

NHS National Commissioning Group - Highly Specialised Services

Chronic Pulmonary Aspergillosis National Service

The National Aspergillosis Centre

Annual Report 2020-2021



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1. Annual Service Overview and Highlights

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

This year has been unique and full of challenge due to the emergence of the Covid-19 (SARS-CoV-2) global pandemic. Our patients have faced the unprecedented intervention of social shielding to reduce their risk of contracting Covid-19. Our team has shown remarkable adaptability, innovation and strength throughout the year. It has been necessary to change many aspects of our service, some of which have brought about benefits for our patients while others have led to uncertainty and concern.

A total of 37 new patients from England and Scotland (and a further 2 patients from Wales) were assessed at the NAC and diagnosed with Chronic Pulmonary Aspergillosis (CPA) between 1st April 2020 and 31st March 2021. This was out of a total of 138 new patients referred and assessed for all forms of Aspergillosis. Referral numbers saw a significant drop due to the emergence of the COVID-19 pandemic in March 2020. The pandemic led to the cancellation of all routine new patient services and appointments. We have observed a steady number of patient deaths within the service as a whole and also for new patients within the first year of referral. We have not seen excess deaths due to the pandemic. There has been a significant increase in discharges from service due to robust MDT discussions of patients with stable disease, not on current antifungal therapy. Many of these patients are discharged from the commissioned service but remain under our care in the tertiary MFT Aspergillosis service. At the end of March 2021, we had 418 patients from England and Scotland on service and a further 22 patients from Northern Ireland, Wales, The Isle of Man and overseas (non-commissioned funding).

With the exception of the period March to July 2020 when we were unable to see new patients, waiting times for new patient appointments have remained low, under 5 weeks. We have maintained our out-patient follow up activity by introducing video consultations, telephone consultations and continued face to face appointments for patients who were unwell or requiring a change to therapy. Hospital admissions have been very low due to the need to only admit critically unwell patients. Non-emergency elective surgical procedures were also cancelled leading to only 1 urgent surgical resection during the last year. Our OPAT service remained active and provided required therapy to 4 patients saving 70 bed days. Overall drug expenditure has reduced compared to last year and reflects the reduction in new patients. The proportion of the different antifungals prescribed has remained stable.

It has been necessary to alter the clinical criteria for determining success to antifungal treatment and our reporting has extended to include Voriconazole alongside Posaconazole and Isavuconazole to give a clearer picture of response to treatment across the commissioned pathway. A total of 28 drug trials were given during the last year with a success rate of 75%.

There have been no serious untoward incidents. There has been 1 hospital reported incident and 1 formal complaint which have been responded to and provided

assurance within trust governance structures. Feedback from the annual patient survey remains extremely good.

Patient support has never been more important than over the last year. Our CARES team (Community, Awareness, Research, Education, Support) have been there to support our highly vulnerable patients providing daily Zoom sessions and continuing the monthly patient and carer's meetings but moving to an online platform. Not only has this provided much emotional and social support but it allowed delivery of educational updates on the Covid-19 pandemic scientific data, information on vaccine development, shielding and employment. Our patient survey reflects the hard work of our team over the last year with very high patient satisfaction. The survey has also highlighted some important areas of development for the future. The CARES team have developed our social media channels this year including Twitter, LinkedIn and Facebook, all of which have seen a dramatic rise in followers. We additionally have taken a new focus on our patient website which has seen a large rise in usage. This will remain a focus for development over the next year. We have continued to raise public awareness and educational outreach via World Aspergillosis Day, monthly newsletters and clinician education throughout the UK.

The NHS Mycology Reference Centre Manchester (MRCM) provides the high-level diagnostic mycology service for the NAC and has successfully retained its UKAS accreditation. 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 and Aspergillus IgG determination by lateral flow assay being the latest developments. The mycology laboratory has seen a significant rise in activity during the pandemic due to the need to provide diagnostics for Covid-19 associated pulmonary aspergillosis (CAPA).

The NAC has continued its reputation in international research with 26 publications relating to aspergillosis diagnostics and treatment. The team delivers educational lectures and seminars nationally and internationally.

Our primary aims for the forthcoming year include re-establishing referrals, adjusting the balance of virtual and face to face appointment both as the pandemic eases and according to patient wishes, establishing a national MDT, developing and formalising our external advice and guidance and improving real-time patient feedback via text survey.

2. Clinical Service

2.1 Clinical Service Overview

The NAC is commissioned by NHSE to provide care for patients with Chronic Pulmonary Aspergillosis (CPA) – this includes initial assessment and diagnosis, evaluation of disease status (banding), prescription of antifungals, and ongoing long-term clinical management. Referrals are from specialist hospital consultants, predominantly in respiratory medicine and infectious diseases. We aim to see patients

within 6 weeks of referral. The service has adapted its delivery of care during the Covid-19 pandemic in accordance with government policies and patient choices.

Whenever possible we have continued to assess new patients face to face but when this has not been possible, we have conducted video consultations (Attend Anywhere). For all new patients requiring prescription of medication, we have ensured face to face consultation. Initial clinical assessment includes a full clinical and medication history, Aspergillus blood and sputum tests, lung function, radiological imaging, and an assessment of immune status. Baseline quality of life assessments, weight and MRC breathlessness scores are documented. Patients are provided with written information 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 for further tailored information such as exercise programmes. We follow a clear diagnostic algorithm to ensure consistent quality of care for all patients.

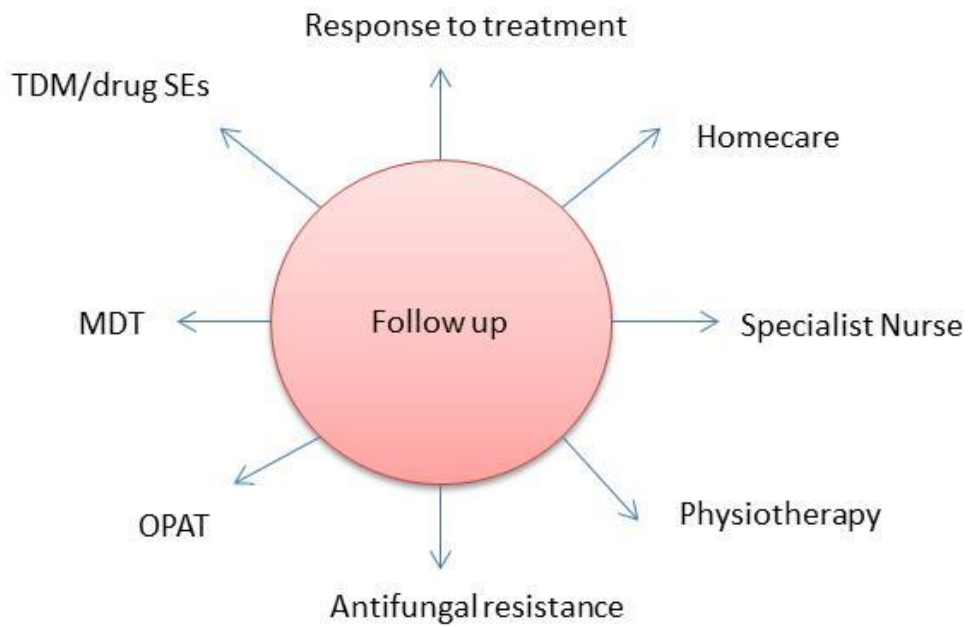
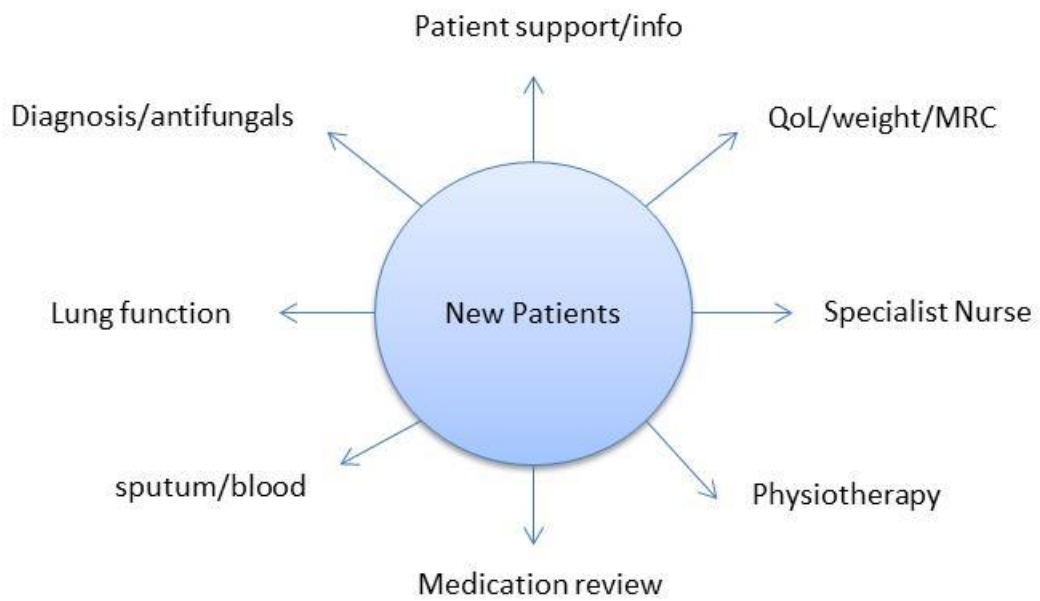
The arrangements for ongoing follow-up appointments have changed drastically due to the Covid-19 pandemic. The majority of appointments have been conducted virtually, either by telephone or video consultation. Our care strategy however has not changed. Ongoing long-term management includes evaluation of symptoms and response to medication, drug side effects, TDM monitoring of drug levels, withdrawing medication when there is no effectiveness as per our agreed clinical pathways, establishing homecare medication delivery direct to the patient every 2 months, liaison with the referring local team and GP to treat co-morbidities and organise necessary tests and delivery of treatment close to home whenever possible. The proportion of investigations performed closer to home has increased during the pandemic, which has often suited patients far better.

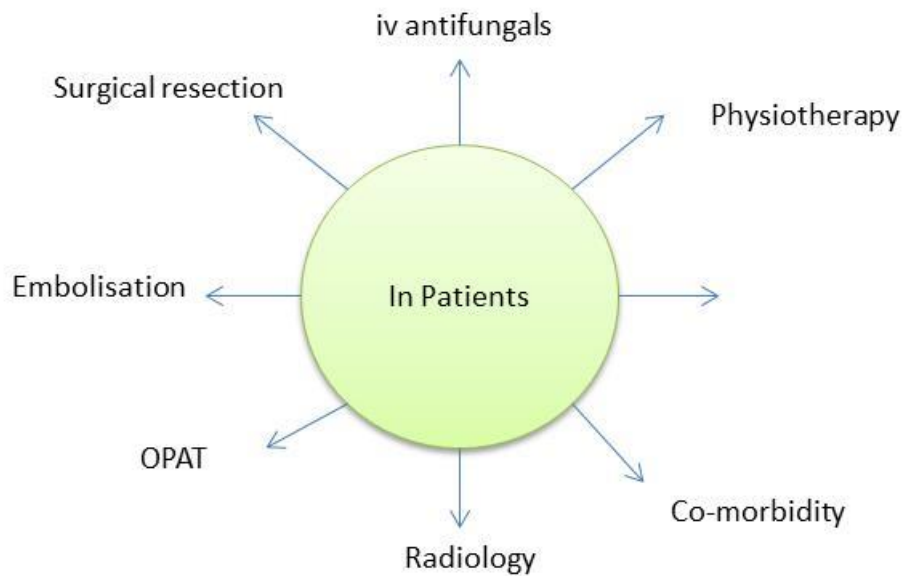
In addition to our out-patient clinics we also deliver short-term inpatient care – this includes evaluation of disease, intravenous therapy, bronchial artery embolisation, surgical resection, training in intravenous line management and delivery of iv antifungals in the community (OPAT). This work has continued throughout the pandemic but seen a significant reduction in activity.

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

It is essential that patient interventions and outcomes are measured continuously, and we undertake a clinically focused programme of audit as agreed with NHS England. This report details the outcomes over the time period 1st April 2020 to 31st March 2021.

