmidis have partnered with MIMS Learning (mimslearning.co.uk) to deliver a CPD course entitled the 'Diagnosis and management of aspergillosis' to primary-level medical professionals (https://www.mimslearning.co.uk/courses/aspergillosis). This course has been offered since January 2022.

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

13. Future Service Developments

The following developments are planned for 2023/2024:

1. Equitable access to the NAC

Equitable access to the NAC for all patients with CPA in England and Scotland is the priority for the coming years. Although the NAC cares for patients from all parts of England and Scotland, historically, patients from the Northwest have been overrepresented (see Appendix 3). We feel we are in a good position to address this now. As we emerge from the pandemic we now have at our disposal the means for remote consultation, remote monitoring and the National MDT which already discusses CPA patients (up to 4 each week) from all parts of the country or patients who are not able to attend the NAC (see Appendix 3, Graph 3).

We aim to improve equitable access to NAC in two ways:

-We will increase awareness of the NAC service among physicians caring for CPA patients via attendance in scientific meetings, teaching activity and our already existing channels of communication. We also aim to explore reasons for absence of referrals from certain parts of the country; this could be due to lack of awareness of the condition or to preference for treatment locally. A survey of clinical practice of respiratory and infectious diseases physicians with regards to CPA is envisaged.

Pros: This approach will increase referrals to our MDT, enabling better management for CPA in patients who are not initially referred to the NAC, as well as education of referring consultants on CPA.

Cons: While remote review in MDT will improve CPA care, there may be issues with availability of MDT if too many referrals arrive. Currently our MDT runs for 2 hours once a week. We will explore ways to increase this when requried.

-In parallel, we plan to continue to work with NHSE to explore other ways for equitable care, such as exporing the hub and spoke model. Preliminary discussions for this were made in 2019. Clinicians from candidate "spoke" centres would be trained in the NAC and subsequently see CPA patients locally, while discussing treatment decisions remotely in our MDT.

Pros: this approach will enable management of CPA closer to home by physicians trained in CPA management by the NAC.

Cons: Identification and training of external consultants will be required, which may take a long time to plan and achieve.

2. Focus on patient reported outcomes and quality of life

Quality of life is significantly affected in CPA patients and treatment has been shown to improve this. Monitoring of the impact of CPA on quality of life has always been a priority for the NAC. This has been happening through the use of the St George's quality of Life questionnaire and this forms part of the reporting requirements. Due to challenges in collecting this questionnaire (due to remote consultations and also due to the complexity; it consists of >50 questions) we have moved to reporting of CT scans and Aspergillus serology instead during the pandemic. However we believe patient reported quality of life should be at the centre of CPA management and be available to patients and treating physicians alike to inform treatment decisions and patient experience. We aim to work within the team and NHSE to explore alternative measures of patient reported outcomes, their capture via electronic means and their incorporation into patient care. We also aspire to develop a CPA-specific patient reported outcome measure.

3. Implementation of an annual review process

Currently, the review process of CPA treatment includes discussion of all 6-month antifungal drug outcomes in MDT. However, patients may remain on antifungals for prolonged periods. We do not currently have a formal review process for these patients. We do have a formal review for patients who die, however we are aiming to introduce an annual review process for all patients. We will work within the team to agree the optimal way for this ongoing yearly review process. This is likely to involve assessment by individual members of the MDT team including a doctor, specialist nurse, physiotherapist and pharmacist. Cases will be subsequently discussed with the wider MDT to ensure optimal clinical care, antifungal stewardship and communication with patient GPs and secondary care consultants.

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

The NAC MDT would greatly benefit from participation of a Consultant Thoracic Radiologist. Most patient discussions and decisions regarding treatment effectiveness in CPA involve review of a chest CT scan. Presence of a radiologist with real time review of imaging would enable more robust decisions on CPA treatment. This would require funding for 4 hours per week of a consultant's time.

5. Understanding the role of new antifungals in CPA

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

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

6. Understanding the genetic background of CPA

Our research has shown evidence of immune system defects in patients with CPA. These are suspected to be linked to genetic defects which remain unrecognised. Identifying those genetic defects will help us understand the causes of CPA as well as potentially have diagnostic implications. We plan to work with the NHS Genomic Medicine Service to take this project forward.

Appendix 1 Categorisation (Banding) of CPA disease complexity

Stage 1

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

Stage 2

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

Stage 3

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

Appendix 2 New Patient Audit

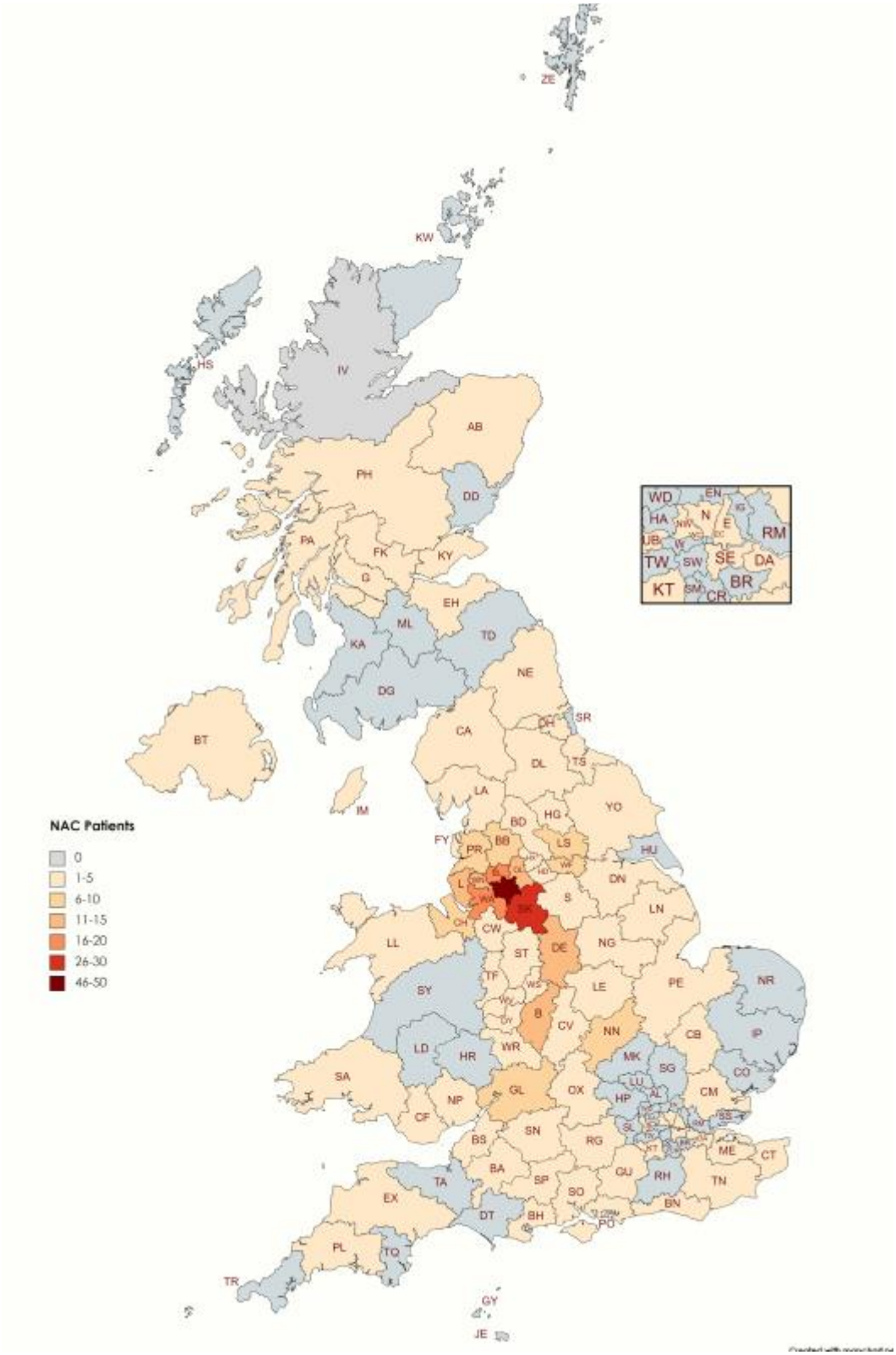
MONTH	DATE REFERRED	APPOINTMENT DATE	WAITING TIME - weeks	POSTCODE	AREA	Band	Antifungal at 1st visit	Antifungal at 3 months	Priority
APRIL	23/02/2022	22/04/2022	8	M9	Manchester	B1	None	None	Routine
MAY	28/02/2022	22/04/2022	7	S018	Southampton	B1	Itra	Itra	Routine
	25/03/2022	13/05/2022	7	FY8	Lytham	B1	None	None	Routine
	26/04/2022	27/05/2022	4	SK8	Stockport	B1	None	Itra	Routine
JUNE	03/05/2022	10/06/2022	5	SK3	Stockport	B2	None	Itra	Routine
	28/08/2022	09/09/2022	2	WR4	Worcester	B2	Posa	None	Routine
JULY	03/05/2022	08/07/2022	9	DE13	Burton on Trent	B1	None	None	Routine
	07/06/2022	15/07/2022	5	SE1	London	B1	Itra	Itra	Routine
	24/05/2022	29/07/2022	6	NN17	Northamptonshire	B2	None	Vori	Routine
	08/06/2022	22/07/2022	5	BL1	Bolton	B1	None	Vori	Routine
AUGUST	16/06/2022	12/08/2022	8	B73	West Midlands	B2	Vori	Vori	Routine
	30/06/2022	19/08/2022	7	LS11	Leeds	B2	None	None	Urgent
SEPTEMBER	13/07/2022	02/09/2022	8	LL34	Wales	B1	None	Itra	Routine
	18/08/2022	18/08/2022	6	M22	Manchester	B1	None	Vori	Routine
OCTOBER	02/08/2022	21/10/2022	9	PE33	Norfolk	B2	Posa	None	Routine
	29/09/2022	28/10/2022	4	OL8	Oldham	B1	None	None	Routine
	15/03/2022	26/03/2022	2	SK23	Derbyshire	B1	Itra	Itra	Routine
NOVEMBER	25/08/2022	04/11/2022	10	CH1	Chester	B2	None	Vori	Routine
	29/09/2022	18/11/2022	7	LS26	Leeds	B2	Itra	Vori	Routine
	02/09/2022	25/11/2022	12	S43	Sheffield	B2	None	None	Routine
DECEMBER	29/02/2022	02/12/2022	9	BB12	Burnley	B1	None	None	Routine
	30/09/2022	09/12/2022	11	WN7	Wigan	B1	None	Itra	Routine

	23/09/2022	09/12/2022	12	LL17	Wales	B2	Posa	Posa	Routine
	07/10/2022	16/12/2022	10	WF12	West Yorkshire	B1	Itra	None	Routine
JANUARY	19/07/2022	09/09/2022	8	M15	Manchester	B1	None	None	Routine
	28/11/2022	13/01/2023	6	BL4	Bolton	B1	None	pend	Routine
	29/11/2022	13/01/2023	6	WF10	Castleford	B2	Vori	None	Soon
FEBRUARY	16/12/2022	03/02/2023	7	B77	Tamworth	B2	Vori	pend	Routine
	09/11/2022	10/02/2023	13	M21	Manchester	B2	Vori	pend	Routine
	10/08/2022	30/09/2022	7	TN40	Bexhill on Sea	B2	Posa	pend	Routine
MARCH	09/01/2023	17/03/2023	9	M9	Manchester	B1	None	Vori	Routine
	21/02/2023	24/03/2023	4	CH8	Wales	B2	Vori	pend	Routine
	20/01/2023	24/03/2023	9	HR3	Herefordshire	B2	Vori	pend	Routine
	10/01/2023	24/03/2023	10	BN3	East Sussex	B1	Itra	pend	Routine
	05/01/2023	27/01/2023	3	WS1	Walsall	B1	None	pend	Routine
	28/08/2022	30/09/2022	4	HG4	N. Yorks	B1	None	pend	Routine
	11/07/2022	02/09/2022	8	SK7	Stockport	B2	None	pend	Routine
	10/10/2022	23/12/2022	8	WF10	Castleford	B2	Vori	pend	Routine
	21/06/2022	10/06/2022	0	M33	Manchester	B1	None	pend	Routine