Schematic diagrams of NAC services





2.2 Workforce infrastructure and sustainability

Clinical and administrative personnel

The following clinical and administrative personnel have been vital members of the NAC staffing team during 2020-2021:

Dr Caroline Baxter, Consultant in Respiratory Medicine (3 PAs)
 Dr Chris Kosmidis, Consultant in Infectious Diseases (3 PAs)
 Dr Gianluca Grana, Consultant in Infectious Diseases (3 PAs)
 Dr Rohit Bazaz, Consultant in Infectious Diseases (3 PAs)
 Dr Giorgio Calisti, Consultant in Infectious Diseases (3 PAs)
 Dr Manuela Barrera, Consultant in Infectious Diseases (3 PAs)
 Dr Riina Richardson, Honorary Consultant in Mycology (2 PAs)
 Mrs Christine Harris, NAC manager (100%)
 Ms Deborah Kennedy, Specialist Nurse (20%)
 Mrs Jenny White, Specialist Nurse (80%)
 Ms Rochelle Baron, Specialist Nurse (20%)
 Ms Smitha James, Specialist Nurse (20%)
 Mr Adam Bartle Specialist Nurse (50%)
 Ms Lincy Cyriac Specialist Nurse (70%)
 Mrs Carol Toner, Band 3 HCA (20%)
 Mr Philip Langridge, Senior Specialist Physiotherapist (100%)
 Ms Mairead Hughes, Specialist Physiotherapist (50%)
 Dr Christopher Eades, Senior Clinical Research Fellow (25%)

Dr Mathilde Chamula, Senior Clinical Fellow (self-funded placement)
Dr Alison Beech, Clinical Fellow (30%)
Dr Dorcas Obeng, Clinical Fellow (30%)
Dr Holly Smith, Educational Clinical Fellow (30%)
Dr Frkhinda Jbueen, Clinical Research Fellow (30%)
Ms Fiona Lynch, Specialist Senior Pharmacist (40%)
Dr Graham Atherton, Senior Information Technology Architect and Patient engagement (100%)
Mrs Lauren Amphlett, Website design and administrator for Patients (100%)
Dr Elizabeth Bradshaw, Medical Writer and Web Manager (100%)
Ms Carmel Marshall, B4 Administration Team Leader (50%)
Ms Soma Pal, B3 Administration and secretarial support (50%)
Ms Ruvimbo Nkomazana, B3 Administration and secretarial support (50%)
Ms Linda Shaughnessy, B2 Administration and secretarial support (50%)
Ms Megan Hildrop, B2 Administration and secretarial support (50%)
Ms Lucy McLachlan, B2 Administration and secretarial support (50%)

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

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

The total referrals, patient caseload, in-patient stays and procedures for 2020/2021 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	0	0	1	27	10	17	14	17	14	15	11	12	138
New Patients Testing	0	3	4	5	4	5	2	4	4	2	3	1	37
Outpatient Follow up attendances	72	102	101	113	53	80	131	115	78	111	107	99	1162
Caseload - Band 1	122	121	120	119	116	115	114	106	106	106	103	99	99
Caseload - Band 2	348	342	333	331	328	330	328	323	315	311	305	305	305
Caseload - Band 3	22	22	22	22	21	21	22	19	18	17	16	13	13
Occupied Bed Days	0	4	0	0	0	3	0	0	9	0	26	1	43
Inpatient Discharges	0	1	0	0	0	1	0	0	1	0	1	1	5
iv Homecare	0	0	0	20	20	0	16	0	0	0	0	0	56
Surgical Resection	0	0	0	0	0	0	0	0	1	0	0	0	1
Embolisations	0	0	0	0	0	0	0	0	0	0	2	1	3
Patient Death	5	8	7	2	3	1	5	10	5	3	5	5	59
Discharge from service	3	2	7	6	4	2	3	8	8	6	7	5	61

* The NCG funds patients from England and Scotland only

** Appendix 1 shows the clinical definition of case bands

Referrals

There was a total of 138 referrals assessed by the service for all forms of Aspergillosis from England and Scotland during the year 2020 to 2021. 37 (27%) of these received a confirmed diagnosis of CPA. All new patients are discussed at our weekly MDT to ensure a unified agreed diagnosis. The proportion of referrals with a diagnosis of CPA remained stable compared to the previous year (35%). However, there has been a large reduction in overall referrals, the major impact being due to the emergence of the global pandemic of COVID-19 (SARS-CoV-2). Additional to this, there has been a steady increase in provision of remote advice alone. We have therefore begun to collect data regarding this advice and guidance.

	Total Received	Advice Only	Rejected	To be seen
Nov 20	31	9	3	19
Dec 20	23	7		16
Jan 21	22	8		14
Feb 21	19	8		11
Mar 21	30	5		25
Apr 21	21	8		13
May 21	30	9		21
Jun 21	19	4		15
Jul 21	22	3	1	18
Aug 21	26	4	1	21
Sep 21	22	6		16

Oct 21	17	2		15
TOTAL	282	73	5	204

Out-patient waiting times

The mean time from referral to clinic consultation was 4.7 weeks (Appendix 2). 3 patients had long wait times due to the Covid-19 pandemic when no patients could be seen April to July 2020. 1 patient had a long wait due to personal choice to reschedule appointments. There were 4 transitions from another form of aspergillosis into CPA. 4 patients had delayed registration onto the service due to administrative error.

Geographical location

Appendix 2 shows the area of residence from which referrals originated. This data highlights and includes 2 referrals from Wales, outside of the commissioned area. Appendix 3 displays maps of the geographical locations (postcode areas) of the new patient referrals and all patients on service. There remains geographical inequity of referrals with a predominance from the North West of England.

Patient Caseload

At the end of March 2021, 418 patients from England and Scotland were on service with an additional 16 patients from Wales, 2 from Northern Ireland, 3 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 2020-2021 there has been a fall in patient numbers across all bandings. Band 1 patient numbers fell from 122 to 99 (19%), band 2 fell from 348 to 305 (12%) and band 3 fell from 22 to 13 (41%). This reduction in patient numbers was due to patient deaths and discharges from service, alongside a reduction of new patients brought onto the service. There were 59 patient deaths which is a stable proportion compared to previous years (69 deaths in 2019-2020, 65 deaths in 2018-19 and 58 in 2017-18). There were 61 discharges from service which is comparable to the previous year (56 in 2019-2020). The number of patients discharged from service remains high due to robust MDT discussions about the need for on-going care of patients not on therapy. Appendix 4 details those discharged from service. We managed to maintain out-patient follow up appointments with a total of 1162 being performed using a combination of virtual and face to face consultations.

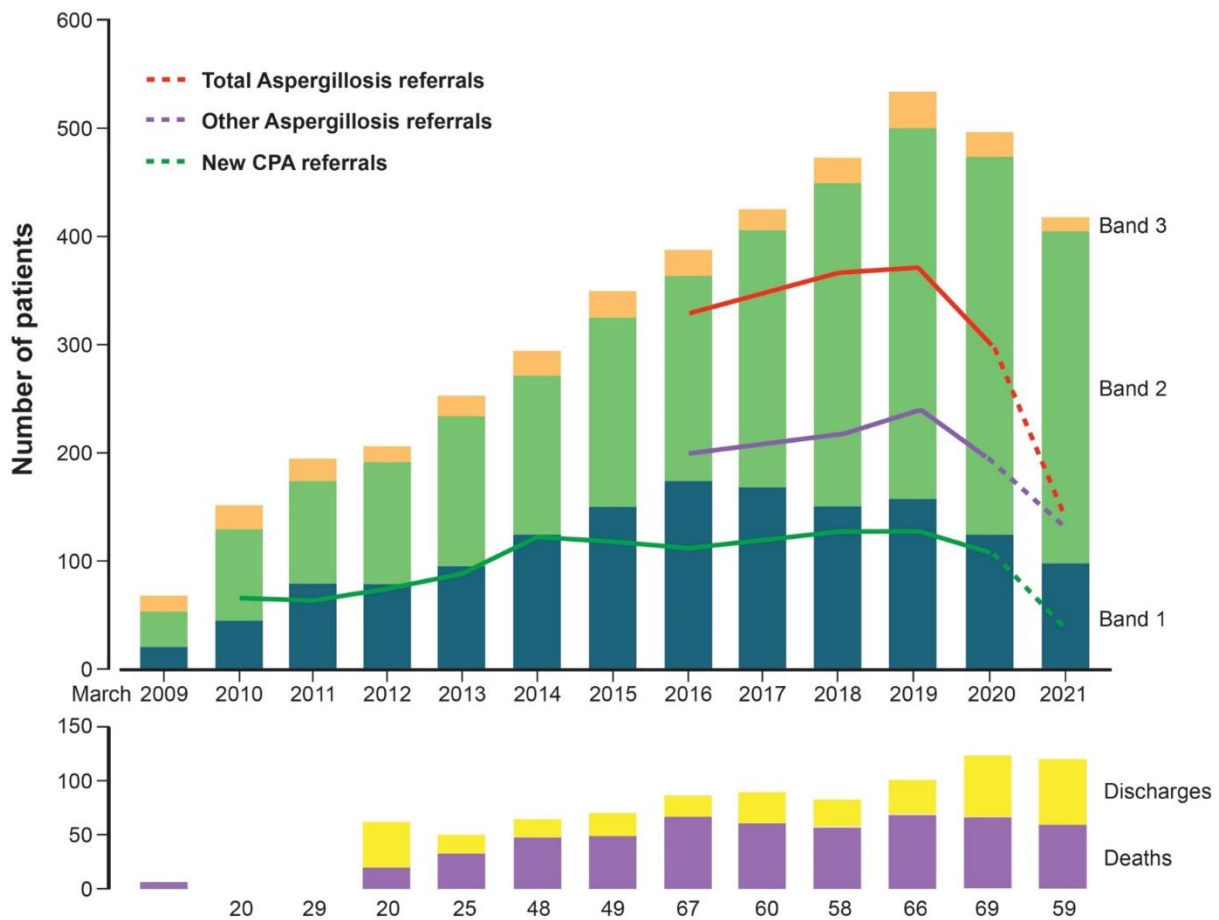
In-Patient Hospital Activity

There were 5 admissions with 43 bed days, which is an all-time low for the service and was predominantly secondary to the Covid-19 pandemic which meant that all but life-threatening conditions were kept out of hospital. There has been a continual reduction in hospital admissions and bed days since 2016. Hospital admissions are also reducing due to more patients being clinically stable on oral antifungals. The reduced use of iv antifungals has been evident since the introduction of Isavuconazole. In-patient bed days are additionally kept low with the use of the OPAT service and some patients receiving courses at their local hospital. Full details of hospital admission data can be found in Appendix 5.

One patient underwent surgical resection and 3 underwent bronchial artery embolization

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

NAC Referrals and Caseload 2009 to 2021



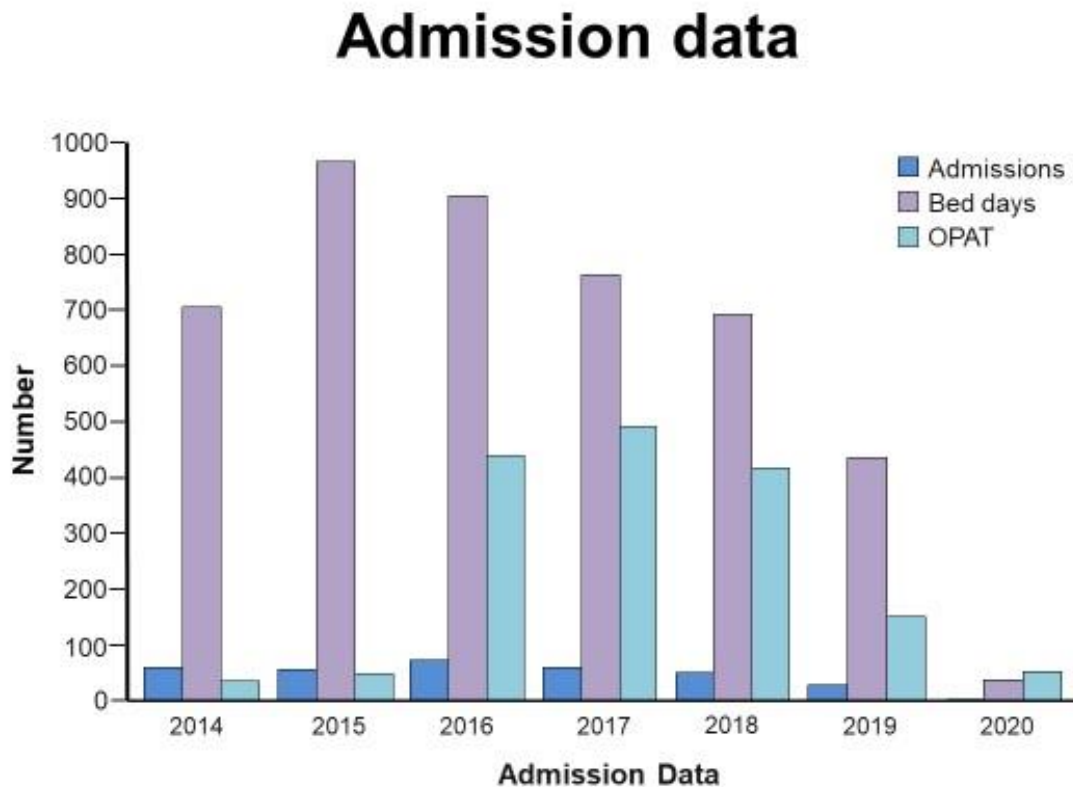
OPAT Activity

The outpatient parenteral antimicrobial therapy (OPAT) team provides intravenous therapy and clinical monitoring for patients deemed suitable to receive their therapy in the community. During the financial year 2020-21 the OPAT team successfully treated the following number of patients referred from the National Aspergillosis Centre:

- 4 courses of iv therapy in total were delivered to 4 patients: 3 iv micafungin, 1 iv antibiotics
- Bed days saved: 70

Intravenous Antifungals

There was a total of 3 courses of iv antifungals administered in 2020-2021 (Appendix 5). All 3 courses were iv Miconazole.



2.4 Treatment Outcomes

New referrals

Clinical data for the first 3 appointments after referral and radiology after 1 year of treatment is presented in Appendix 6. Clinical markers that are monitored include the MRC (medical research council) dyspnoea scale, SGRQ (St George's Respiratory Questionnaire), weight, serum Aspergillus IgG antibody levels and radiological chest imaging.

There were 9 deaths and 4 patients who were discharged within the first year of referral.

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

- improvement in 47%
- stability in 45%
- deterioration in 8%

Of the 4 patients with evidence of deterioration: 1 had antifungal therapy changed successfully, 2 underwent surgical resection and 1 awaits surgical resection.

2.5 Antifungal Trial Data

We continue to use n-of-1 trials for posaconazole and isavuconazole but now additionally include data for voriconazole. Determining a successful outcome of therapy has changed due to the Covid-19 pandemic. In previous years a successful outcome was determined by demonstrating a 3kg increase in weight or a 12-point improvement in SGRQ after 6 months. Due to the remote nature of many appointments these measures could not be monitored with accuracy. A successful outcome is now determined by demonstrating improvement or stability in CT scan and improvement in Aspergillus IgG. We still recognise the importance of measures of quality of life and try to collect this data when possible.

14 patients were trialled on posaconazole, 7 on isavuconazole and 7 on voriconazole in the year April 2020 to March 2021. All antifungal trial outcomes are discussed within our MDT. The outcomes are shown in the table below alongside data from the previous 2 years. The complete clinical data of the antifungal trials can be found in Appendix 7.

Overall success for all antifungal therapy was 75% (21 out of 28 patients). This compares favourably to previous years, likely due to a combination of reduced patient numbers and careful patient selection for treatment during the pandemic.

Trials of posaconazole/isavuconazole/voriconazole 2020-2021						
Outcomes	Posaconazole		Isavuconazole		Voriconazole	
		%		%		%
Success	9	64	5	71	7	88
Failure	5	36	2	29	0	0
Death	0		0		1	12
Total	14		7		8	
Pending	5		2		6	

Trials of posaconazole and isavuconazole 2019-2020				
Outcomes	Posaconazole		Isavuconazole	
		%		%
Success	15	48.3	4	33.3
Failure	13	41.9	8	66.7
Death	3	9.9	0	0
Total	31		12	

Trials of posaconazole and isavuconazole 2018-2019					
Outcomes	Posaconazole		Isavuconazole		
		%		%	
Success	15	41.7	7	46.7	
Failure	19	52.8	8	53.3	
Death	2	5.6	0	0	
Total	36		15		

2.6 Intravenous antifungal therapy

Intravenous antifungal therapy is most often used when azole therapy has failed, or resistance has developed.

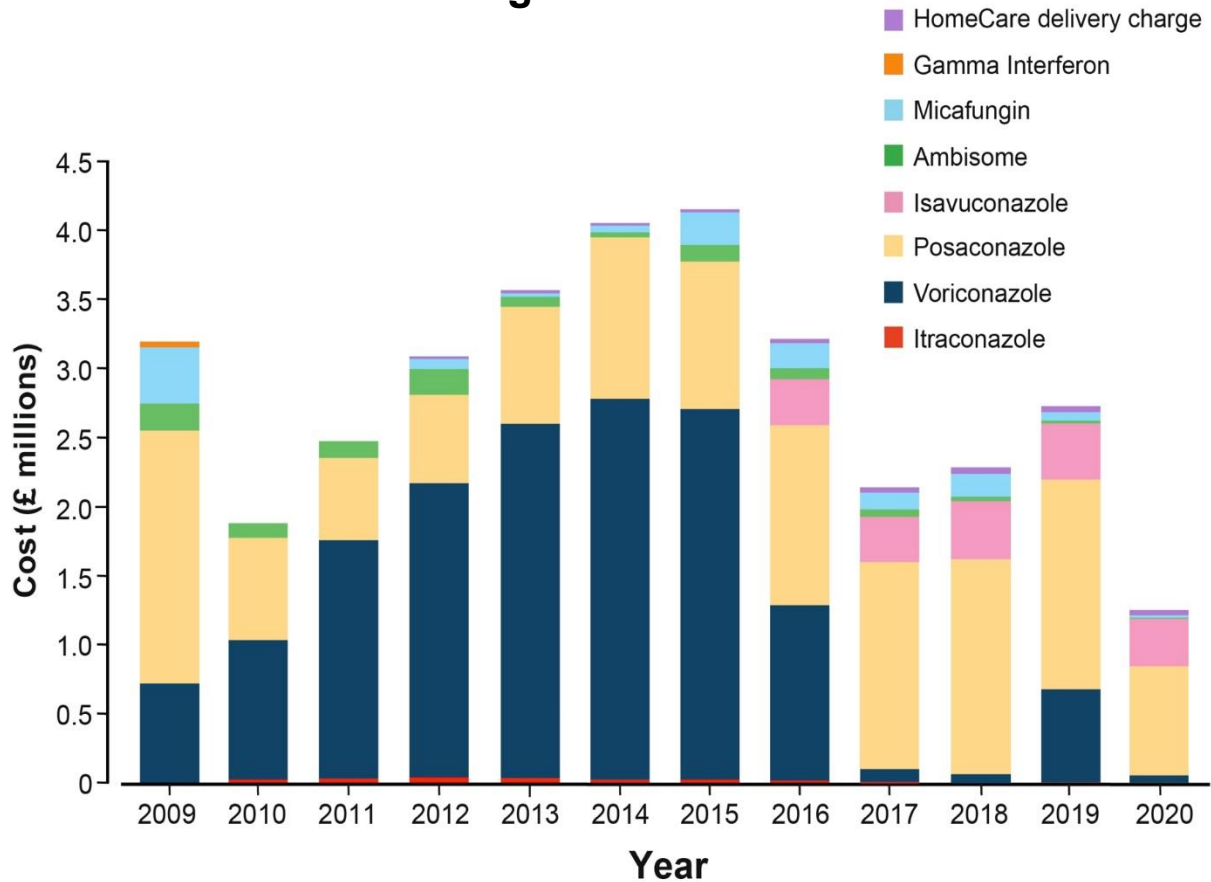
There was a total of 3 courses of intravenous antifungals given in 2020-2021.

All 3 courses were of Micafungin and all showed a documented improvement with therapy as evidenced by a combination of SGRQ, weight, CT findings and serology.

2.7 Antifungal prescribing and expenditure

Antifungal prescribing has fallen due to reduced patient referrals. Overall proportion of costs across antifungal drugs appears stable. 2019-2020 saw the cost of voriconazole increase due to national pharmaceutical supply problems of the generic brand raising costs through prescription of brand name. This issue was present for approximately 3 months.

NCG drug costs



3. Specialist Nurse Service

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

- Independently review patients in outpatient clinics via telephone, video and face-to-face appointments
- Answer patient enquiries and provide support via a patient phone line available 5 days a week.
- Provide high quality care to patients attending clinics and for those admitted to hospital.
- Provide remote antifungal therapeutic drug monitoring through reviewing results daily, adjusting patient doses and communicating these changes to the patient, GP and homecare delivery service.
- Deliver a paid postal service to provide remote blood and sputum testing
- Senior nurses continue to independently prescribe treatment

The NAC nursing service challenges in 2020-2021:

- Maintaining the quality of telephone enquiries through the COVID-19 pandemic, due to time and staffing constraints, which may have led to dissatisfaction for some patients
- Complex clinical presentations and outpatient consultations due to patients not seeking alternative healthcare resources
- Providing resource to the trust COVID-19 virtual ward by undertaking daily patient assessments

Developments for the nursing team 2021-2022:

- Audit programme development with a focus on patient safety and satisfaction
- A plan to work closely with the communications (CARES) team to help improve the patient-nurse rapport that has been a challenge due to the turnover of staff and increased remote working
- Plan to continue to develop the team to increase their skills and knowledge. An additional independent prescriber is due to start and complete competencies in 2022.
- Develop real time patient feedback to help guide learning and development
- Plan to develop and deliver more educational sessions for other healthcare teams

The service continues to have positive feedback from patients, and this is reflected in the annual patient survey.

4. Physiotherapy Service

The physiotherapy service is delivered by 2 specialist respiratory physiotherapists who provide patient assessments for airway clearance, nebulised drug challenges, spirometry, and provision of appropriate exercise programmes including referral/signposting to pulmonary rehabilitation.

As for many services, the Covid-19 pandemic has meant 2020-2021 has been a turbulent and challenging time for the physiotherapy service. This was primarily because most of the services described above were deemed aerosol generating procedures (AGPs) which carry a greater risk of Covid-19 transmission and therefore required personal protective equipment (PPE), enhanced patient testing and clinical space with adequate ventilation. It has been a period when the team have required to be flexible and adapt to quick changes in national and local policy/ procedures. Despite these challenges it has been a great period of service development and success.

Service development

At the onset of the Covid-19 pandemic the team were involved in:

- respiratory skill training for the Manchester Nightingale Hospital physiotherapy team
- PPE training rollout

- guidance of local policy regarding face-to-face inpatient and outpatient physiotherapeutic interventions.
- helped ensure shielding patients were couriered nebulising equipment/medications that they would otherwise have struggled to obtain

The team were able to influence local policy, successfully pressing the case to deliver essential physiotherapeutic interventions when patients attend face-to-face appointments. There is now protected space throughout clinics to ensure those that need intervention can be treated.

Our models of working now include the capacity for telephone and video appointments. Our exclusive range of video resources have been used successfully to support our patients. A patient survey was conducted to gain feedback on these services and the results were used to submit a poster to the Association of Physiotherapists in Respiratory Care Conference which was accepted and awarded “highly commended”. The salient points were:

- 55% of eligible patients responded.
- 100% benefitted “a lot” from their appointment.
- 73% would opt for a virtual or telephone appointment in the future, citing distance or shielding as the main reasons for this.
- 100% received additional resources in the form of video links or leaflets which were deemed very (64%) or extremely (36%) useful.
- 82% understood all and 18% understood most of the information provided.

All patients surveyed reported that the remote physiotherapy consultations and the resources provided were useful. Additionally, patients indicated they would agree to a remote consultation in future. Remote consultations will continue to be an integral part of the NAC physiotherapy service as a result of this feedback and due to the ongoing need for a new service model emerging from the Covid-19 pandemic.

Education

Both physiotherapists now have their independent prescribers’ qualification which strengthens the team’s skill mix and brings direct benefits to patient care.