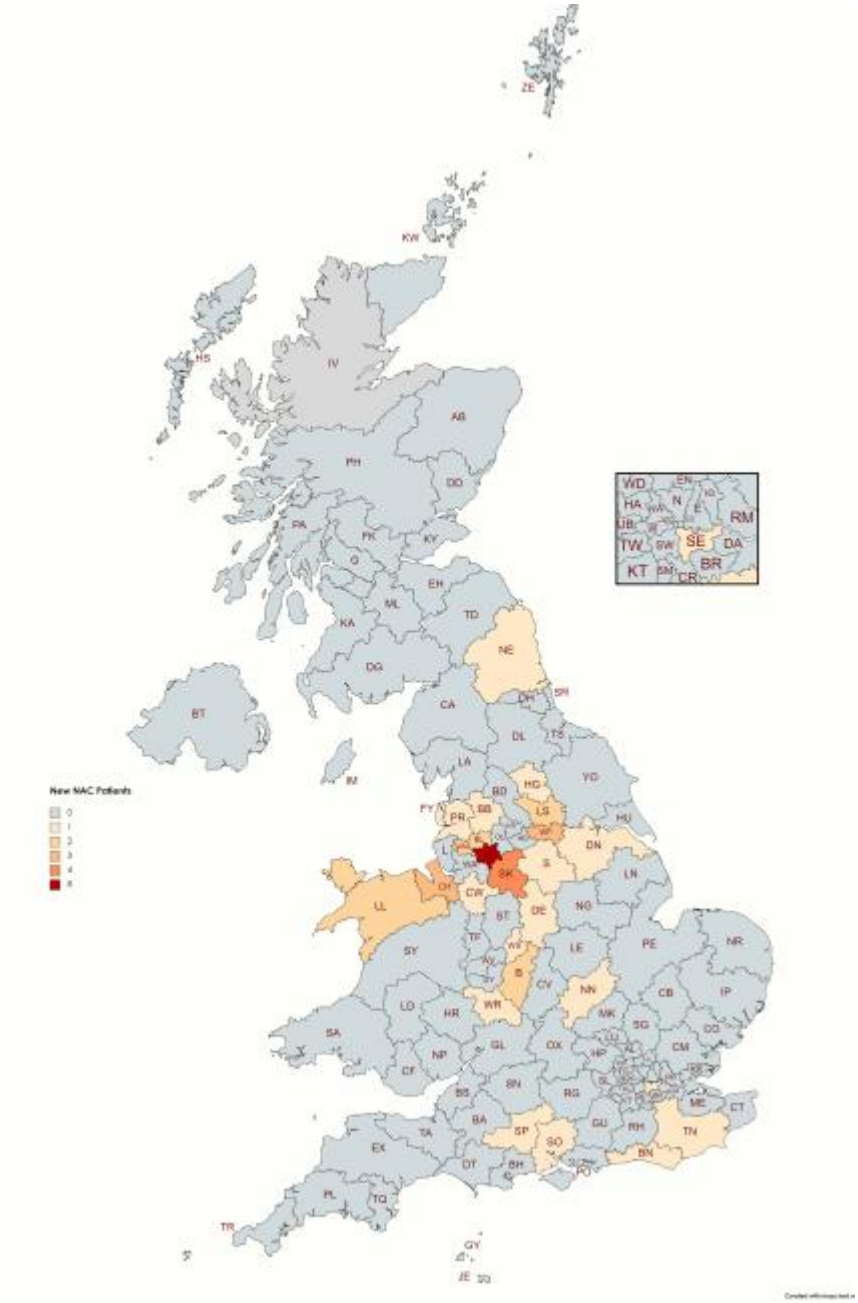
Note: Average referral time in weeks was 7.0. The three months following implementation of the new EPR (September-December 2022) appeared to have increased the average time (8.3 weeks). Thereafter, average referral time was 6.8 weeks.

Appendix 3 Geographical location of patients attending NAC

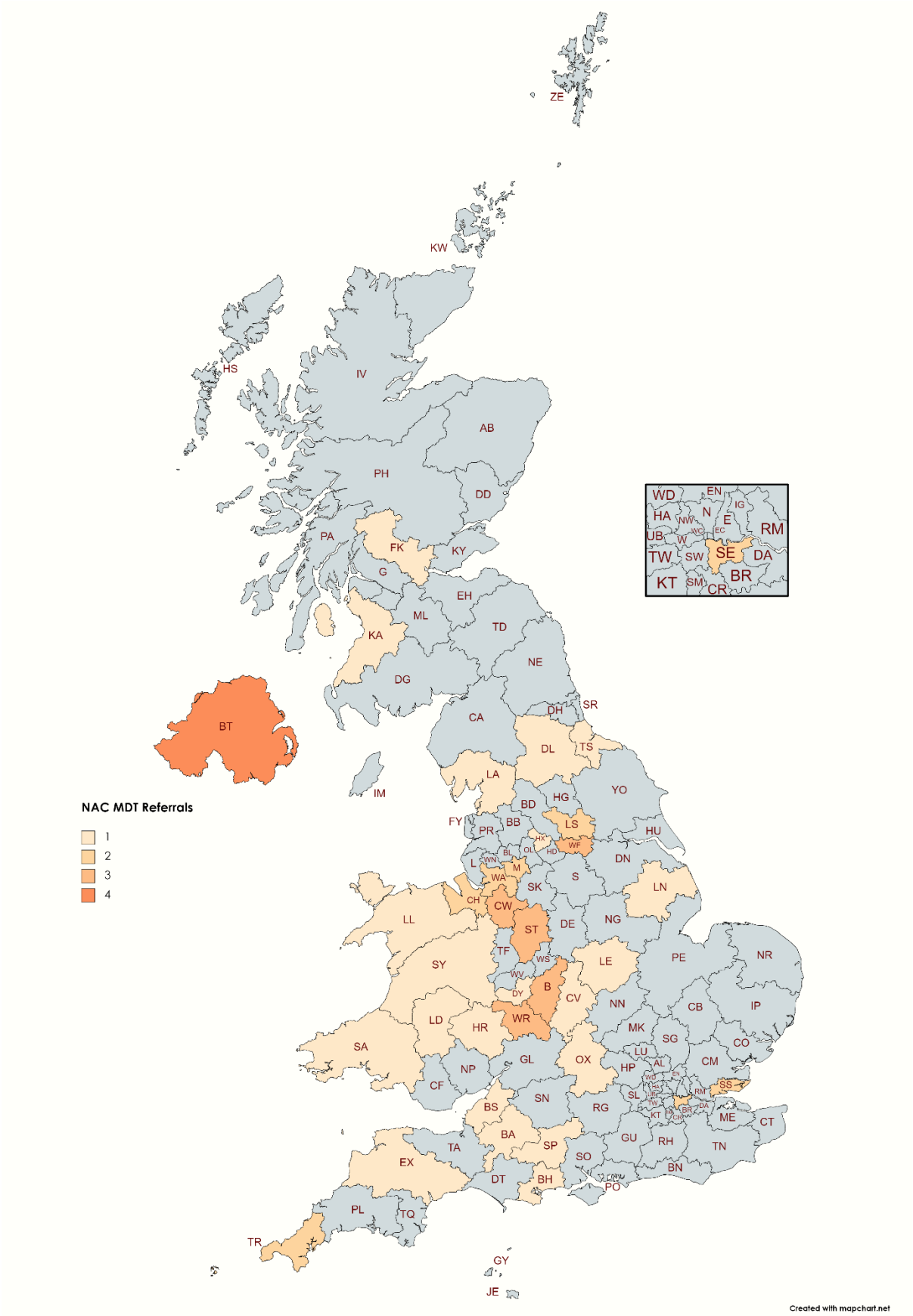
Graph 1. All patients on NAC service in March 2023



Graph 2. New patient referrals 2022-2023



Graph 3. Patients discussed in National Aspergillosis MDT in 2022-2023



Appendix 4 Antifungal Trial Data

Voriconazole 2022/23 trial data

Date Commenced	6-m review	Outcome
21/02/2022	Aug-22	success
01/03/2022	Sep-22	success
24/12/2021	Jun-22	success
30/09/2021	Mar-22	success
Apr-22	Oct-22	success
Aug-22	Feb-23	success
Jul-22	Jan-23	success
Apr-22	Oct-22	died
21/07/2022	Jan-23	side effects (photosensitivity)
01/04/2022	Oct-23	side effects (photosensitivity)
09/09/2022	Mar-23	success
27/01/2023	Jul-23	pending
Mar-23	Sep-23	pending
Jan-23	Jul-23	pending
Feb-23	Aug-23	pending
Nov-22	May-23	pending
Mar-23	Sep-23	pending
Dec-22	Jun-23	pending
Mar-23	Aug-23	pending
Dec-22	Jun-23	pending
24/03/2023	Sep-23	pending
08/12/2022	Jun-23	pending
Nov-22	May-23	pending

Posaconazole 2022/23 trial data

Date commenced	6-mo review	Outcome
Feb-22	Aug-22	Side effects (breathlessness, fatigue)
Jan-22	Jul-22	Success
01/10/2021	Apr-22	Success
31/12/2021	Jun-22	Success
14/01/2022	Jul-22	Success
Feb-22	Aug-22	side effects (raised blood pressure)
Jan-22	Jul-22	Success
Mar-22	Sep-22	side effects (neuropathy)
Mar-22	Sep-22	Success
Mar-22	Sep-22	Success
Feb-22	Aug-22	Failed - switch to Isavu
03/03/2022	Sep-22	Success
May-22	Nov-22	Success
Oct-22	Apr-23	side effects
Apr-22	Oct-22	side effects
01/07/2022	Jan-23	Success
Oct-22	Apr-23	Failed - switch to Isavu
Mar-23	Sep-23	Pending
Jan-23	Jul-23	Pending
Jul-22	Jan-23	Pending
Dec-22	Jun-23	Pending

Isavuconazole 2022/23 trial data

Date commenced	6-mo review	Outcome
21/01/2022	Jul-22	Success
05/10/2021	Apr-22	Success
21/01/2022	Jul-22	Success
Feb-22	Aug-22	Success
Feb-22	Aug-22	Success
12/11/2021	May-22	Failed
25/10/2021	Nov-21	Success
Apr-22	Oct-22	Success
Apr-22	Oct-22	Success
Jun-22	Dec-22	Success
Apr-22	Oct-22	Success
Aug-22	Feb-23	Success
Dec-22	Jun-23	Failed
Jan-23	Jul-23	Pending
Mar-23	Sep-23	Pending

Appendix 5 Publications

NAC/MRCM Journal publications 2022/2023

- **Amona**, F.M.; Oladele, R.O.; Resendiz-Sharpe, A.; Denning, D.W.; Kosmidis, C.; Lagrou, K.; Zhong, H.; Han, L. Triazole Resistance in Aspergillus Fumigatus Isolates in Africa: A Systematic Review. *Med Mycol* **2022**, *60*, myac059, doi:10.1093/mmy/myac059.
- **Angulo**, D.A.; Alexander, B.; Rautemaa-Richardson, R.; Alastruey-Izquierdo, A.; Hoenigl, M.; Ibrahim, A.S.; Ghannoum, M.A.; King, T.R.; Azie, N.E.; Walsh, T.J. Ibrexafungerp, a Novel Triterpenoid Antifungal in Development for the Treatment of Mold Infections. *J Fungi (Basel)* **2022**, *8*, 1121, doi:10.3390/jof8111121.
- **Bassetti**, M.; Vena, A.; Giacobbe, D.R.; Trucchi, C.; Ansaldi, F.; Antonelli, M.; Adamkova, V.; Alicino, C.; Almyroudi, M.-P.; Atchade, E.; et al. Risk Factors for Intra-Abdominal Candidiasis in Intensive Care Units: Results from EUCANDICU Study. *Infect Dis Ther* **2022**, *11*, 827–840, doi:10.1007/s40121-021-00585-6.
- **Brown**, L.; Chamula, M.; Weinberg, S.; Jbueen, F.; Rautemaa-Richardson, R. Compliance with the Updated BASHH Recurrent Vulvovaginal Candidiasis Guidelines Improves Patient Outcomes. *JoF* **2022**, *8*, 924, doi:10.3390/jof8090924.
- **Driemeyer**, C.; Falci, D.R.; Oladele, R.O.; Bongomin, F.; Ocansey, B.K.; Govender, N.P.; Hoenigl, M.; Gangneux, J.P.; Lass-Flörl, C.; Cornely, O.A.; et al. The Current State of Clinical Mycology in Africa: A European Confederation of Medical Mycology and International Society for Human and Animal Mycology Survey. *Lancet Microbe* **2022**, *3*, e464–e470, doi:10.1016/S2666-5247(21)00190-7.
- **Giacobbe**, D.R.; Prattes, J.; Wauters, J.; Dettori, S.; Signori, A.; Salmanton-García, J.; Maertens, J.; Bourgeois, M.; Reynders, M.; Rutsaert, L.; et al. Prognostic Impact of Bronchoalveolar Lavage Fluid Galactomannan and Aspergillus Culture Results on Survival in COVID-19 Intensive Care Unit Patients: A Post Hoc Analysis from the European Confederation of Medical Mycology (ECMM) COVID-19-Associated Pulmonary Aspergillosis Study. *J Clin Microbiol* **2022**, *60*, e0229821, doi:10.1128/jcm.02298-21.
- **Mead**, M.E.; de Castro, P.A.; Steenwyk, J.L.; Gangneux, J.-P.; Hoenigl, M.; Prattes, J.; Rautemaa-Richardson, R.; Guegan, H.; Moore, C.B.; Lass-Flörl, C.; et al. COVID-19-Associated Pulmonary Aspergillosis Isolates Are Genomically Diverse but Similar to Each Other in Their Responses to Infection-Relevant Stresses. *Microbiol Spectr* **2023**, *11*, e0512822, doi:10.1128/spectrum.05128-22.