The team have continued to provide patient education offering 2 patient talks via Zoom on the subjects of “Managing Breathlessness” and “Exercise” which were topics patients had expressed an interest in. These talks were recorded and are available online:

- <https://aspergillosis.org/managing-breathlessness-recording/>
- <https://www.youtube.com/watch?v=nYruaG4ZcvI>

“Managing Breathlessness” Patient Feedback
<ul style="list-style-type: none"> • Excellent talk • Thank you for scheduling in the afternoon. Most helpful for my ability to attend. • I had no questions as I have not had any information from my consultant as yet on how to manage the aspergillus the only information I hold has been from the internet

<ul style="list-style-type: none"> • It was well put together and I really appreciated the presentation.
<ul style="list-style-type: none"> • It was an enjoyable and useful seminar and much appreciated
<ul style="list-style-type: none"> • I submitted a question via Facebook for the presentation. I was sad it didn't get asked. Perhaps it was a silly question.
<ul style="list-style-type: none"> • Phil was very nice and informative.
<ul style="list-style-type: none"> • Looking forward to talk on exercise. Thanks Phil.
<ul style="list-style-type: none"> • Personally, I feel if you suffer from breathing difficulties the more knowledge you glean the better when we are ill or recovering from a flare-up it's easy to forget the techniques and this presentation was a good way to refresh my memory about breathing techniques, discover new techniques, when your recovering you don't take everything in and store it for future so it's a bit like revision for exams only it's breathing exercises, also learning about the chest muscles. I have had serious breathing problems for 22years plus and I found this talk taught me a few things and I'm sure most people know when they become so breathless that they need to call 999. If we weren't shown these breathing techniques and practised them several of us wouldn't be here now. I thought it was great, explained the different types of breathlessness, breathing techniques and what happening to your airways whilst your doing them. Thanks and I'm really looking forward to the exercise session on 29th, thankyou everyone x

<p>“Exercise” Patient Feedback</p>
<ul style="list-style-type: none"> • Phil on form as usual, very professional and approachable
<ul style="list-style-type: none"> • Must have taken Phil a long time to structure the presentation whilst at the same time covering the question patients had it was well presented content was excellent. I also enjoyed the smart exercise slides I took a lot away from the presentation thanks for doing it
<ul style="list-style-type: none"> • Good thoughts on setting realistic goals for our individual medical condition on advice from our consultant thanks
<ul style="list-style-type: none"> • I really like Phil's approach as he feels like one of us and is very personable and not too academic

- Would it be possible to post or email some physio exercises? I'm very interested in the whole care of the patient & the Manchester team seem to do this, promote it & seek ways to improve care. This was represented in your presentation. I find this is not the same in my area, even when you try to help yourself & seek out help/support. I know you are a specialist centre so there are differences, I understand that. The presentation was informative & useful. The goals I was glad to hear as it's something I've been doing myself since January without any support or advice. So it was reassuring to hear that it was the correct approach. And like you said, take it one step at a time which I've done & I've had setbacks but also made progress but with the right medication. Without the right medication I would still be ill in bed. However, I did not realise that it takes 4-6 weeks for improvements that was really interesting to hear & I can really resonate with this. This is what is happening with me. I would like to join another exercise presentation for those of us who prior to illness have been very active like myself. Cycling 35 miles in the hills in County Durham to trail running, doing HIT daily & mountain walking all day on a weekend. Thank you for your specialist talk. I am so grateful to be able to have access to the specialist centre in this way. It has been a lifeline for me to know that you and other specialist professionals are out there. It gives me hope.

- Thank you for answering my question re: lung exercising devices.

- I learned some new techniques to stop some of my early hours breathlessness, which seem to be working. Thankyou Phil, interesting chat.

- I really like Phil's approach as he feels like one of us and is very personable and not too academic

The year ahead

The team are committed to providing the highest quality and timely physiotherapeutic interventions for our patients. This will involve continued responsiveness to rapidly changing infection prevention policies and procedures alongside clinical space availability during hospital service restoration. The team will continue to develop services and education to provide a holistic care model to patients.

5. Manchester Regional Mycology Centre

Background to the Mycology Reference Centre

The laboratory, in partnership with the National Aspergillosis Centre, was awarded the status of the first European Confederation of Medical Mycology Centre of Excellence in January 2017. This accreditation has been maintained for 2020 - 2021.

The Mycology Reference Centre Manchester (MRCM) has completed its twelfth year of operations and has expanded in step with the evolution and continued growth of the National Aspergillosis Centre. There have been numerous developments and continued growth in its portfolio of tests and activities. In 2018 the laboratory became a member of the Manchester University NHS Foundation Trust Division of Laboratory Medicine and became the only stand-alone mycology laboratory in the UK to be accredited by the UK Accreditation Service (UKAS). The laboratory has successfully retained its accreditation status following UKAS surveillance inspections.

The objective of the MRCM is to provide a mycology reference service embracing all aspects of medical and public health mycology. The vision, scope and research activities can be viewed on the Centre's website: www.mrcm.org.uk



Role and Functions

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

- An exemplary reference mycology service for the National Aspergillosis Centre (NAC), clinics and hospitals in the UK and beyond
- International, national and local leadership in medical mycology diagnostic services, and training
- A service, which is comprehensive, interpretative, accredited and appropriate to user needs
- Education and training for all staff, including participation on national and international courses, that is appropriate and relevant to the departmental goals
- A safe, appropriate and comfortable working environment which is inspirational and motivating that empowers a team environment
- To maintain UKAS ISO 15189 Accreditation

- Maintain a research programme in house at the MRCM in collaboration with the NAC and support others undertaking mycology research within the Manchester Fungal Infection Network, within industry, and playing an integral part in clinical trials
- An excellent and close working relationship with the Infectious Diseases Department and the NAC. Good working relationships within microbiology, pathology and with other departments within the Trust, and colleagues in other hospitals and Universities.

Service Strategy

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

Research and Development

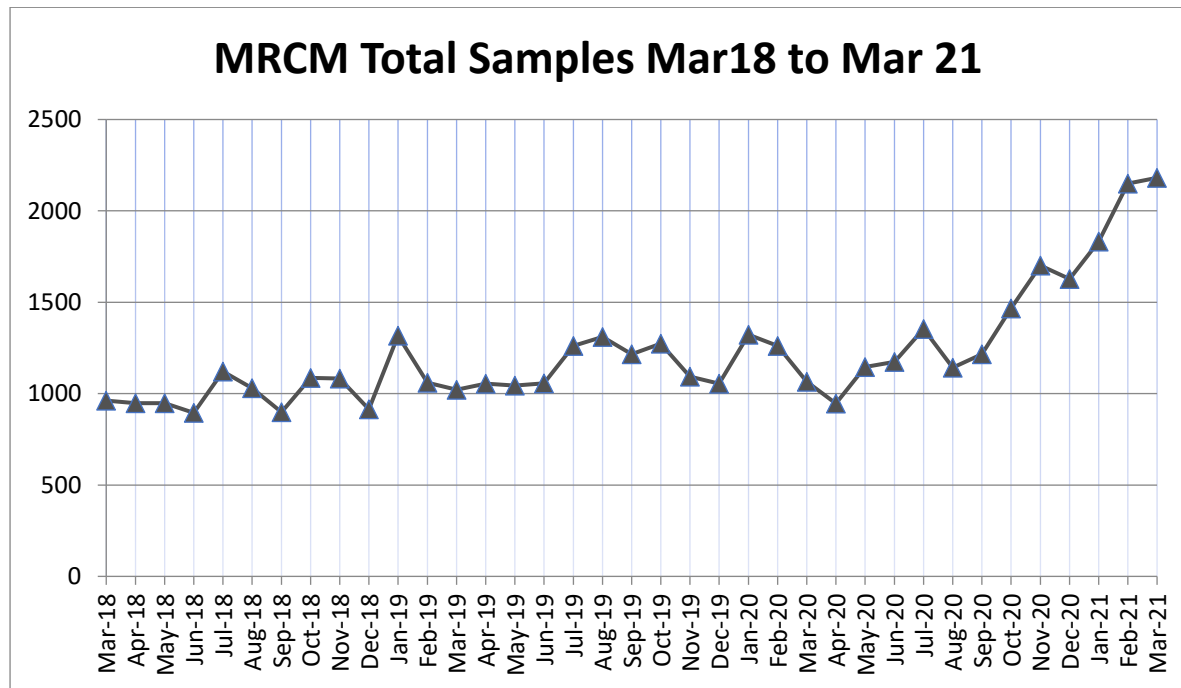
- Provision of undergraduate and post-graduate research training and supervision in many areas of medical mycology: BSc research projects, Masters projects, MD and PhD programmes.
- Supporting clinical trials and Infectious Diseases research and development projects
- Continued development, evaluation and validation of new and existing diagnostic tests:
 - Validation of IMMY Cryptococcal antigen lateral flow assay, now in routine use following UKAS accreditation
 - Revised processing of respiratory samples for GM testing to enable testing samples from COVID-19 patients.

Key Achievements - Summary

One of the hottest topics in medical mycology this past year has been how often COVID-19 is associated with fungal co-infections. This is particularly important for COVID-19 associated invasive pulmonary aspergillosis (CAPA) where prompt treatment with antifungals is essential for patient survival but the medications used have significant side effects. An algorithm for detecting CAPA in critically ill COVID-19 patients was developed and implemented during the first wave. Patients who were not improving on ICU were to be screened twice-weekly using fungal biomarker tests. When this was included in the national and international guidelines, the number of samples the MRCM as the NHS Reference Centre received increased further. A high number of specimens from critically ill patients are received from hospitals throughout the country including Edinburgh, Southampton, Belfast, and Isle of Man.

Our activity increased exponentially as the pandemic progressed. Almost overnight, the number of daily fungal biomarker runs doubled.

Even as COVID-19 patient numbers have decreased, biomarker test requests remain high – this is likely related to increased clinician awareness of utility of such testing for all critical care patients, and the excellent turnaround time (TAT) we offer. Throughout the pandemic we have been able to achieve our KPI targets of 95% ≤ 1 -day TAT for GM and ≤ 2 day TAT for BDG.



- Rapid adaptation of operational practices to enable safe testing of respiratory specimens from COVID-19 patients
- Rapid validation of safety protocols to ensure such procedures did not impact our assays
- Achieved and exceeded our turnaround times for all our biomarker tests – never once dropping below our KPI standard – despite significant staffing shortages
- DLM Excellence Award to MRCM for handling the exponential increase in *Aspergillus* and *Candida* biomarker assays during the first COVID-19 wave
- MRCM nominated for MFT STAR Award – ‘Working Together – Non-Clinical Team’
- Advanced mycology technologist, Katie Rawson, nominated for and winning MFT STAR Award – ‘Everyone Matters - Rising Star’
- Sustained development of a rapid-access clinical advice and support service
- New staff members appointed

- Regular huddles to inform staff on COVID-19 developments and provision of emotional support as needed.
- Introduction of new diagnostic test: IMMY Cryptococcal antigen lateral flow assay, and successful UKAS Extension to Scope
- Centralisation of superficial mycology service for Greater Manchester
- Maintaining UKAS accreditation following inspection in December 2020
- Involved in development of the HIVE EPR/Beaker IT system being implemented across MFT hospitals

Representation on National and International Committees:

1. EUCAST Antifungal Susceptibility Testing Committee as a Collaborating Laboratory
2. Dr Caroline Moore (CBM) is the UK representative for the European Committee on Antibiotic Susceptibility Testing (EUCAST) Subcommittee on Antifungal Susceptibility Testing
3. Standards for Microbiology Investigations (SMI) Steering Committee and Bacteriology Working Group (Dr Riina Richardson)
4. CBM is Honorary Treasurer of the British Society for Medical Mycology
5. International Society for Human and Animal Mycology
6. Public Health England English surveillance programme for antimicrobial utilisation and resistance (ESPAUR)
7. Academy of the European Confederation of Medical Mycology
8. British Society for Antimicrobial Chemotherapy Grants committee
9. Testing laboratory for UK NEQAS for Microbiology – Mycology identification and susceptibility schemes
10. Test centre for all Fungal PCR Initiative (FPCRI) schemes – fungal PCR for *Aspergillus*, *Candida*, *Pneumocystis*, *Mucorales* and tissue
10. Prof Malcolm Richardson: Co-authorship of *Global guideline for the diagnosis and management of mucormycosis: an initiative of the European Confederation of Medical Mycology in cooperation with the Mycoses Study Group Education and Research Consortium*. *Lancet Infectious Diseases*, 2019.
11. Dr Riina Richardson (RR) is the speciality representative for the Steering Committee and the Working Group for Microbiology Standards in Clinical Bacteriology (SMIs). These are standards for microbiological diagnostics in the UK but broadly used in Europe and beyond.
12. RR is the UK representative for the European Confederation of Medical Mycology (ECMM) Excellence Centre Assessment Committee setting the standards and accrediting centres for the diagnostics and management of mycoses globally.
13. RR is the Mycologist on the British Association for Sexual Health and HIV (BASHH) UK National Guideline on the Management of Vulvovaginal Candidiasis working group.
14. 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).
15. RR was elected as the Educational Officer for the ESCMID Fungal infection study group.

16. RR is the Lead for the European Fungal PCR Initiative (EFPCRI) *Pneumocystis* Working Group.

Research and Test Evaluation Activities:

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

- The use of Beta-D-glucan, PCR and other diagnostic tests in antifungal stewardship
- Ongoing experience regarding sensitivity testing on *Aspergillus* isolates to include terbinafine, micafungin, isavuconazole, and investigational compounds, for example, ibrexafungerp.
- Real-time PCR for *Aspergillus* in respiratory secretions and blood
- Molecular identification of fungi, including unusual *Aspergillus* species. This is a nationwide service
- Monitoring of NAC/CPA patients houses, workplaces for *Aspergillus*
- Provision of mycology services to national and international pharmaceutical companies who are developing new antifungal drugs.