- **Kosmidis**, C. Special Issue: Chronic Pulmonary Aspergillosis. *J Fungi (Basel)* **2022**, *8*, 714, doi:10.3390/jof8070714.
- **Ocansey**, B.K.; Otoo, B.; Gbadamosi, H.; Opintan, J.A.; Dei-Adomakoh, Y.; Kosmidis, C.; Denning, D.W. Invasive Aspergillosis among Haematological Malignancy Patients in Ghana: A Pilot Study on Prevalence and Antifungal Prophylaxis at the National Referral Hospital. *West Afr J Med* **2023**, *40*, 613–618.
- **Ocansey**, B.K.; Otoo, B.; Adjei, A.; Gbadamosi, H.; Kotey, F.C.N.; Kosmidis, C.; Afriyie-Mensah, J.S.; Denning, D.W.; Opintan, J.A. Chronic Pulmonary Aspergillosis Is Common among Patients with Presumed Tuberculosis Relapse in Ghana. *Med Mycol* **2022**, *60*, myac063, doi:10.1093/mmy/myac063.
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Appendix 6 Patient Survey Results

Patients survey 2023

NAC clinics remain only partially face-to-face with most patients seen remotely we have again offered this survey in a variety of ways in order that every patient was given an opportunity to complete it.
We used Accurx internet services to send all patients a text message offering a link to the survey and phone number so that they could complete the survey with our assistance over the phone. We also used our new myMFT patient portal messaging.
The patients survey was offered from March 29th to May 31st, which was a total of 468 patients.
Of those, 29 patients (6.2%) responded and completed a survey. This is less than we received in 2022 (when there were 40 surveys completed).

Action points
The details of patient's responses to the survey are detailed below and action points have been identified for attention.
Offering the survey online and via phone was noted last year as one reason why we received fewer completed surveys. This year we used myMFT and Accurx to contact all patients, including offering the option to complete the survey by phone. We were unable to send out printable copies by the time the survey went out but have since found a way to do this using myMFT.
How do we reach patients who are not using online resources?

- There are now some (not many) patients coming to clinic for face-to-face consultations so that offers an opportunity to hand out printed versions of the survey
- Ideally we could send out paper copies to all patients attending clinic by post, but past experience showed us that this is very laborious so is not a practical option.

****Action point A: Patient comment*: *I am rarely told who is who and given their full names, so I'm not sure who I am commenting on so some ratings may not be correct. Everyone should give their full name and title so it is clear. It is also not made clear who I will be seeing and the purpose if the visit and what it will entail.*
Response: Issue reminder to all staff to introduce themselves when meeting a patient.

****Action point B*: *34% of patients had received an information leaflet in 2023, which is significantly less than last year (47% 2022).*
Response: Issue reminder for clinicians to give patients information leaflets

****Action point C:* *One patient asked for the option for information to be posted out rather than online.*
Response: Add an option to request an information leaflet by post to our patient messages ie. Accurx, myMFT, Newsletter, videoconference, in clinic.

****Action point D*: *52% of patients were informed about possible side effects of antifungal medication which is a small increase on 2022 (48%) but there is some way to go to get back to the numbers informed in 2021 (76%).*
Response: Issue reminder to give patients information of side effects.

****Action point E: No patient who completed a survey form had had an in-patient stay. This is a big drop from 2022 (30%).*

Response: Verify that this is a result of COVID restrictions on in-patient care for our patients.

****Action point F: Not satisfied, recently my prescription was over a fortnight overdue, did not receive the usual telephone call from them to re order and staff were unable to tell me what had gone wrong, not very helpful.*

Response: Review this with the company providing the service.

****Action point G Can we arrange meetings at a better time?: 73% did not feel they needed this type of support (81% in 2022), but 27% expressed a wish to attend a meeting and the reason why they could not was lack of access to the internet (10% - this was 8% in 2022) or the meeting was put on at an inconvenient time for them (19% - this was 11% in 2022).*

Response: We have discussed this several times over the years we have been holding the meetings. Adjustments have been made from time to time but it is not possible to please everyone – we already runs meetings in the mornings and afternoons over 3 days of the week.

****Action point H – can we improve this? 28% had heard of our weekly meetings.*

Response: Almost everyone who attends a clinic appointment recieves texts from CARES team via Accurx containing links to information on how to attend meetings. We will review these.

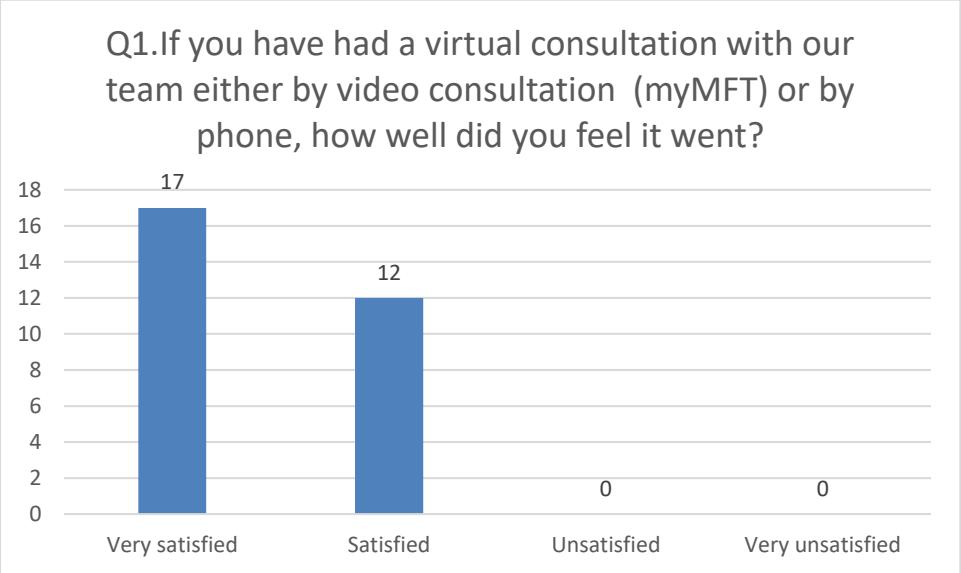
****Action point I: 31% would like to hear more of Telegram (40% in 2022).*

Response: Almost everyone who attends a clinic appointment recieves texts from CARES team via Accurx containing links to information on how to use Telegram. We will review these.

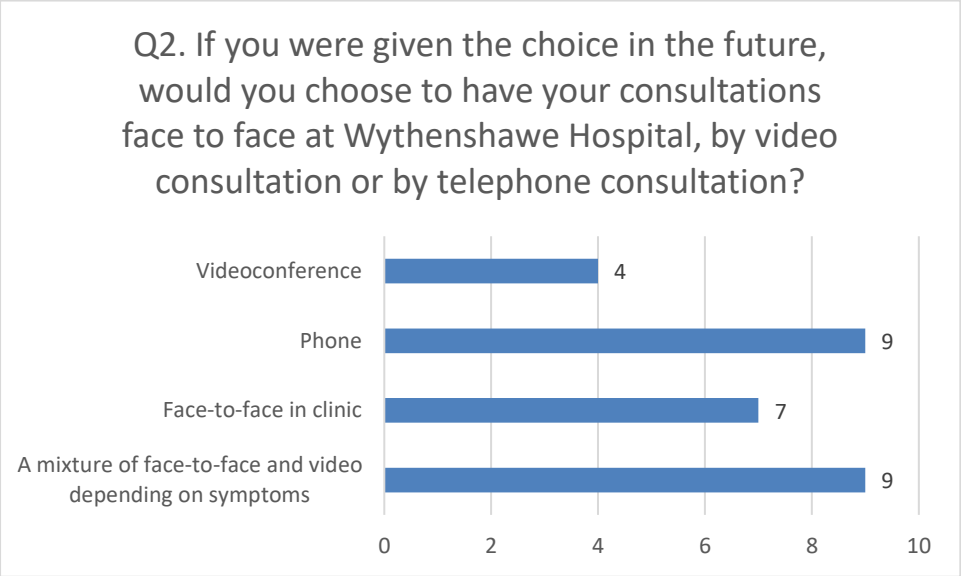
****Action point J: not all people particularly senior citizens have smart phones and are not able to manipulate their way round websites which might seem simple to younger people!*

Response: This is a very good point but it is less easy to solve. Patients who attend our clinics get some printed material and text messages reach those who have less modern phones. Our improved offer to post out printed material should help (Action point C)

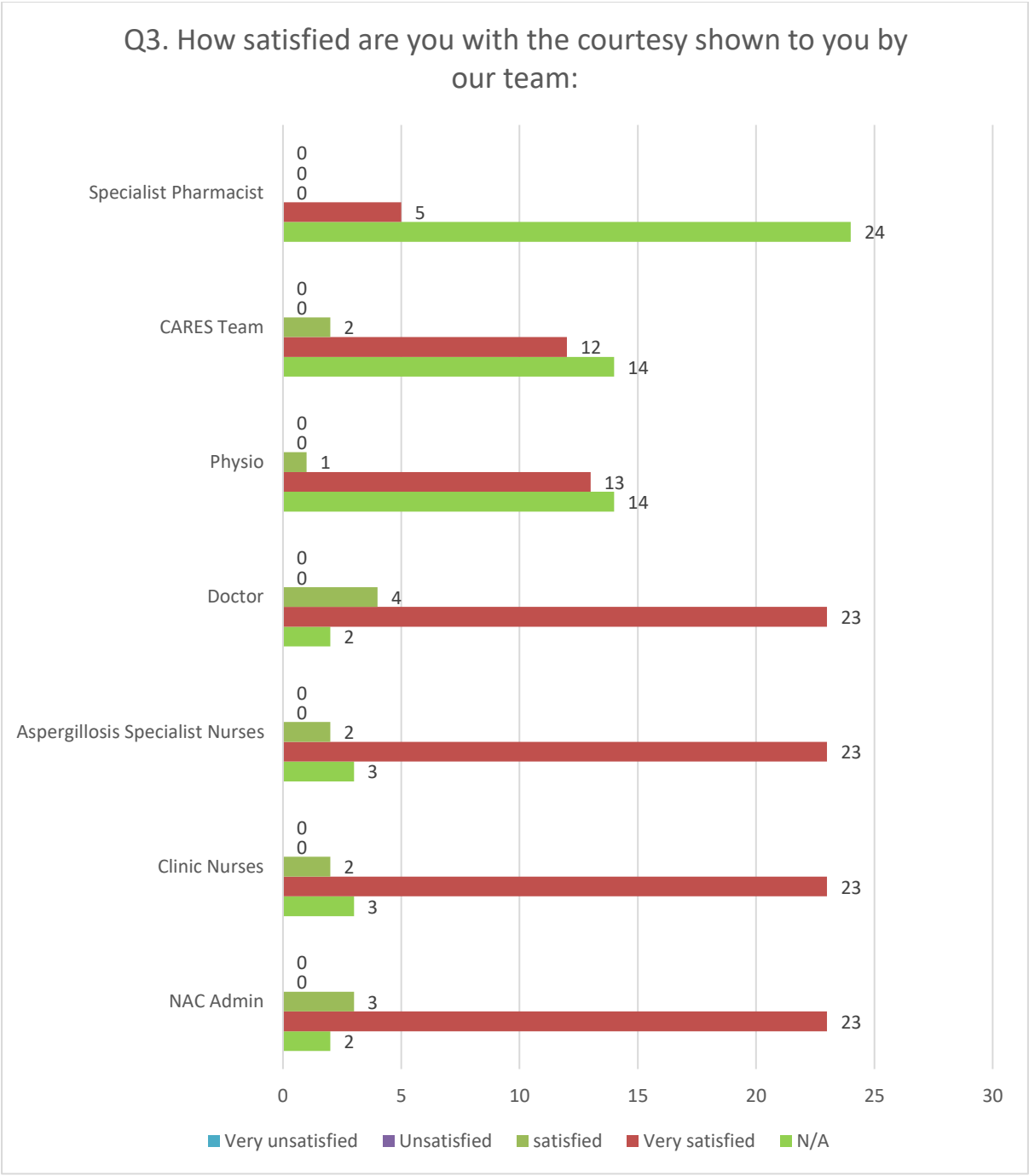
Survey responses



0/29 (0%) were unsatisfied or worse with video consultations (2022 18%). This is a significant improvement over previous years
Patient comments suggest that most were offered a phone appointment and that video appointments remain difficult for some due to poor access to the internet (4 people). 4 were not offered a video appointment but all seem to be aware of it compared with 15% unaware that video was an option in 2022.