Publishing Activities:

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

Training:

- Contributions to the development of an on-line histopathology of fungal infections training course, in collaboration with the University of Manchester, Leading International Fungal Education (www.LIFE-Worldwide.org - UK charity).
- Host to four University of Manchester PhD students
- Host to one University of Manchester MD student
- Host to University of Manchester undergraduate students for placement year
- Host to medical microbiology trainees
- Institute Pasteur, Paris – lectures
- Lecturing on University of Leeds Masters in Bioscience
- Lecturing on University of Keele masters in Medical Microbiology

Presentations and Global Outreach:

- Society for Indian Human and Animal Mycologists meeting (SIHAM)
- INFORM: ISHAM Regional Meeting in collaboration with Gilead Sciences (Dubai) meeting
- Departments of Haematology, UK

- Departments of Clinical Microbiology, UK
- Filmed lectures: Gilead Antifungal Information Network

Challenges:

We supported the critical care units not only at MFT but beyond by testing patient samples for markers of serious fungal infections. It was challenging at times because our workload increased exponentially as the pandemic progressed, whilst we coped with staff needing to self-isolate or shield.

During this time, we successfully retained our accredited status following a stringent UKAS assessment, and also added a new test on to our scope.

Despite these challenges, last year has also been amazing! It has been remarkable to witness how our team has pulled together, helping each other through such difficult times and enabling us to make a big contribution in the fight against Covid-19.

6. Mortality Report

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

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

For the period April 2020 to March 2021, 45 patients were discussed. The key issues identified, and lessons learnt are presented below:

1. Patient died but clinic appointment was not cancelled, leading to distress for relatives when contacted. Learning points: a cause for this can be that our administrative systems rely on GP data being pulled in from across the UK which can be delayed. Our teams must take all steps possible to prevent non-cancellation of appointments upon becoming aware of a patient's death.
Actions: Clinical staff to inform administration team if they are made aware of any deaths by local teams, clinical staff to carefully check electronic patient record before making calls, maintain clinical relationships with parent teams so that they inform NAC when patients have died at local hospital.
Administrative team to ensure all appointments are cancelled for patients that have died.
2. Patient with high frailty and multiple antifungal drug intolerances with limited treatment options. Lack of evidence in records for good anticipated palliative

care. Learning point: need to consider palliative care input at an earlier stage to manage expectations. Action: Involve MFT palliative care team to provide our staff with training around Gold Standards Framework and available support for patients and their families.

3. Patient had developed antifungal resistance and there was a delay in considering alternative antifungal medications and informing the patient. There was a delay in obtaining the sputum culture and resistance results because plating of the sample was delayed. This was due to the need for new Covid-19 safe processes in the mycology laboratory. The patient reported worsening symptoms during this time. Patient was offered hospital admission but declined due to fear of hospital acquired Covid-19. Patient was later admitted to local hospital and died of bacterial pneumonia. Learning points: the Covid-19 pandemic led to delays in patient care across the health care system, delay of sample processing could not be prevented. The patient was offered appropriate admission but declined. Actions: none
4. Patient was not seen for one year due to patient choice to re-schedule appointments. Significant disease progression during this time. No contact with medical team to review case and requirement for direct patient contact. Action: administration team to identify each month any patients on partial booking that are >100 days over scheduled appointment date.
5. Improving documentation – clinical team to ensure pre and post iv antifungal weight/SGRQ/immunology results are documented in clinic letter/EPR to aid assessment of whether further courses would be beneficial
6. Wider team referrals - immunology referral to be considered in those with evidence of immune dysfunction.

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 was 1 formal complaint received. This was responded to within expected timeframes. The theme of the complaint was communication surrounding reasons for discharge from the service. There were no lessons learnt or actions to be taken.

7.5 Hospital Incident Reporting System (HIRS) alerts

There was 1 HIRS alert with no patient harm attributed. A 7-minute briefing was completed. Lesson learnt – there is a need for a more robust administrative

systems to record when patients are discharged from the service. Action: to undertake an audit of all patients on service to ensure they remain within the scope of the commissioned pathway. This audit should then be carried out on a 3-monthly basis.

	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

8. Audit and Quality Improvement Report

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

1. Smoking cessation advice audit

This was a re-audit. 100% of the patient's had their smoking status checked at their first appointment. 89% had their cessation date recorded, which is above our set standard of >75%. Overall improvement noted in checking status and giving advice noticed as compared to the previous audit of 2020.

Actions:

- a. Continue the use of the template introduced after the previous audit as it has helped but to inform new doctors where to find the template
- b. Team to complete CURE module in the learning hub
- c. Reminder of checking smoking status to be added to induction pack for new doctors

2. Retrospective assessment of itraconazole treatment in Aspergillus bronchitis

This audit is examining the rate of exacerbations before and after itraconazole treatment, as well as the degree of toxicity to itraconazole leading to discontinuation, in patients diagnosed with Aspergillus bronchitis. Data is still being collected and outcomes will be presented to the team.

3. Risk factors for CPA development following TB treatment

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

4. Risk factors for CPA development following lung cancer treatment

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

9. Research and Publications

Despite the disruption caused by the COVID-19 pandemic and the retirements of both Professor Richardson and Professor Denning, our staff continued to produce high-quality research that will improve the care of patients around the world. NAC has a critical mass of clinical and laboratory experience and a large cohort of CPA and ABPA patients that allows us to carry out research that would be very difficult to co-ordinate elsewhere.

During the year 2020 there have been 26 original publications directly relevant to Aspergillosis. A full list of publications can be seen in Appendix 9. A selection of our scientific papers is summarised below, with a focus on studies involving our own patients and that are directly relevant to changing clinical practice.

Each year NAC/MRCM staff also contribute their expertise to various clinical guidelines, conference posters/presentations and professional training courses for clinicians and laboratory staff. As well as working closely with MFIG and other UK universities, we also have several very productive collaborations with overseas doctors who have previously worked at NAC and are working to transfer their experiences to their home countries (e.g. Indonesia, Uganda).

Diagnostics

MRCM is at the leading edge of developing fungal diagnostics for the NHS and helping our clinicians find innovative ways to apply them to patient care.

- MRCM staff developed a new method for detecting azole resistance in *Aspergillus fumigatus* strains using new pyrosequencing technology, which sequences the *cyp51A* gene directly from samples – thus bypassing the time-consuming culture step. It was validated using 50 different *Aspergillus* isolates and 326 respiratory samples taken from NAC patients ¹⁸.
- MRCM developed a method that greatly improves sensitivity of fungal culture, which involves spreading a much larger amount of a clinical sample onto each agar plate. This allows species identification and antifungal susceptibility testing to be done for more patients, which is important for guiding the choice of antifungal ⁶.
- Dr Bongomin and Professor Denning worked with Dr Garcez from the Immunology Service at MFT to investigate whether the antibody tests done for

new patients could be used to predict their response to treatment. Patients with a high (>200) baseline *Aspergillus*-specific IgG were more likely to gain weight during treatment, but no significant differences were seen in quality-of-life measures (SGRQ) ¹¹.

- Dr Kosmidis and Professor Richardson worked with MFIG researchers to look for subtle problems with the immune systems of CPA patients, including deficiencies in: MBL, IgG, IgA, IgM, IFN gamma, IL12 or IL17 production, low cell marker counts (CD4, CD19, CD56). Several cases were identified where the patient had one or more of these deficiencies, which caused a false negative result to be returned by the ImmunoCAP *Aspergillus* IgG (antibody) test. However, similar kits from Bordier and LDBio were not affected by false positives in this way ²¹.
- Dr Kosmidis worked with researchers in Jakarta (Indonesia) to define the sensitivity and specificity of *Aspergillus* antibody tests for diagnosing CPA in patients who previously had TB ²⁴.

Treatments

Our large patient group allows us to measure rarer side-effects of antifungals, as well as outcomes from treatments such as surgical resection or IFN-gamma that are used infrequently in clinics.

- Our staff worked with Dr Setiangerinum, a visiting pharmacist from Indonesia, to publish a study of outcomes following surgical resection of CPA. The main finding was that relapse after surgery is more common when antifungals are not given around the time of surgery. This can lead to the advice that antifungals are given in the peri-operative period in CPA patients ¹³.
- Interferon-gamma is used as salvage therapy in CPA, but the clinical benefits of this approach are not known. A study based on our CPA patients showed that those who tolerated interferon-gamma for at least 12 months has a significant reduction in exacerbation rates (3.1 vs 1.4/year) and hospital admissions (0.8 vs 0.3/year). Prospective studies are currently being planned at the NAC ³.
- Voriconazole causes photosensitivity which can increase the risk of skin cancer. CPA patients often receive voriconazole for long periods of time. This study showed that the risk of skin cancer in CPA patients was only 1.35 times higher than the general population. This helps inform clinical decisions on continuation of this antifungal ¹⁵.

Antifungal stewardship and therapeutic drug monitoring

Most published antifungal stewardship research addresses acute/invasive infections in immunodeficient patients and critical care settings, but CPA/ABPA outpatients have different needs and are much less studied. Long-term antifungal treatment is even more likely to cause problems with toxicity and resistance.

NAC is uniquely able to fill this knowledge gap by having a specialist pharmacist and mycology lab working alongside our clinicians. Large cohort of patients receiving newer antifungals such as isavuconazole, for which little real-world data has been published.

- Dr R Richardson co-created the RCPATH-accredited [Antifungal Stewardship course](#) (currently 3,413 enrolled and rated 4.8/5 stars) and we are currently

writing a more detailed wiki for MFT staff to use internally as part of our antifungal stewardship programme. Our specialist pharmacist Fiona Lynch also recently gave a well-received talk and Q&A session for patients about how we use TDM to reduce the side effects they experience.

- Isavuconazole is our newest antifungal, with little real-world data available to guide dosing and predict the tolerability of longer courses (>6 months) required by some CPA patients. Dr Kosmidis and MRCM staff evaluated the results of 45 CPA patients who started on the recommended dose of 200 mg daily. They found that lowering the dose to 100 mg daily gave fewer severe side effects while maintaining adequate blood levels, which allowed patients to tolerate longer courses¹⁷.
- CPA often takes hold in the lung cavities created by tuberculosis but treating both at the same time is notoriously difficult because of drug interactions. In a letter to the editor of the Journal of Global Antimicrobial Resistance, we described 2 cases where rifampicin was co-administered with posaconazole¹⁶

Supporting new drug development

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

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

10. Patient and public engagement

The NAC CARES team consists of four people, Chris Harris, Beth Bradshaw, Lauren Amphlett (joined us in November 2020) and team lead Graham Atherton.

NAC CARES (Community, Awareness, Research, Education, Support) rose to the challenge of supporting our groups of highly vulnerable people and their families and carers through the highly unusual year April 2020 – 2021 when the UK experienced three (some say four) waves of the Covid-19 pandemic, beginning in early 2020.

The team were tested in several ways:

1. Of necessity, change was abrupt, imposed by UK government with little chance for us all to prepare.

2. There was little guidance at first (for several weeks) for patients needing to know how vulnerable they might be to infection and serious illness.
3. Precautions to protect everyone from COVID-19 evolved rapidly alongside new scientific understanding as new research was published.
4. We frequently had to pre-empt or interpret government guidelines to give our patients the best guidance we could, considering their vulnerability.
5. Patients were not seen in clinic face-to-face for many months, which meant that we could no longer provide them with face-to-face support e.g. no leaflets, booklets or meetings could be provided.
6. All monthly face-to-face support meetings were stopped as many patients were not permitted in the hospital to ensure their safety and to maximise capacity for COVID patients.
7. From April 2020 to October 2020 three of the CARES team had to work from home.
8. A member of staff left the team (Helen Findon) in May 2020 and the post was not filled again until November 2020 (Lauren Amphlett).

In short – we had a pressing need to offer support to our patient groups whilst at the same time we had to work with much reduced lines of communication. We had to do this while having no access to our office and we had limited knowledge of how COVID-19 may behave over the year ahead.

One of our first actions was to establish a daily Zoom meeting in an attempt to answer the flow of questions coming from patients & carers, but also to provide a NAC presence in those difficult moments during the first wave of the pandemic when patients, and in some cases, carers were isolating alone at home. These meetings were well attended with 10-20 participants a day from April through to September 2021.

Other than providing an opportunity to socialise, patients were most interested in the CARES team interpreting daily scientific data on progress of the pandemic, how best to protect themselves from infection, whether or not they may need to shield, how they could access priority supermarket deliveries. As time went on other problems took priority particularly as shielding was lifted e.g., how to deal with an unsympathetic employer, what to do if living with children who were returning to school.