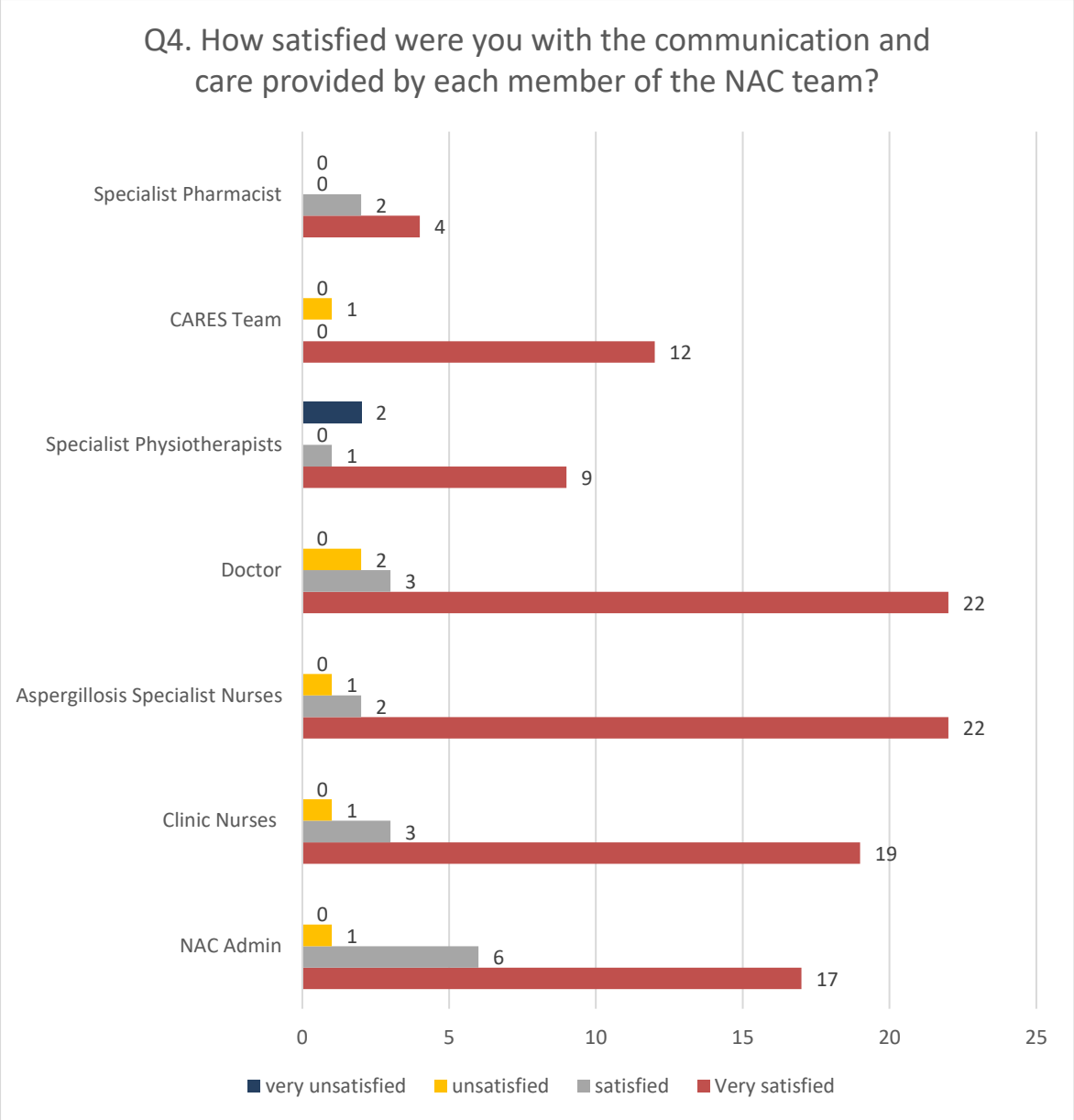


It is striking that a face-to-face consultation is no longer the option most people want. In 2023 most (66%) patients preferred a mixture of face-to-face & video and phone, whereas it was the third most popular option in 2022, though not by much. Two thirds of patients opted for a mixed approach or phone. Videoconferencing on its own remains unpopular in 2023 with only 14% preferring that option (18% in 2022).



Approval of courtesy shown by all groups of staff achieved 100% in 2023 with no patient unsatisfied or worse. This is a marked improvement on 2022 when approval ratings for each team were:

- NAC Admin 91% satisfied or better.
- Clinic nurses 94% satisfied or better
- Specialist nurses 91% satisfied or better
- Doctor's 89% satisfied or better
- Physio's 100% satisfied or better
- CARES team 94% satisfied or better
- Specialist pharmacist 100% satisfied or better

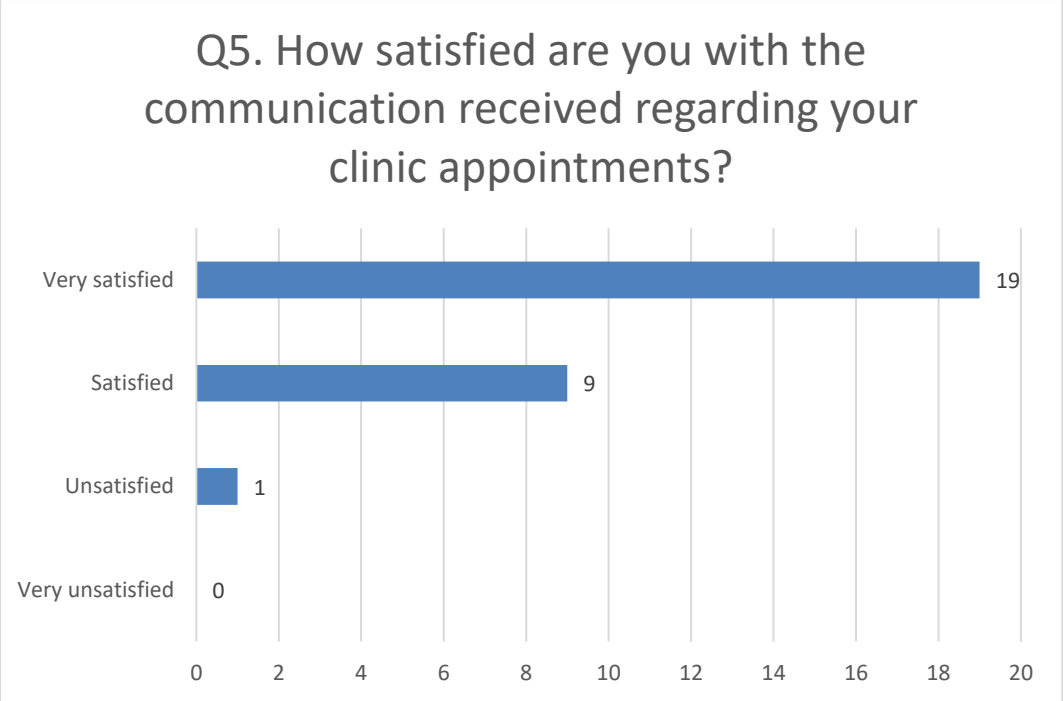


Satisfaction improved for most staff groups in 2023:

- NAC Admin 96% satisfied or better (91% 2022)
- Clinic Nurses 96% satisfied or better (94% 2022)
- Aspergillosis Specialist Nurses 96% satisfied or better (94% 2022)
- Doctors 93% satisfied or better (95% 2022)
- Specialist Physiotherapists 85% satisfied or better (92% 2022)
- CARES Team 92% satisfied or better (100% 2022)
- Specialist Pharmacist 100% satisfied or better (100%)

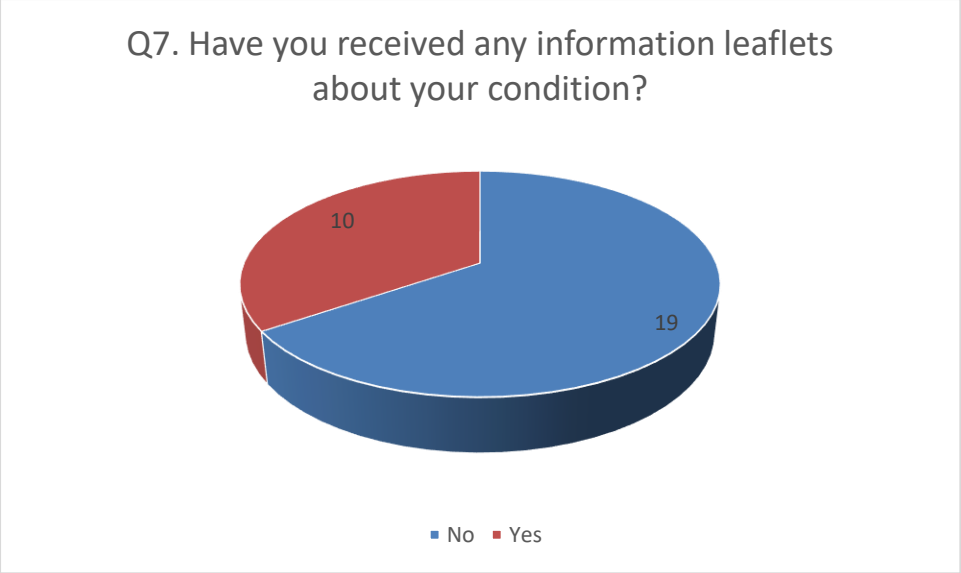
Negative/constructive comments from patients

- I am rarely told who is who and given their full names, so I'm not sure who I am commenting on so some ratings may not be correct. Everyone should give their full name and title so it is clear. It is also not made clear who I will be seeing and the purpose if the visit and what it will entail. ****Action point A*
- I feel the doctor I spoke to left me with more questions than answers

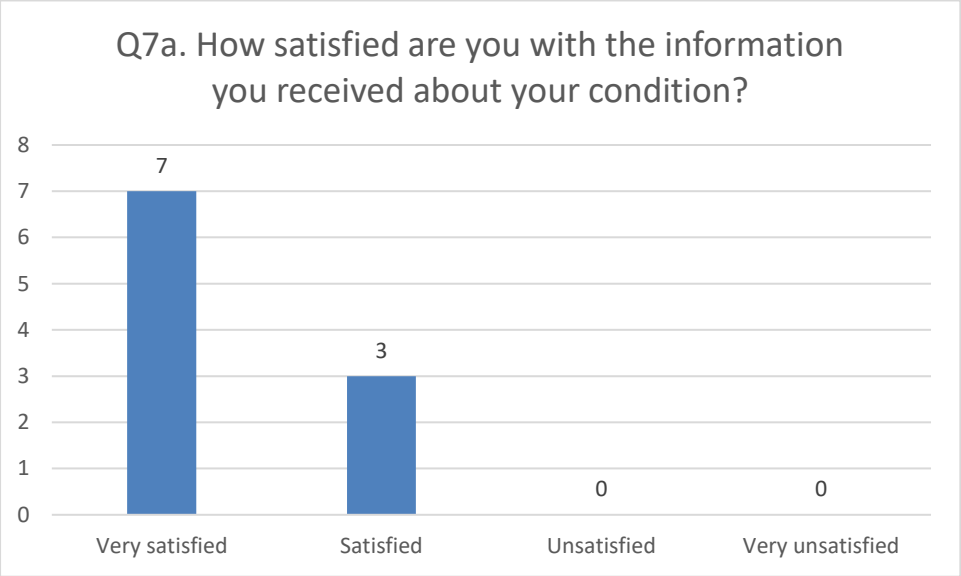


97% were satisfied or better of communication received regarding appointments, which is a marked improvement on 2022 (88%).
There were no negative/constructive comments.

24% had had a consultation between appointments, virtually the same as 2022 (25%).

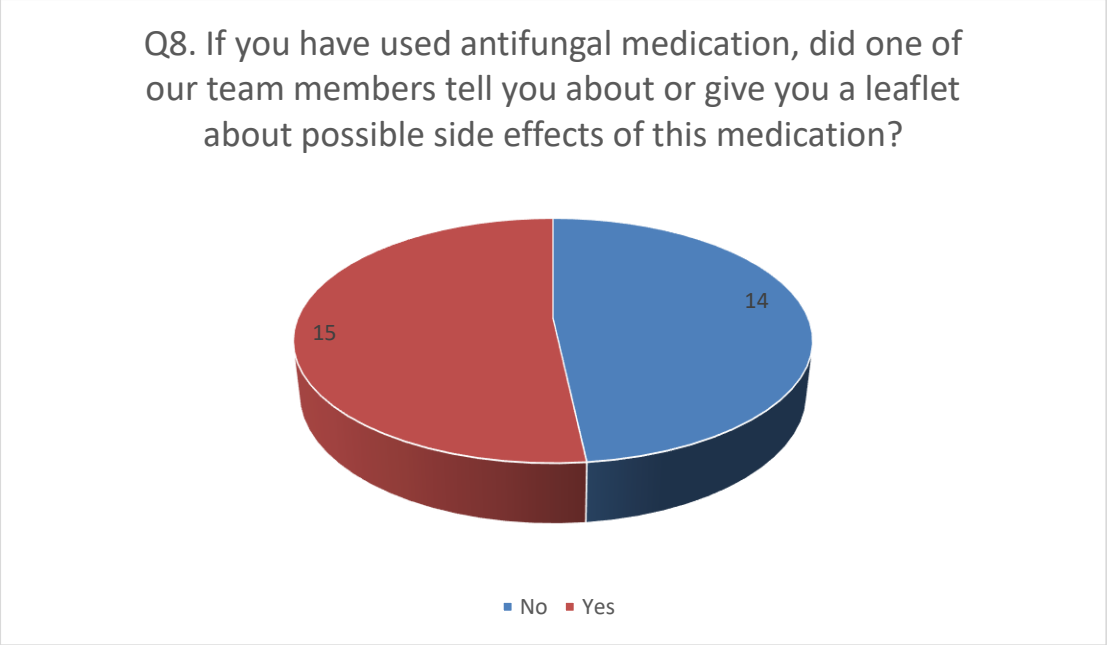


34% of patients had received an information leaflet in 2023, which is significantly less than last year (47% 2022). ****Action point B*

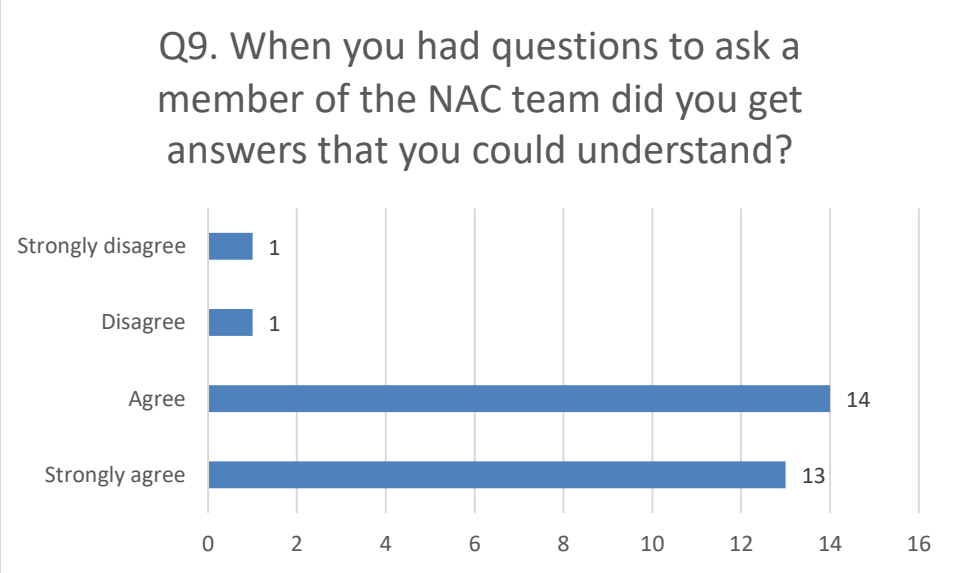


100% of patients were satisfied or better with the information they received about their condition, which is an improvement on 2022 (90%).

****Action point C: One patient asked for the option for information to be posted out rather than online.*



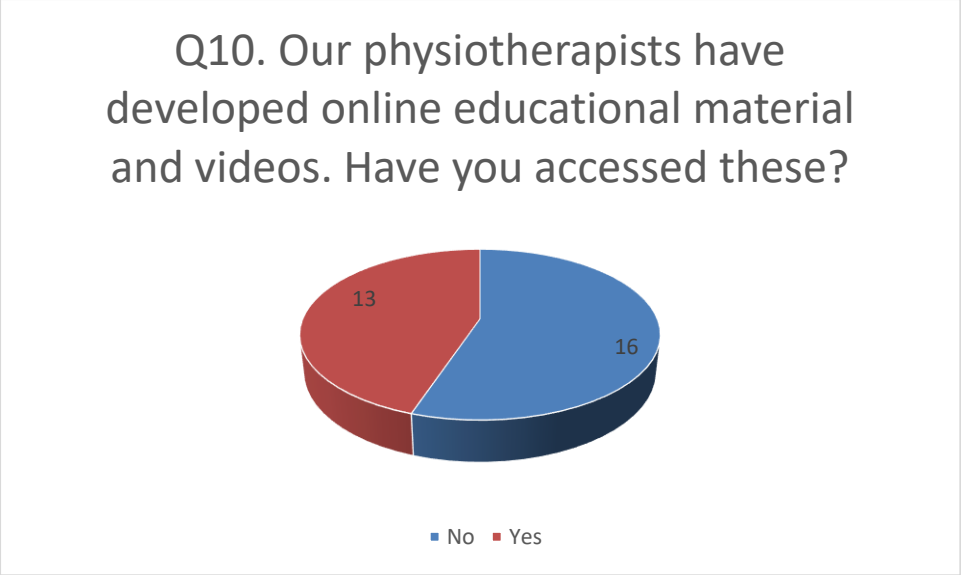
52% of patients were informed about possible side effects of antifungal medication which is a small increase on 2022 (48%) but there is some way to go to get back to the numbers informed in 2021 (76%). ****Action point D*



93% understood answers to questions they had asked of NAC team (100% 2022).

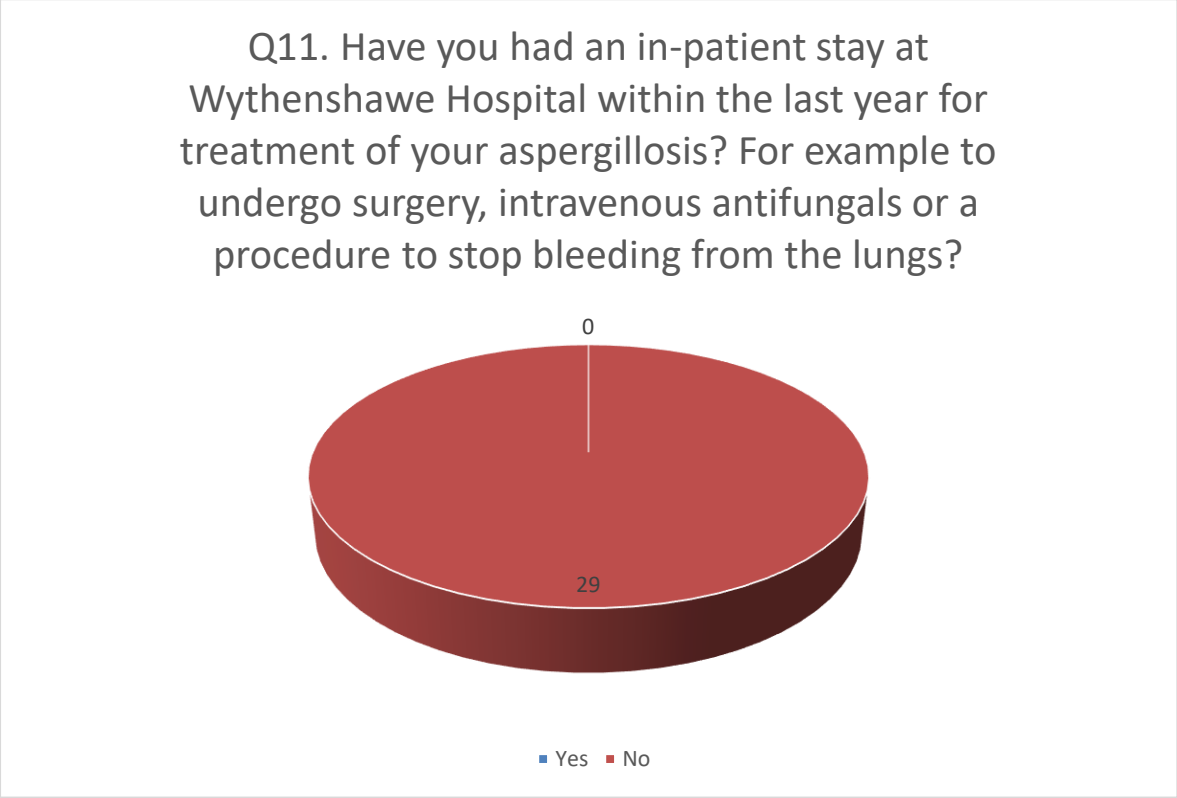
Constructive patient comments:

- I am currently a bit confused about my medication but it is being looked into for me



45% of patients had accessed Physio educational material and videos.
Patient comments:

- Useful content and guidance supporting breathing exercises
- very helpful. I learnt about how to provide a sputum sample

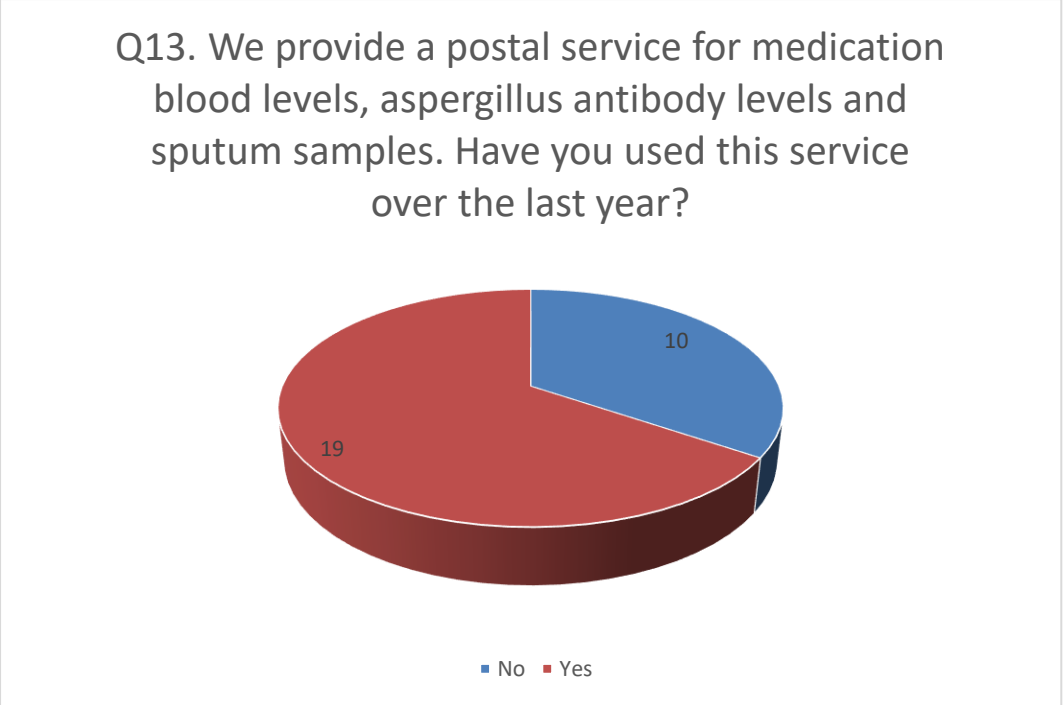


No patient who completed a survey form had had an in-patient stay. This is a big drop from 2022 (30%). ****Action point E*

94% would recommend Wythenshawe Hospital to family and friends (98% 2022)

Patients were asked to give a few details why they would recommend:

- It's too far away but if they need the specialism then there is no choice really
- Everyone has been friendly and helpful
- Resourceful, informative and helpful staff
- They are the only ones who seem to I understand my condition
- Informative staff across disciplines, supportive and helpful
- Everything runs very smoothly at Wythenshawe when I have a clinic appointment except for the x-ray part of it which seems to be a complete shambles. ****Action point E*
- very friendly and caring staff. Easy to communicate with
- staff are very caring
- staff very efficient and friendly



66% had used the postal service over the last year, which is a big increase on 2022 (35%)

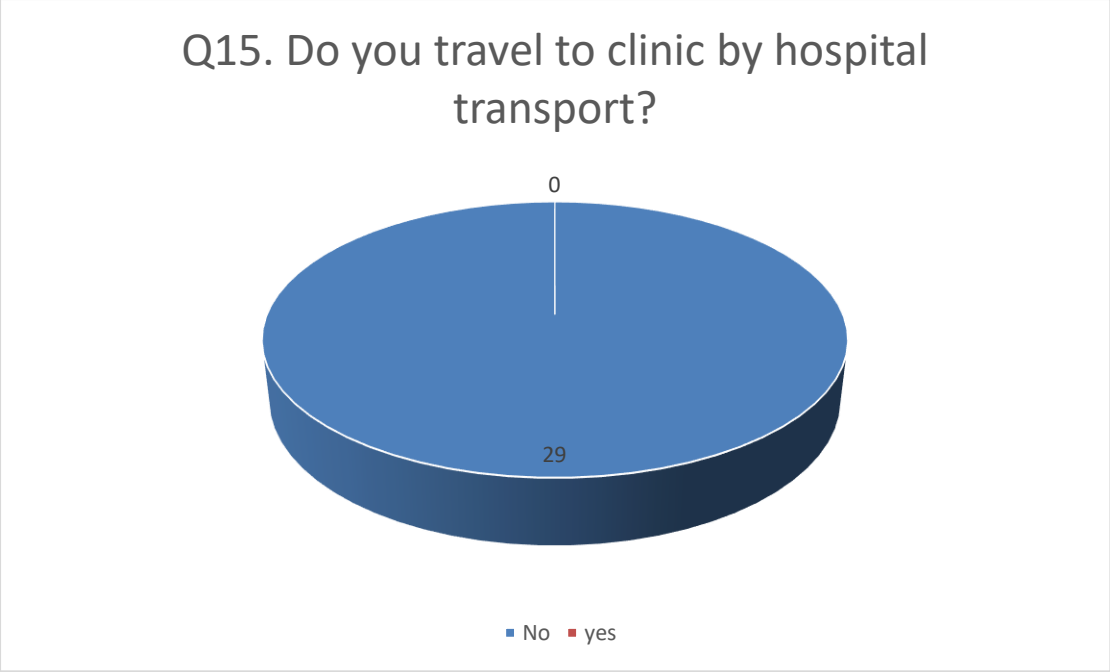
Patient comments

- Always excellent
- Samples submitted and test results relayed
- Ideal easy to use saves a long journey
- Efficient service and provision of feedback regarding results
- I think I will be using this service following my most recent appointment
- my doctor's practice have refused to do this in the past. I'm going to ask them again.
- Very satisfied
- excellent service

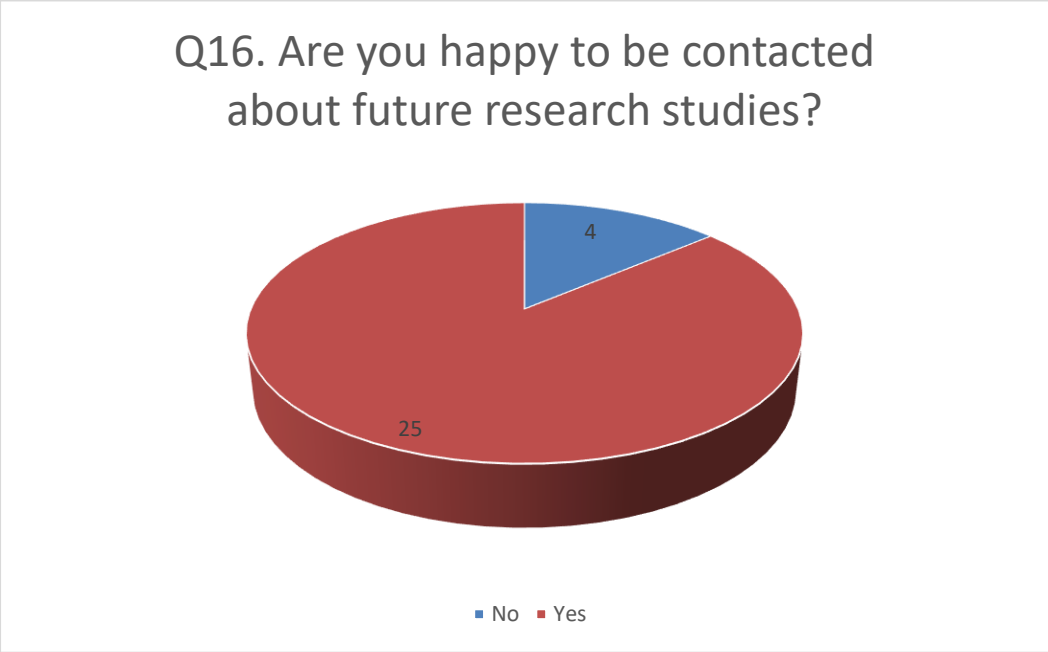
Q14. We have commissioned a company to deliver certain antifungal medication to patient's homes. If you have received this service, are you satisfied with it? Please comment below.