Then of course as the possibility of vaccines becoming available grew, we assessed and discussed the probability of a new treatment or vaccine being developed, how the new vaccines worked, discussed vaccine safety and what that meant, described what new variants of COVID-19 might be, when they came from and why they were a concern to everyone, answering questions such as when will lockdown end, is it safe to go out now?

We continued with our monthly patients & carer meeting programme, taking it online using Zoom software. We lost a significant number of volunteer speakers immediately as the research groups at the University of Manchester closed and staff were sent to work from home or in some cases were redeployed elsewhere to help with the national COVID effort. Similarly, clinical staff were at full stretch and could not offer us talks.

This was in part compensated for by the need for information on the COVID pandemic in more depth and breadth that we were able to provide over the longer monthly meetings. There was a lot of new research on COVID emerging rapidly and it was well received when we interpreted some of this for our patients & carers. We established a monthly pattern of summarising the published COVID data and what it meant for our

community and the progress of the pandemic, followed by talking about any new research and answering any questions asked.

Facebook and other social media were also an important tool to manage patient & carers concerns about COVID-19 alongside the patient and carer website at www.aspergillosis.org

10.1 Patients Survey

The NAC administers a patient survey annually. Some questions are retained each year, while others vary according to service changes.

The complete results of the patient survey are detailed in Appendix 9.

The full report demonstrates that despite a remarkably difficult year NAC staff have performed remarkably well. Patient approval standards have remained very high and, in many cases, improved since 2020.

Summary of main points (2020-2021)

- Importantly 95% of patients approved of the new virtual consultations that have been in operation over the last 12 months and 48% would like to carry on using them.
- We saw some significant changes in communications with a shift in which team is making patient contacts between clinic consults from nurses (down 22%) to doctors and physio teams.
- The specialist nurses have continued to increase consultations with patients and have maintained a very high level of patient satisfaction.
- Physio team continues to increase the proportion of patient consults and maintains excellent satisfaction levels.
- Written information we send out has increased significantly this last year, which is perhaps not unexpected as face-to-face meetings have declined, and we have had a dramatic increase in requests for information about improving quality of life via palliative care. This was a theme the CARES team talked to the patient communities about several times during the year, emphasising the value of palliative care backed up by the personal experience of patients.
- Postal packs and medication deliveries continue to be well received.
- The proportion of patients happy to get involved in clinical research rose significantly.
- Information leaflets have performed well with an increase in use from 74 to 93%, but there is a little room for improvement sending the leaflets out to patients on request.
- In 2020 the patients' website (aspergillosis.org) had not long been launched and we hoped that awareness of it would improve over time as it was indexed by Google – not least because it would get easier to find as the majority of patients would use the Google Search Engine to find it. This view has been

borne out and there has now been a large increase in the proportion of patients who use it from 16% to 44% with 95% satisfaction.

- Attendance of monthly Zoom meetings for patients have markedly increased from 3% (2020) to 21% in 2021. Those who do not attend mostly do so because they do not feel that they need that type of support. Comparing these figures with the same figures for 2020 suggest that we have reducing the number of people who cannot attend due to technical or physical barriers from 50% to 21%.
- There has also been a large increase in interest in watching recordings of our monthly meeting amongst the NAC patient population. The proportion of patients who have watched a recording increased from 7% (2020) to 29%.
- Lots more NAC patients have joined one of our support groups on Facebook, the proportion rising from 14% to 43% during 2020/21.
- There is a lot more awareness of our weekly Zoom meetings both in the number of people who have heard of it (from 11% - 41%) and those who have attended it (12% - 27%).
- There have been large increases in interest in our regional Facebook groups from 26% - 37% increase in awareness and from 3% - 48% increase in making contact with a group. Three patients have volunteered to help us by setting up their own regional group.
- 41% are interested in communicating with the CARES team using the secure and highly confidential Hospify APP that we introduced this year.

General comments made by patients filling in the survey are nearly all very positive about the NAC service as shown below:

- Keep up the good work. I'm only alive today because of you. Happy to help in return
- You mention that the Hospify app is completely private yet I get notifications when somebody e.g. a patient posts something so I am able to view this?
- Yes A great big thank you to everyone.
- Excellent doctors and nurses and very grateful for the support I receive
- The NAC service is a wonderful help and full of wonderful, supportive people who are very approachable and caring. This means the world when you have a horrid affliction like Aspergillosis.
- Very grateful for all the help from Wythenshawe, especially the nurses who are incredibly informative. Thank you, so much. I don't think the Hospify app is very good. If I need help I'll ring the nurses.
- Your service has changed my life can't say it more simply than that. Not sure where I would be without you. The care and specialist knowledge I have received is second to none. I am fortunate as I realise my condition is moderate to many of your other patients, however the impact on my life has been huge. I have been shocked by the lack of knowledge about Aspergillus by the wider healthcare system. For example, I diagnosed myself and found you via Google and with my previous experience of nursing immuno-compromised patients with fungal infections. So I had to ask my chest consultant to test me for a fungal infection, which he reluctantly did. So thank you so much you are a brilliant service and I hope

you continue to spread the knowledge in supporting others. Kind regards
***@** happy to be contacted if needed.

- You're all doing a brilliant job. I have been coming since 2006 and have seen many changes. I have received great care overall. Many thanks.
- A great service overall, just teething problems for myself with getting my bloods done locally. I prefer a face-to-face appt so I can be seen in the clinic for consultation and blood sampling etc.
- I think NAC do a great job.
- Always find everyone friendly and helpful. Very thorough whenever I've visited the hospital. Waiting times are sometimes not great so video calls are much better and have helped to cut down the wait.
- I have been a patient of the NAC since 2008. The treatment I have received has always been top quality. It saved my life. The large aspergilloma that I had when I became a patient has gone and the condition is generally benign now, controlled by the drug therapy. Long may it remain so.
- I wish to thank all the staff at the NAC for the commitment and help provided for my father.
- I have to travel a distance and the round trip can take up to two and a half hours. With the long delays in clinic and possible delays on the motorway this makes it a full day out. I would suggest that the clinic and blood room appears chaotic on some visits.
- I really appreciate the NAC, live a long distance from Wythenshawe the video has not been working for the last two appointments and they have been call only, but they have been really good for me at the moment as my condition is stable, not just the travelling but being in the hospital I find stressful. I would still like the option of attending, having the nurses available if there is a problem has been invaluable in the past, as has the reassurance of a same day xray. For my first remote appointment my teen daughter was at home I felt it could have been difficult if I had received news that I wanted to keep confidential
- The last 2 times I have a telephone conversation with a doctor they have suggested taking me off my medication without checking the state of my lungs and whether or not the fungus is growing. This is rather silly. Every time I have been to the actual clinic I have been very satisfied with my care.
- Used to get all info from Dr or 3 monthly visits
- It was nice to hear from you (Denning Team) after so long.
- I am almost 70 years old. Prof Denning is very much in favour of my heavy gym work. I have been told that I have the fitness level of an average 55 year old man. Everybody should join a gym & have a healthy diet. An SAE would have been nice!
- Many of the question not applicable during covid 19
- I have been happy with the treatment (antifungal) and life has become much better with posaconazole medicine.
- All positive ones stay safe everyone

10.2 Social media impact report

As a national leader in the clinical management of chronic pulmonary aspergillosis (CPA), the need to communicate and engage well with our patients, their carers, the public, clinicians, researchers and other key stakeholders is essential for the provision of long-term care for patients with the condition.

In November 2020, we employed a PR & Communications Specialist to support the delivery of NAC communications.

An important element of this role has been the development of social media channels, which has focused on raising the profile of the National Aspergillosis Centre, increasing awareness of aspergillosis, driving engagement, and supporting broader health promotion campaigns through:

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

As with all providers of NHS services, there has been a need in the last 12 months to address the challenges associated with communication and engagement during an unprecedented national crisis. The Covid-19 pandemic has altered the landscape of communication, and social media has become a primary source of information. Unfortunately, however, social media is also a breeding ground for fake news and disinformation. Therefore, it has been important that we not only ensure our patients, their carers, and other key stakeholders remain informed of (NAC and the wider NHS) service provision (despite restrictions and reduced face to face contact); but that we also position ourselves as a source of trusted information for facts on Covid-19 and vaccination.

This report looks at the impact of activities undertaken across all social media platforms.

Social media platforms utilised by the National Aspergillosis Centre

Channel	Audience	Content
Twitter	<ul style="list-style-type: none"> • Patients • Carers • Clinicians (Drs/Nurses/Physiotherapists) • Fungal research community • Media • Academia 	<ul style="list-style-type: none"> • Information about aspergillosis • NAC news • Job opportunities • Achievements • Research • Useful third-party information (for example, mental health day, information about Covid19) • Information about NAC and the service • Interest pieces • Links to more detailed content on other platforms
LinkedIn NAC Page	<ul style="list-style-type: none"> • Clinicians (Drs/Nurses/Physiotherapists) • Fungal research community • Academia 	<ul style="list-style-type: none"> • NAC news • Information about NAC and its services • Research • Interest pieces (professional focus) • Blogs • Job opportunities • News from the wider community • Press releases

Facebook NAC	<ul style="list-style-type: none"> • Patients • Carers 	<ul style="list-style-type: none"> • Information about aspergillosis • NAC news • Achievements • Useful third-party information (for example, mental health day, information about Covid19.) • Information about NAC and the service • Patient stories
Facebook Aspergillosis Support	<ul style="list-style-type: none"> • Patients • Carers 	<ul style="list-style-type: none"> • NAC news • Advice/support • Useful third-party information (for example, mental health day, information about Covid19)

Channel analytics

Channel	Followers / Growth Growth across social media platforms is reported in the table below over a ten-month period. The growth of our platforms is important because it will allow us to extend our reach further and engage with key stakeholders in the table above.	Total engagement Engagement is a measure of participation / interaction with content. This can include: <ul style="list-style-type: none"> Liking Sharing Commenting Opening a link within the post 	Total reach / impressions This is the potential size of the audience reached when content appears on a social media feed, regardless of if the content is interacted with.
Twitter	Nov 2020 – 2009 Sept 2021 – 2654 Growth +32%	5156	680K
LinkedIn NAC Page	Nov 2020 – 746 Sept 2021 – 1411 Growth +89%	3448	58K
Facebook NAC	Nov 2020 – 378 Sept 2021- 503 Growth +33%	-	21.5K

NOTE: Facebook does not make analytics available earlier than the previous 6 months, so we have been unable to provide data to show the increase in activity that occurred during the first few months of 2020, but a four to five fold increase was noted during the first wave, a more modest 2-3fold rise during the second wave in late 2020/early 2021 as we discussed vaccines.

10.3 Aspergillosis Patients and Carers Website (aspergillosis.org)

In late 2020 all of the CARES team moved to be directly employed by the Manchester University NHS Foundation Trust after leaving the University of Manchester, and the Aspergillus Website (aspergillus.org.uk) was retained by the University for future development for the purpose of promoting understanding of all forms of aspergillosis throughout the world. The Aspergillus Website had become very large, difficult and expensive to maintain and much of it was less relevant to our work at the National Aspergillosis Centre.

The CARES Team opted to refocus their website efforts on the support of patients and carers in particular using the website aspergillosis.org with supporting information intended for clinicians and other users of NAC being brought into an updated version of the NAC webpages on the Manchester University NHS Foundation Trust website at <https://mft.nhs.uk/wythenshawe/services/respiratory-and-allergy/national-aspergillosis-centre/>

The Patients and Carers website became a space for all government & NHS updates relevant to NAC patients that we could refer to in our social media groups. As can be seen in fig 1 usage of aspergillosis.org increased dramatically as we entered the second wave of the COVID pandemic towards the end of 2020.