28% had used this service. One person expressed dissatisfaction:

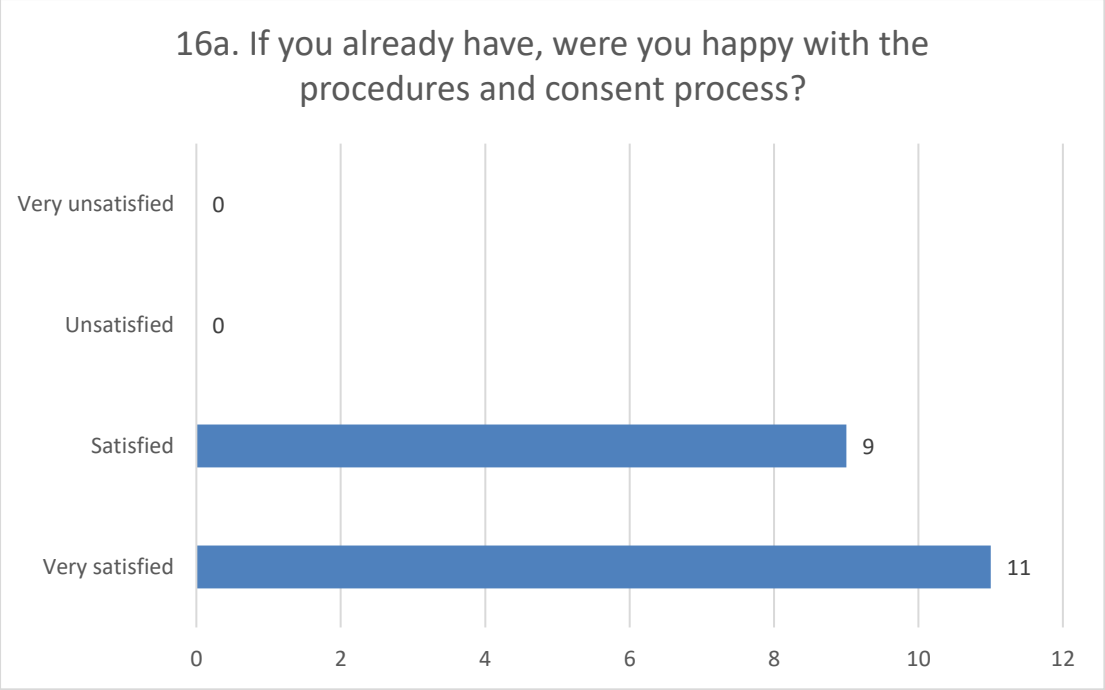
- Not satisfied, recently my prescription was over a fortnight overdue, did not receive the usual telephone call from them to re order and staff were unable to tell me what had gone wrong, not very helpful. ****Action point F*



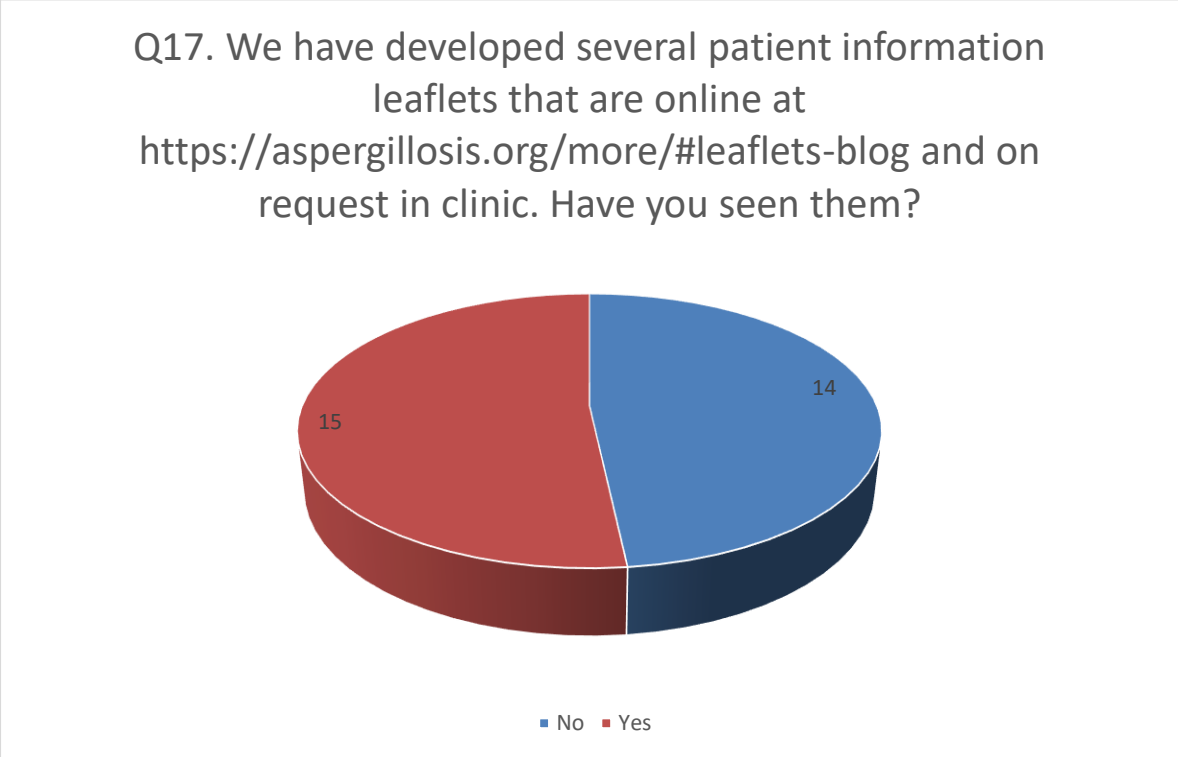
No patient travelled to the clinic using hospital transport in 2023 (0% 2022)



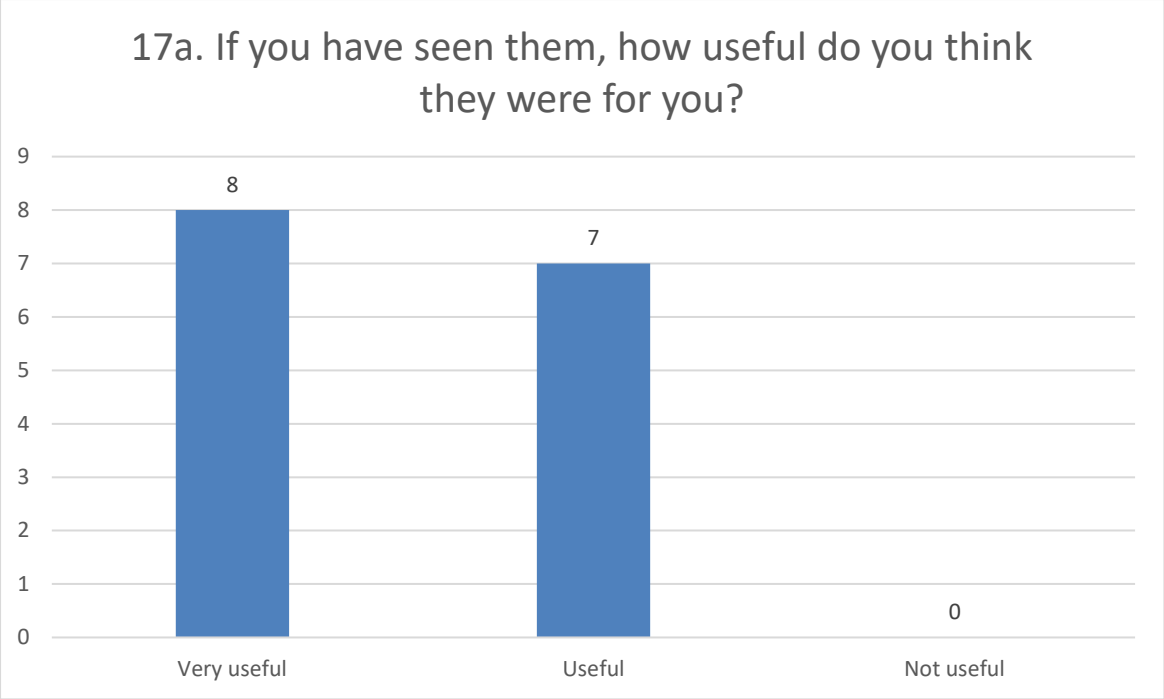
86% were happy to be contacted about research studies (88% 2022)



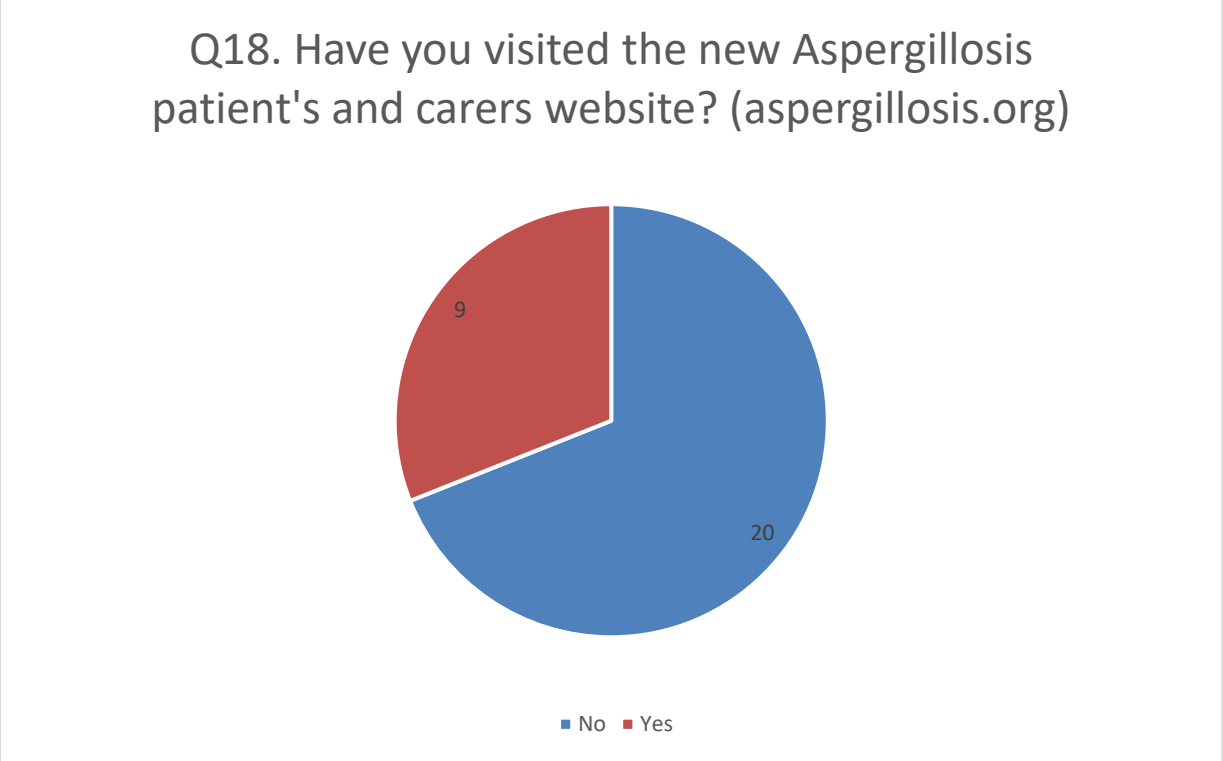
100% of patients were happy with the procedures and consent process (94% 2022)



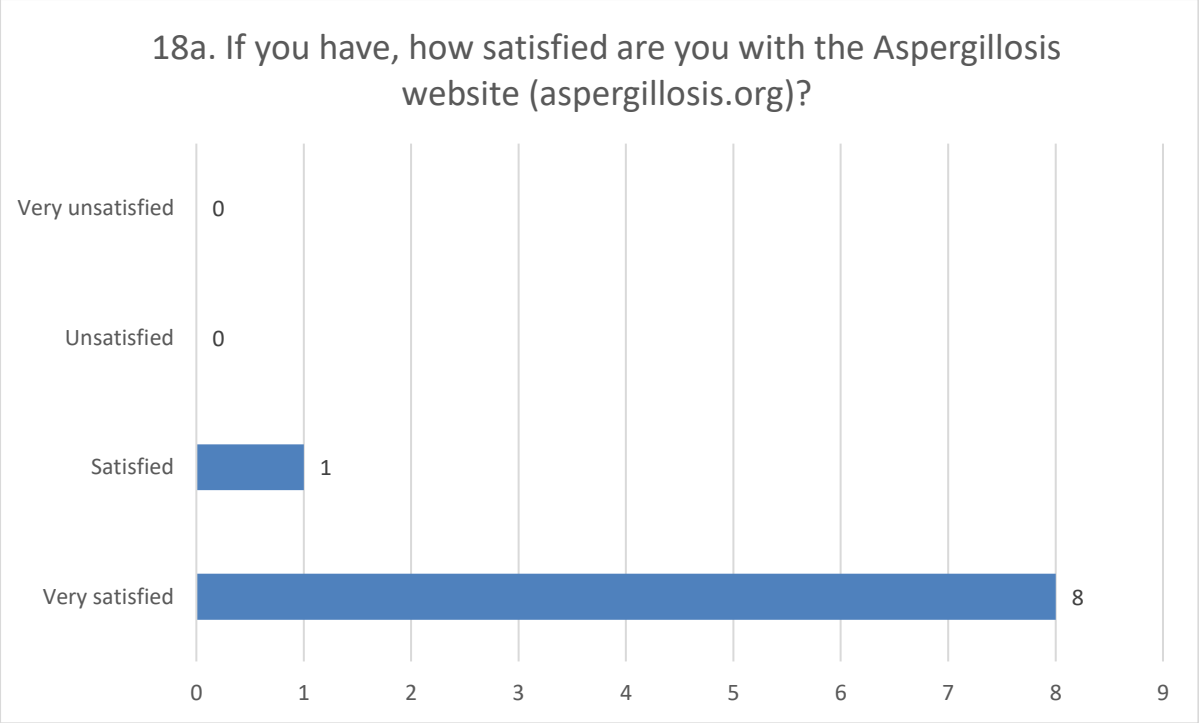
52% have seen our online patient information leaflets which is a marked improvement on 2022 (28%).