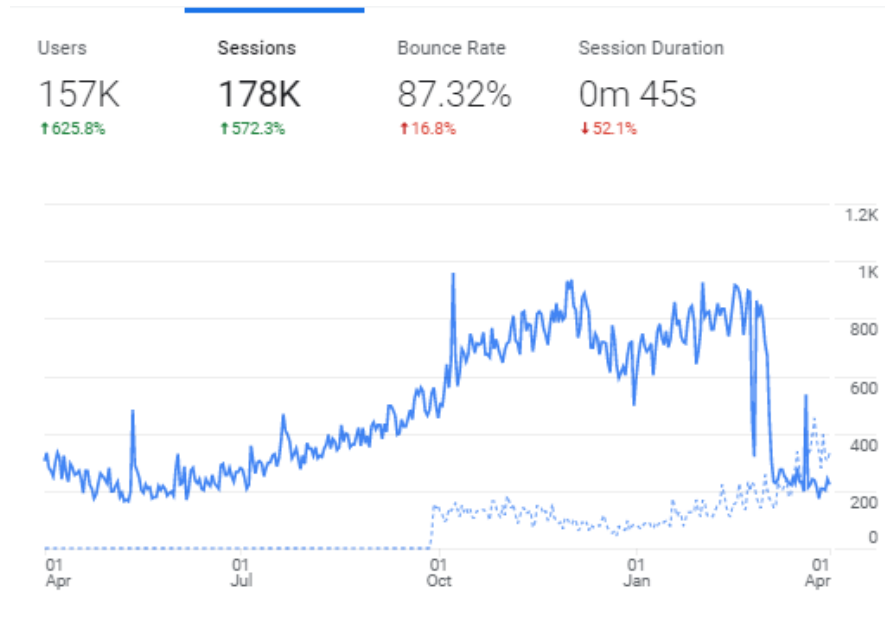
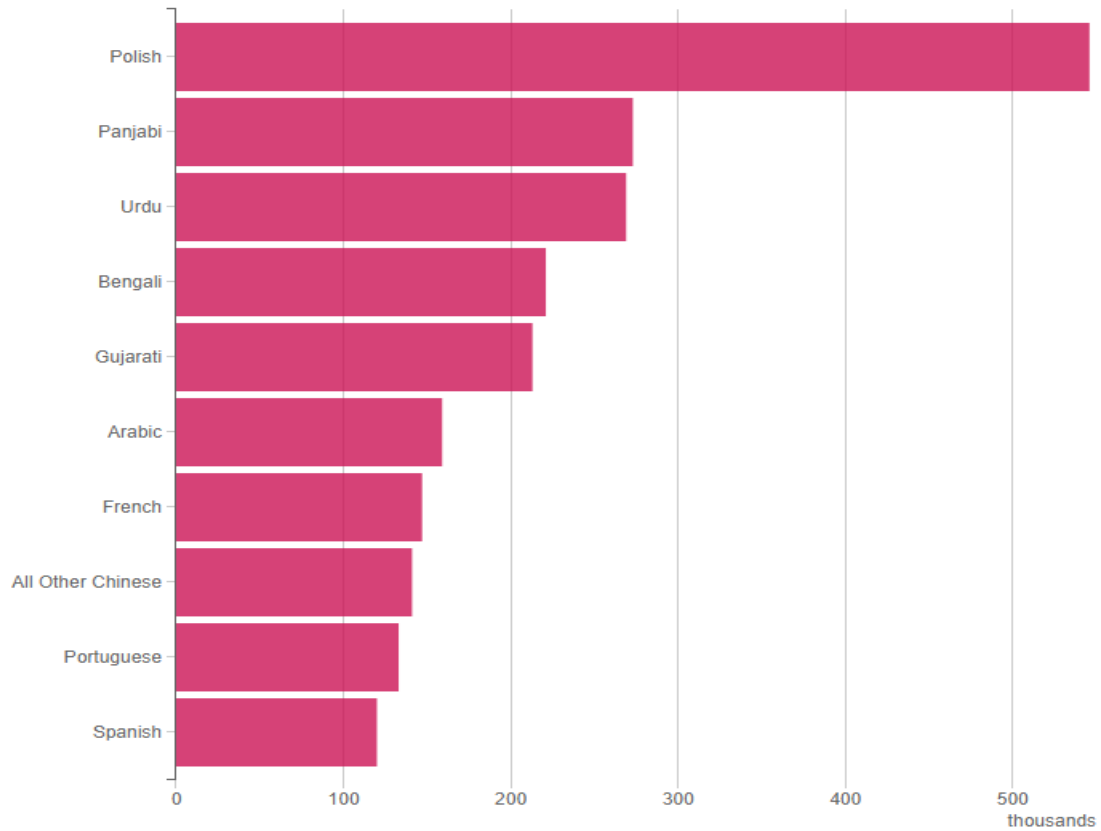


Fig 1.

We aimed to translate aspergillus.org into the top ten languages spoken in the UK (fig 2).

Top 10 main languages other than English (English or Welsh in Wales), England and Wales, 2011



2011 Census Analysis, ONS

Fig 2.

Unfortunately, due to software and budget limitations we are only able to offer a select few of the languages we originally wanted to. As I write this, we are able to offer aspergillus.org in 7 commonly spoken languages (fig 3).



Fig 3.

It is apparent from our usage statistics that these translated versions of the website are very popular with users:

21.4% of pages viewed are in Russian, 19% English, 5.5% Spanish, 4.8% French, 2.6% Portuguese, 0.9% Polish (fig 4.)

Page ?	Page Views ?
	5,921 % of Total: 100.00% (5,921)
1. /ru/heightened-sensitivity-to-smells/	599 (10.12%)
2. /	280 (4.73%)
3. /food-allergies-and-fungus/	275 (4.64%)
4. /sex-and-breathlessness/	215 (3.63%)
5. /es/sex-and-breathlessness/	196 (3.31%)
6. /ru/fungal-sinusitis/	181 (3.06%)
7. /ru/antifungals/	168 (2.84%)
8. /ear-eye-and-nail-aspergillus-infections/	164 (2.77%)
9. /pt/sex-and-breathlessness/	153 (2.58%)
10. /ru/insect-fungus-crawling-on-my-skin/	109 (1.84%)
11. /common-herbs-and-their-uses/	94 (1.59%)
12. /fungal-sinusitis/	90 (1.52%)
13. /fr/food-allergies-and-fungus/	88 (1.49%)
14. /ru/ear-eye-and-nail-aspergillus-infections/	74 (1.25%)
15. /ru/sex-and-breathlessness/	73 (1.23%)
16. /ru/aspergillus-bronchitis/	71 (1.20%)
17. /fr/fungal-sinusitis/	68 (1.15%)
18. /fr/sex-and-breathlessness/	68 (1.15%)
19. /es/food-allergies-and-fungus/	67 (1.13%)
20. /fr/ear-eye-and-nail-aspergillus-infections/	63 (1.06%)
21. /es/ear-eye-and-nail-aspergillus-infections/	57 (0.96%)
22. /ru/health-hazards-from-damp/	57 (0.96%)
23. /cpa-chronic-pulmonary-aspergillosis/	52 (0.88%)
24. /insect-fungus-crawling-on-my-skin/	48 (0.81%)
25. /pl/fungal-sinusitis/	48 (0.81%)

Fig 4.

10.4 Building a new offline community

It is in the interests of reaching everyone in the UK NAC community, whether or not they had access to online resources & communities to be able to learn about and obtain our resources and support. We had known that there was a substantial number (45%) of our CPA patients that were unable to get online and the need to support those people was made more urgent by the COVID pandemic as clinics closed.

We have set up a support phone number, distinct from those that NAC uses for clinical support and started sending out a new monthly email newsletter designed to target patients and carers which is also sent out as a paper version via post. By the end of April 2021 we were sending out 20-30 a week by post.

11. Raising public awareness and educational outreach

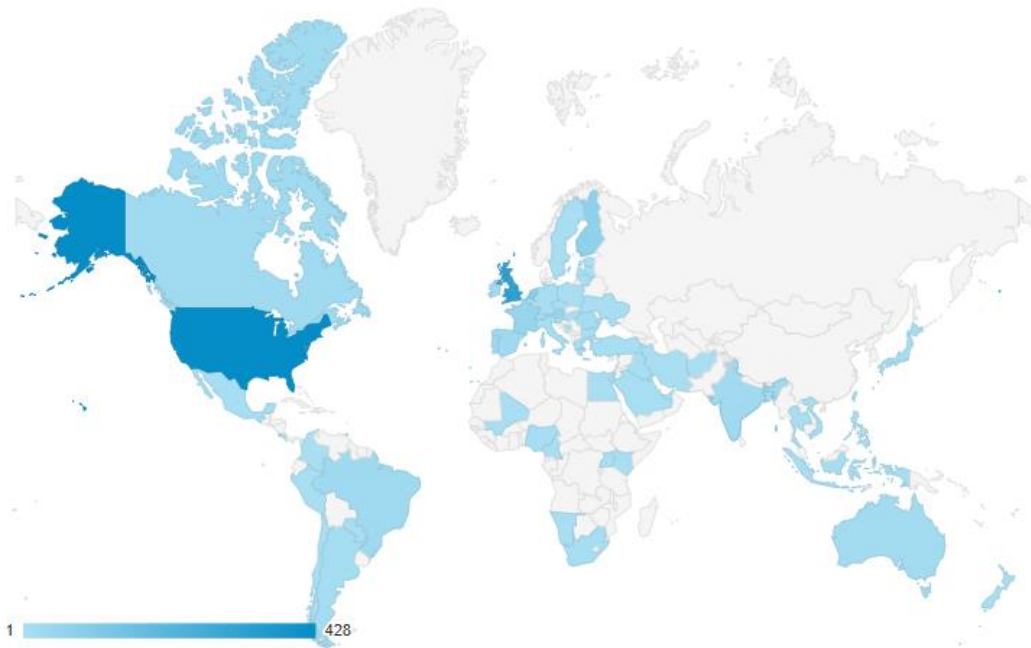
Part of the remit of the CARES team is to raise awareness of the National Aspergillosis Centre and aspergillosis itself nationally, throughout the UK. The purpose of this being to both encourage doctors to think about an aspergillosis diagnosis, to provide the resources to support them doing so and to spread expertise in diagnosing and managing aspergillosis. In this way we can support every patient in the UK receiving the right medical care no matter which UK region they live. Our activities were severely impacted by the COVID pandemic as we were unable to travel to attend national conferences or meet people face-to-face and of course, much of our time and effort was devoted to providing COVID-related support rather than just aspergillosis support.

However, the pandemic also presented us with opportunities. Many of our face-to-face meetings were replaced by contact via videoconference and by post. We discovered that patients were far more likely to spend time writing feedback when presented with a survey at home rather than in the clinic.

1. World Aspergillosis Day 2021

World Aspergillosis Day (WAD2021) has been run since 2016 and each year seems to get more attention from patients, researchers, doctors, nurses and laypeople. In 2021 after 24 hours we had reached 806 000 people – for full details see our World Aspergillosis Day Online Engagement Report (attached).

- The World Aspergillosis Day website (aspergillosisday.org) featured the main message of the day which was to highlight the impact aspergillosis was having on some critically ill people who had been infected by the COVID-19 coronavirus ([COVID-19-associated pulmonary aspergillosis \(CAPA\)](#)).
- Medical Mycology & clinical colleagues held events to mark the day in France, Brazil, Ghana and Vietnam – Vietnam, France and Ghana each held a day of talks on aspergillosis on World Aspergillosis Day, which were highly successful.
- Pfizer supported the day using their social media platforms throughout the world.
- In Manchester, we held an online meeting with our patient communities reflecting the themes of the day and Beth Bradshaw launched her new WAD2021 knitting patterns for patients to complete.
- The World Aspergillosis Day website received 1400 visitors on the day from 67 countries. All social media activity i.e. those engaging with the posts gave us a combined total of over 40 000 activities.



World Aspergillosis Day visitors Jan-Feb 2021

2. Clinician Education

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

- Sheffield Difficult Lung Diseases Annual Conference 2020 – ‘ABPA and CPA in the Respiratory Clinic – when and how should we treat?’
- British Thoracic Society Bronchiectasis Short Course 2021 – ‘Aspergillus in the Bronchiectasis Clinic’ – A series of case presentations

3. Monthly newsletters

A newsletter is sent out on a monthly basis to 6080 subscribers gathered from the subscriber base at aspergillus.org.uk and the new aspergillus.org websites. There had been a large number of inactive subscribers in the aspergillus.org.uk subscriber group so prior to importing them to the aspergillus.org website the list was thoroughly cleaned and re-authorised via opt-in to fully comply with GDPR regulations.

The new aspergillus.org newsletter contains much more content designed for the interested patient & carer rather than professional scientists as aspergillus.org is predominantly a website intended for patients & carers. As mentioned earlier the aspergillus.org.uk website is now maintained at the University of Manchester for a more professional medical research audience.

The new newsletter enjoys far more active interest compared with the old one, with up to 29% opening it, compared with 13-17% opening the old newsletter.