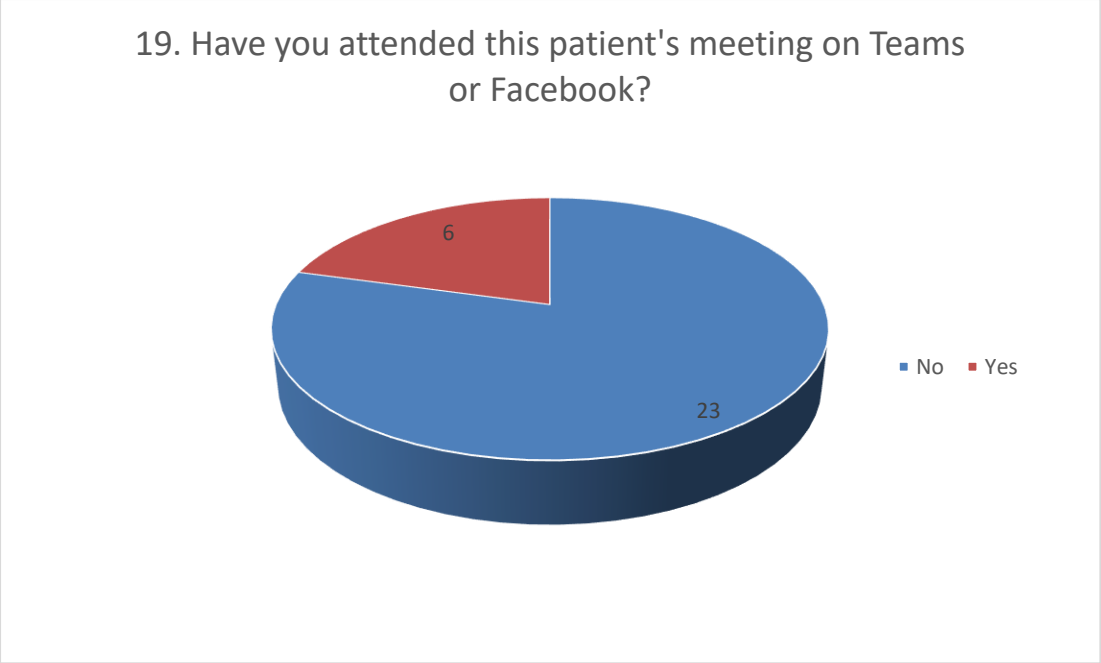
100% found our information leaflets useful



31% have visited the new aspergillosis.org website (40% 2022)



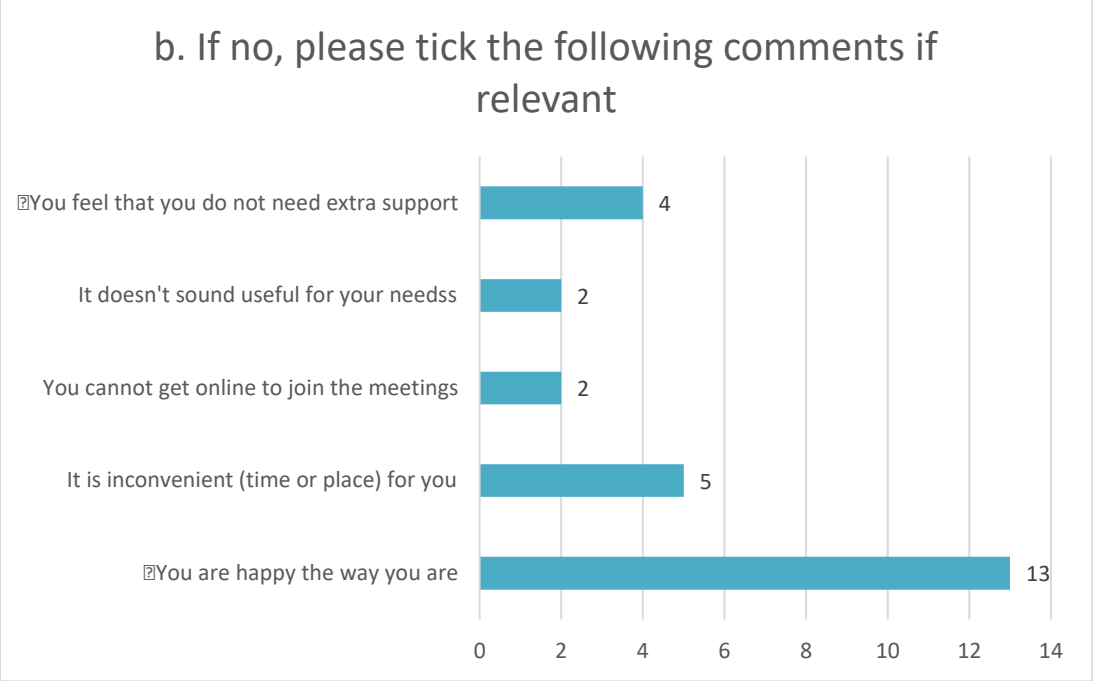
100% are satisfied or better with the aspergillosis.org.website (100% 2022).



21% have attended one of our online meetings which is a large increase on 2022 (7%)

Patient comments:

- These are excellent with time to catch up with others and very interesting and useful talks
- excellent range of talks by staff
- I attend Tuesday and the monthly zooms. The team are really knowledgeable and answer patients queries and advise on action we may need to take.
- I attended a few years ago, but not recently

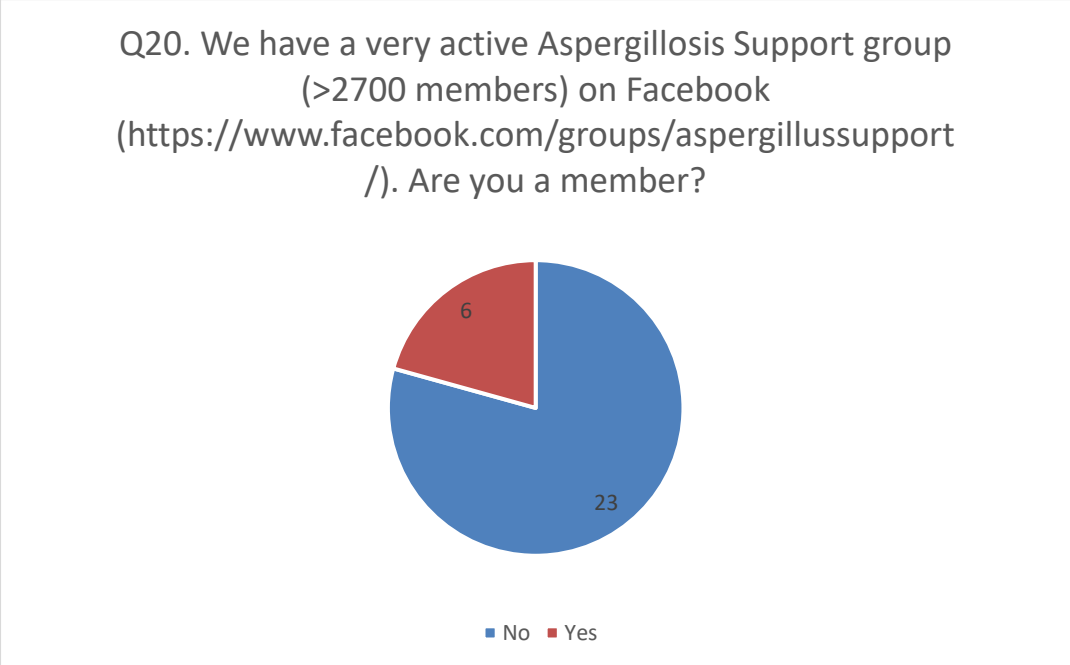


73% did not feel they needed this type of support (81% in 2022), but 27% expressed a wish to attend a meeting and the reason why they could not was lack of access to the internet (10% - this was 8% in 2022) or the meeting was put on at an inconvenient time for them (19% - this was 11% in 2022).

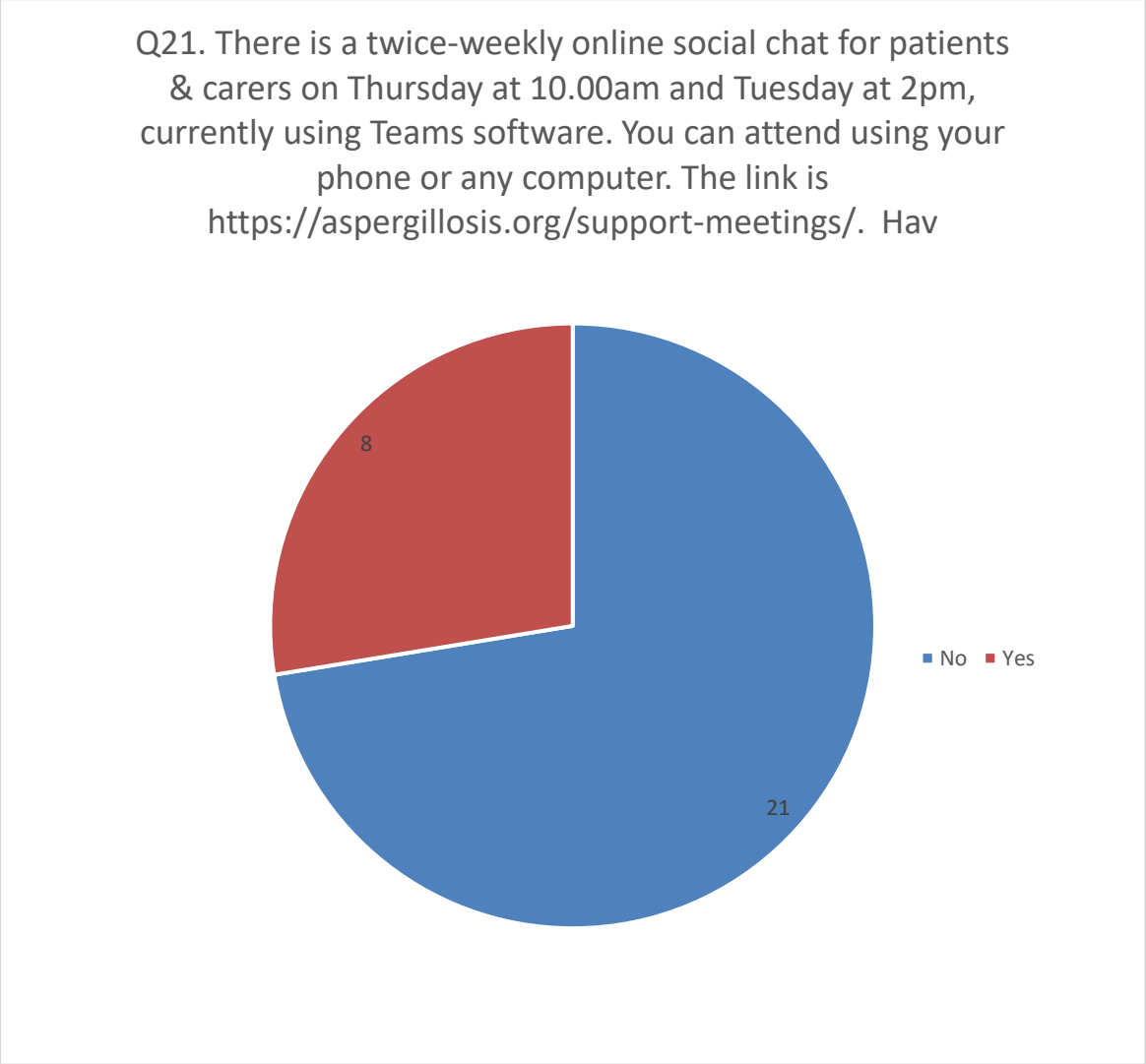
****Action point G Can we arrange meetings at a better time?*

Comments:

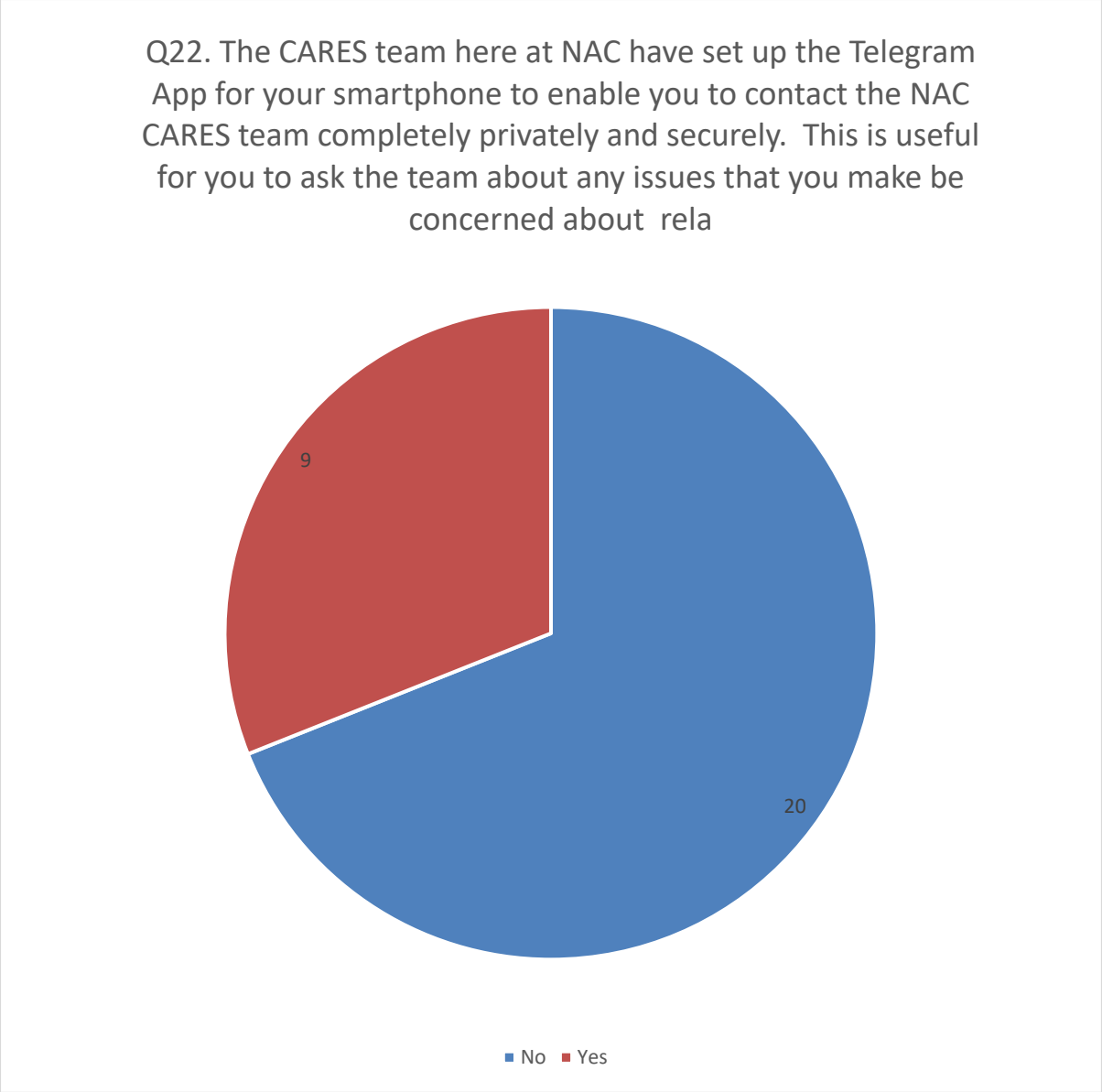
- These are excellent with time to catch up with others and very interesting and useful talks
- excellent range of talks by staff
- I attend Tuesday and the monthly zooms. The team are really knowledgeable and answer patients queries and advise on action we may need to take.
- I attended a few years ago, but not recently
- Didn't know about it
- They were quite difficult to understand



21% of patients are members of our Facebook group (18% 2022).



28% had heard of our weekly meetings ****Action point H – can we improve this?*



31% would like to hear more of Telegram (40% in 2022) ****Action point I*

Q23. Do you have any other general comments about the NAC service?

I expect to hear from Dr. ….. once he has the results of blood tests and my next CT scan.
Excellent patient care and I'm extremely lucky to be under their care. Thank you.
Thank you for all your support and treatment and advice
Would welcome any opportunity to be actively involved in new NAC drug and / or therapeutic treatments to suppress condition or improve lung - breathing condition . I am an active person and any new treatments providing benefits would be welcome .
Very professional, reassuring and friendly
Superb care received, thankyou !
Nebulised Fungizone has freed me from harmful steroids and my condition is hugely improved.
A big thank you to all the staff and doctors you're all appreciated keep up the great work you do
keep up the great support. I really appreciate it
not all people particularly senior citizens have smart phones and are not able to manipulate their way round websites which might seem simple to younger people ! ****Action point J*

Appendix 7 Engagement and Impact report

Social Media Impact and Patient Engagement Report

Summary

This section comprehensively outlines the multi-faceted communication strategies the National Aspergillosis Centre (NAC) employs. It highlights the importance of our digital support meetings, Telegram support groups, monthly newsletters, and social media channels. Our alignment with national NHS campaigns and World Aspergillosis Day 2023 is also discussed.

Digital Support Meetings

Twice-Weekly Informal Meetings

The NAC CARES team hosts twice-weekly digital support meetings via Microsoft Teams. These meetings are designed to be informal, providing a safe space for aspergillosis patients to ask questions, seek emotional support, and gain insights from our dedicated NAC CARES team and, more importantly, fellow patients with lived experience. The virtual format allows for broad participation, enabling patients from all over the UK to attend without the burden of travel.

To ensure seamless access, our team provides hands-on assistance to resolve any technological issues patients may encounter. Registration is streamlined through Eventbrite, which allows us to manage attendance effectively and send timely reminders to participants.

A survey of all attendees in the last twelve months was conducted in September 2023 and was completed by 13 attendees. A summary of the results is below:

The majority of respondents were aged 65 and above (71.4%), primarily discovered the virtual support meetings through the website (57.1%), and have attended 10 or more meetings (71.4%). The overall experience was rated as 'Excellent' by 85.7% of participants, and a significant 92.9% would definitely recommend these meetings to others. Most found the meeting times to be either very convenient (57.1%) or convenient (42.9%), and all agreed that the frequency of the meetings was 'Just Right'. When it comes to sharing thoughts, 71.4% felt very comfortable doing so. The meetings had a significant positive impact on the understanding of aspergillosis for 85.7% of respondents and improved the emotional well-being for 71.4%. Qualitatively, the meetings were highly praised for their informative content and sense of community. Many respondents highlighted the significant positive impact the meetings had on their emotional well-being and understanding of aspergillosis, reducing feelings of loneliness and increasing their knowledge of the condition.

Monthly Formal Meetings

In addition to the twice-weekly sessions, we also host once-monthly virtual meetings that are more formal in nature. These sessions feature talks from NAC staff or guest speakers on topics highly relevant to our patient community. For instance, given our patients' frequent use of steroids, we invited an endocrinology specialist nurse to discuss secondary adrenal insufficiency. Other talks have been delivered by our specialist pharmacist and physiotherapists, providing a well-rounded educational experience for attendees.

Telegram Support Groups

We have established support groups on the Telegram messaging app as an alternative channel for patient engagement. These groups allow patients to seek advice, ask questions,

and find emotional support. This multi-platform approach ensures that every patient has at least one accessible way to connect with our support services, fulfilling our commitment to inclusivity.

Monthly Newsletter

Our recently implemented monthly newsletter serves as a comprehensive source of information, featuring articles from our website and other trusted providers like Asthma UK. It also informs patients about essential updates, such as industrial actions that could affect their appointments.

Social Media

Our social media strategy is not a one-size-fits-all approach; instead, it is tailored to engage different community segments. Each platform serves a specific purpose and audience:

Facebook: A Patient-Centric Community

Facebook is primarily used to engage with patients and those living with aspergillosis. There are two facets: a virtual support group where we share patient stories, educational content, and updates about our digital support meetings, and a 'business page where we share educational content and information about resources and raise awareness of national NHS health campaigns. The platform allows us to create a sense of community among patients, providing them with a space to share experiences and seek advice.

X (Formerly Twitter): Medicine and Research

Our Twitter account is largely focused on the medical and research communities. We use this platform to share the latest research findings (our own and other organisations), medical guidelines, and updates about seminars and talks. Twitter allows us to engage in real-time conversations with clinicians, researchers, and other healthcare professionals, fostering a collaborative environment. In addition, we use this platform to align with and promote national NHS healthcare campaigns.

LinkedIn: Research and Medical Communities

LinkedIn is exclusively used for engaging with the research and medical communities. We share research publications and professional opportunities, aiming to establish the NAC as a thought leader in aspergillosis.

YouTube Channel

Recognising the value of making educational content accessible for future reference, we have developed a YouTube channel where all talks from our digital support meetings and World Aspergillosis Day content are uploaded. This allows those who could not attend the live sessions to watch back at their convenience, extending the reach and impact of our educational efforts.

Cross-Promotion and Content Sharing

We make a concerted effort to stay abreast of relevant topics and trends in the healthcare sector. This includes sharing and promoting content from other organisations that align with our objectives. By doing so, we not only enrich our content but also foster relationships with like-minded organisations.

World Aspergillosis Day 2023

Founded and led by the National Aspergillosis Centre, World Aspergillosis Day is a global call to raise awareness about this often-underdiagnosed fungal infection. For World Aspergillosis Day 2023, the NAC spearheaded a series of ten seminar talks featuring experts from various fields. Topics ranged from the current scenario of CPA in India to new research models for studying Aspergillus infections. The event also included discussions on damp

homes and their health implications and collaborative efforts to improve awareness and patient outcomes for those affected by fungal diseases. By leading this initiative, the NAC continues to set the standard for education, awareness, and patient support in the field of aspergillosis. A survey sent to participants after the event indicated that the World Aspergillosis Day Seminar Series 2023 was a success, drawing an audience of 185 attendees from diverse professional backgrounds such as clinicians, researchers, microbiologists, and patients. The seminars received overwhelmingly positive feedback; approximately 70% of survey respondents rated the event as "Excellent," and an additional 25% rated it as "Good." Moreover, about 80% of attendees indicated a high likelihood of recommending the event to colleagues and friends. While the seminars were generally well-received, with over 85% of respondents expressing satisfaction with the talks, there were constructive suggestions for improvement, particularly concerning technical aspects like sound quality. The event not only met but often exceeded expectations, setting a high standard for future seminars in the series.

Channel analytics July 2022 – July 2023

Growth and Metrics

Our social media channels have seen consistent growth, indicating their effectiveness in community engagement (detailed statistics will be provided in the table below). We continually assess the performance of our social media content through analytics, focusing on engagement metrics to fine-tune our strategies.

Overview

The table presents a comprehensive year-on-year analysis of key performance indicators (KPIs) for our social media platforms—Twitter, LinkedIn, and Facebook—from 2021 to 2023. The metrics covered include Growth/Followers, Total Engagement, and Total Reach/Impressions.

Columns

Year: This column lists the years under consideration—2021, 2022, and 2023.

Platform: This column specifies the social media platform for which the metrics are being reported.

Followers: Total number of followers.

Growth: This column shows the annual growth in the number of followers for the 12-month period.

Total Engagement: This column provides the total number of interactions for the 12-month period, which is a measure of participation or interaction with content. Engagement can include:

- Liking
- Sharing
- Commenting

Total Reach/Impressions: This column indicates the total number of people who saw any content from our social media page, or the total impressions made by the content, for the 12-month period.

Platform	Year	Followers	Annual Growth	Total Annual Engagement	Total Annual Reach / Impressions
Twitter	**2021**	2543	19.39%	4242	2.9million

	2022	3300			
	2023	3940			
LinkedIn	**2021**	1291	44.53%	8403	132.8K
	2022	1736			
	2023	2509			
Facebook	**2021**	435	22.30%	-	7K
	2022	601			
	2023	735			

Summary

In summary, the data from 2022 to 2023 shows consistent growth across all platforms, with LinkedIn leading. The lower growth and follower count on Facebook can be attributed to its target audience, which is significantly smaller due to the rarity of aspergillosis, which means that the community of patients and carers is smaller. Therefore, the potential for growth on a platform targeted at this specific patient group, like Facebook, is inherently limited. The high levels of engagement observed on Twitter and LinkedIn among researchers and clinicians are highly encouraging. This heightened interaction not only signifies a growing interest but also suggests an active pursuit of knowledge and collaboration within the medical community. Such engagement is crucial for a rare disease like aspergillosis, as it fosters a conducive environment for research, improved patient care, and potentially, more effective treatments. The strong digital presence of professionals in this specialised field is a positive indicator for future advancements in aspergillosis research and treatment.