The majority of the newsletters sent out for the period 2020-2021 are in the old format so contain one or two **headline articles**. Here are a selection:

- Knowledge into invasive fungal diseases during COVID-19 continues to develop

- Diagnosing COVID-19-associated pulmonary aspergillosis.
- Levels of evidence supporting clinical practice guidelines on invasive aspergillosis
- Clinical outcomes of patients with chronic pulmonary aspergillosis managed surgically.
- A Multi-Institutional Review of Outcomes in Biopsy-Proven Chronic Invasive Fungal Sinusitis
- Patient testimony: hyper-IgE syndrome and associated lung infections.
- Global Action Fund for Fungal Infections (GAFFI) and the Fudan University in Shanghai, China report on the human burden of fungal disease in China in a new paper calculated that over a million people suffer from invasive aspergillosis, a far higher number than was anticipated.
- Biological drugs & ABPA.
- No azole-resistant strains of *Aspergillus fumigatus* found on root vegetables.
- Opportunist Coinfections by Nontuberculous Mycobacteria and Fungi in Immunocompromised Patients
- The global impact of *Aspergillus* infection on COPD.
- MSGERC release recommendations for antifungal stewardship programmes.
- *cyp51* azole resistance genes
- Investigation of skin microbiota reveals *Mycobacterium ulcerans-Aspergillus* sp. trans-kingdom communication

Reviews (3 -4 per newsletter)

- Treatment of allergic bronchopulmonary aspergillosis: from evidence to practice.
- Diagnosis of severe respiratory infections in immunocompromised patient.
- Diagnosing invasive pulmonary aspergillosis in ICU patients: putting the puzzle together.
- Applying Pharmacogenomics to Antifungal Selection and Dosing: Are We There Yet?
- Microbiome-mediated regulation of anti-fungal immunity.
- Classification of *Aspergillus*, *Penicillium*, *Talaromyces* and related genera (Eurotiales): An overview of families, genera, subgenera, sections, series and species.
- Smoking as a risk factor of invasive fungal disease: Systematic review and meta-analysis.
- Fungal infections in humans: the silent crisis.
- How good are animal models of invasive aspergillosis?
- Genetic susceptibility to fungal infection in children.
- Review of the Novel Investigational Antifungal Olorofim.
- Intestinal Aspergillosis: Systematic Review on Patterns of Clinical Presentation and Management.
- How are bedside tests being used to diagnose aspergillosis?

- Can molecular imaging be used for aspergillosis?
- Molecular Epidemiology of *Aspergillus fumigatus* in Chronic Pulmonary Aspergillosis Patients

Patients & carers

- Coronavirus Outbreak 2020 ANNOUNCEMENT: A notice for all patients that attend the National Aspergillosis Centre, Manchester, UK, 10th April.
- Mental well-being while staying at home
- The implications of partially lifting the coronavirus lockdown for people who are vulnerable and highly vulnerable.
- Considerations for people who are classified as highly vulnerable to COVID-19 severe symptoms as they are being asked to stop shielding.
- [Read a patient's story about taking Xolair on the Aspergillosis Patients & Carers website.](#)
- World Aspergillosis Day 2021 - Monday 1st Feb.
- ELF-EMBARC Virtual Bronchiectasis Patient Conference
- Did you miss the November Patients & Carers meeting? You can catch up on [our YouTube channel](#):
 - How can CPA/ABPA patients keep safe during COVID-19
 - COVID-19 and invasive aspergillosis
 - Are distance appointments working well at NAC?
 - How often do patients with CPA relapse following surgery?
- The *Aspergillus* newsletter is dividing!

12. Financial Position

Redacted for web version

13. Future Service Developments

The following developments are planned for 2020/2021

- **Service re-specification with NHSE**
We plan to continue our work with NHSE to re-develop the NAC service specification to ensure the service delivers the best possible patient care and experience without regional variation.
- **Remote advice and guidance service**
There is an ever-increasing demand for clinical advice and guidance without direct patient consultation. We plan to develop standardised documentation for this advice and formalise a process for recording and reporting the activity of this service.
- **Intravenous antifungal outcome measures**
We aim to improve and standardise reporting of outcomes for patients receiving iv antifungals
- **Patient Feedback**
We aim to improve patient feedback. We want to be able to reach a wider and more representative cohort of patients and allow feedback to be done continually, in real-time, rather than retrospectively annually.
- **Palliative Care**
We wish to form partnerships with our local palliative care teams to enhance end of life care and delivery of the gold standards framework for patients in our service.
- **Preparation for Hive (powered by EPIC)**
Hive is our new Trust innovative digital healthcare solution. Hive will bring our patient information into one easily accessible place to make services more effective. Our team has significant preparation and training to undergo prior the launch of this electronic patient record in September 2022 at MFT. We are required to adapt all of our paperwork and develop patient resources.
- **Implementation of an annual patient review process**
We have not managed to achieve this over the last year but wish to keep it at the forefront of our clinical development. We are aiming to introduce an annual clinic review process for all patients. Patients will be assessed by individual members of the MDT team including a doctor, specialist nurse, physiotherapist and pharmacist. Cases will be subsequently discussed with the wider MDT to ensure optimal clinical care, antifungal stewardship and communication with patient GPs and secondary care consultants.

Appendix 1 Categorisation (Banding) of CPA disease complexity

Stage 1

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

Stage 2

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

Stage 3

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

Appendix 2 New Patient Audit

MONTH	DATE REFERRED	APPOINTMENT DATE	WAITING TIME -weeks	POSTCODE	AREA	Band	Antifungal at 1st visit	Antifungal at 3 months	Priority
APRIL	NO REFERRALS DUE TO COVID 19								
MAY	Transition			SK13	Glossop	1	Itra	Itra	Asp bronchitis
	30/01/2020	06/03/2020	5	PA16	Scotland	2	Posa	Posa	Late registration
		01/06/2018		M44	Manchester	1	Itra	Itra	Died 27/11/20 Late registration
JUNE	25/05/2020	19/06/2020	3	M15	Manchester	2	Vori	Posa	
	Transition			M41	Manchester	2	None	None	Invasive Asp
	Transition			B43	Birmingham	1	None	None	Died 26/10/20
	Transition			SK4	Stockport	2	None	None	Sub-acute invasive
JULY	23/06/2020	15/07/2020	3	PR9	Preston	1	Itra	Itra	Soon
	17/06/2020	23/07/2020	6	NN15	Northamptonshire	1	None	None	Routine
	25/02/2020	10/07/2020	5 months	WN8	Skelmersdale	1	None	None	Routine
	30/03/2020	10/07/2020	4 months	L34	Merseyside	2	Vori	Vori	Routine
	12/03/2020	17/07/2020	4 months	WF2	Wakefield	2	Vori	Vori	Routine
AUGUST	19/06/2020	06/08/2020	7	LE4	Leicester	2	None	Vori	Routine
	24/06/2020	07/08/2020	6	NN3	Northamptonshire	2	Vori	Vori	Routine
	24/07/2020	21/08/2020	4	FK5	Scotland	2	Vori	Vori	Routine

	30/12/2019	13/02/2020	6	M20	Manchester	1	None	None		Late registration
SEPTEMBER	28/02/2020	04/09/2020	7 months	M16	Manchester	2	Vori	Vori	Routine	DNA x2
	10/08/2020	04/09/2020	4	SK7	Stockport	1	None	None	Not stated	
	01/09/2020	18/09/2020	2	LS14	Leeds	2	Isavu		Not stated	Died 02/10/20
	28/07/2020	25/09/2020	8	NW1	London	2	Posa	Posa	Not stated	
	08/04/2019	17/05/2019	5	CW8	Northwich	2	Vori	None	Routine	Initial CT monitoring
OCTOBER	07/10/2020	23/10/2020	2	SY3	Shrewsbury	1	None		Not stated	Died 12/12/20
	17/08/2020	25/09/2020	5	CW8	Northwich	1	Itra	Vori	Routine	
NOVEMBER	08/10/2020	06/11/2020	4	EH55	Scotland	2	None	f/u April	Routine	
	12/10/2020	13/11/2020	4	FY1	Blackpool	1	Itra	Itra	Routine	
	12/10/2020	13/11/2020	4	FK1	Scotland	2	Vori	Vori	Routine	
	09/11/2020	27/11/2020	2	NP13	Wales	2	Vori	None	Routine	
		26/07/2017		BN11	West Sussex	1	Itra	Itra	Routine	Late registration
DECEMBER	05/11/2020	04/12/2020	4	CV11	Warwickshire	2	Vori	f/u May 21	Routine	
	29/10/2020	04/12/2020	5	DE73	Derby	2	Vori	Vori	Routine	
	09/11/2020	11/12/2020	5	HD3	Huddersfield	1	Itra	f/u April 21	Routine	
	15/10/2020	18/12/2020	9	WN8	Wigan	1	None	f/u April 21	Routine	
JANUARY	24/11/2020	08/01/2021	6	BB11	Burnley	2	Vori	f/u April 21	Routine	
	04/01/2021	15/01/2021	1	M3	Manchester	2	Vori	f/u April 21	Not stated	
	08/12/2020	22/01/2021	6	SA9	Wales	1	Itra	f/u May 21	Routine	
FEBRUARY	18/02/2021	26/02/2021	1	M13	Manchester	2	Vori	f/u April 21	Urgent	
	30/12/2020	05/02/2021	5	PR6	Preston	1	None	f/u June 21	Routine	
	14/12/2020	15/01/2021	4	DN14	West Yorkshire	2	Vori	f/u May 21	Routine	

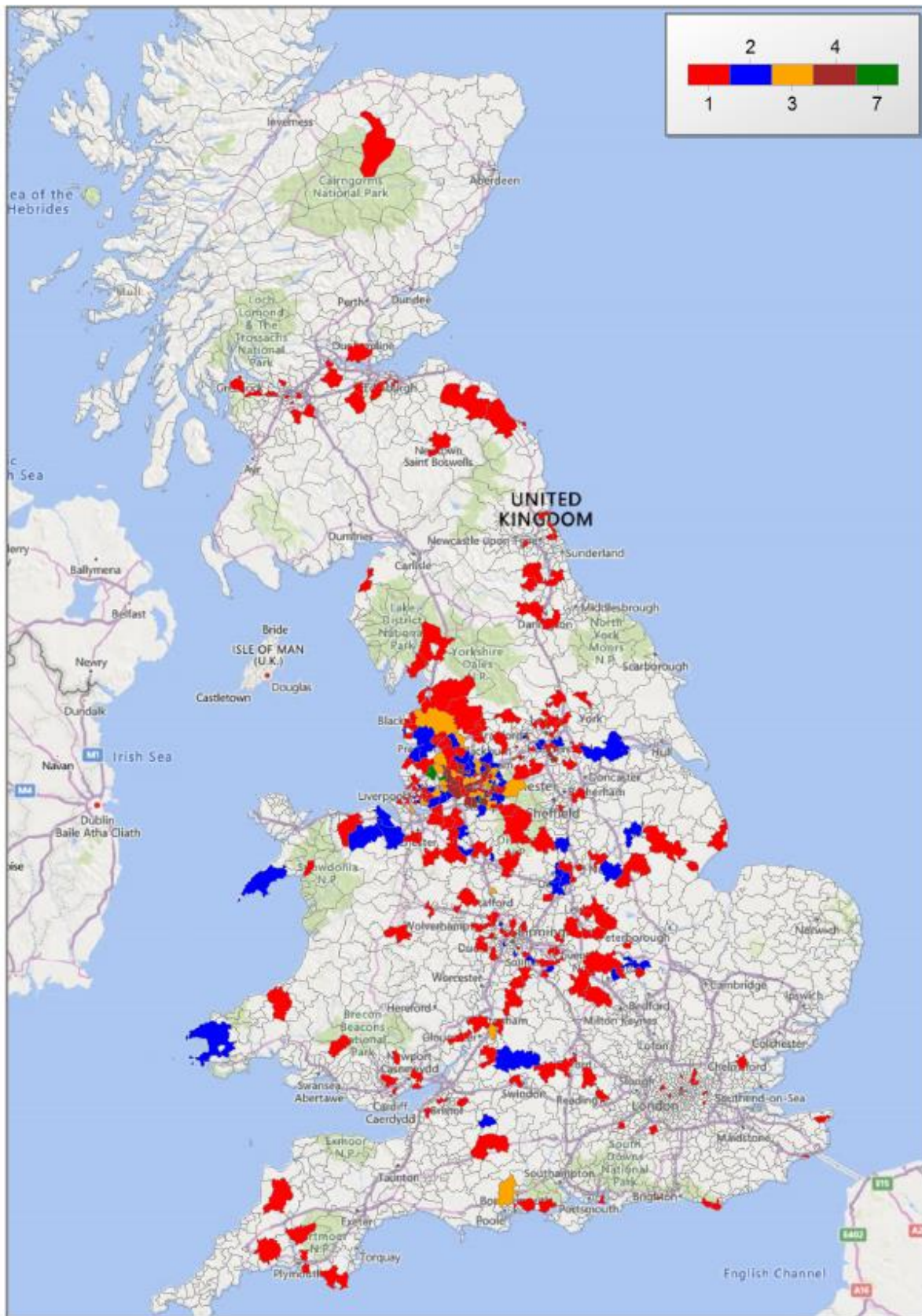
MARCH	26/02/2021	19/03/2021	3	BD14	Bradford	2	Vori	f/u July 21	Routine
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Notes

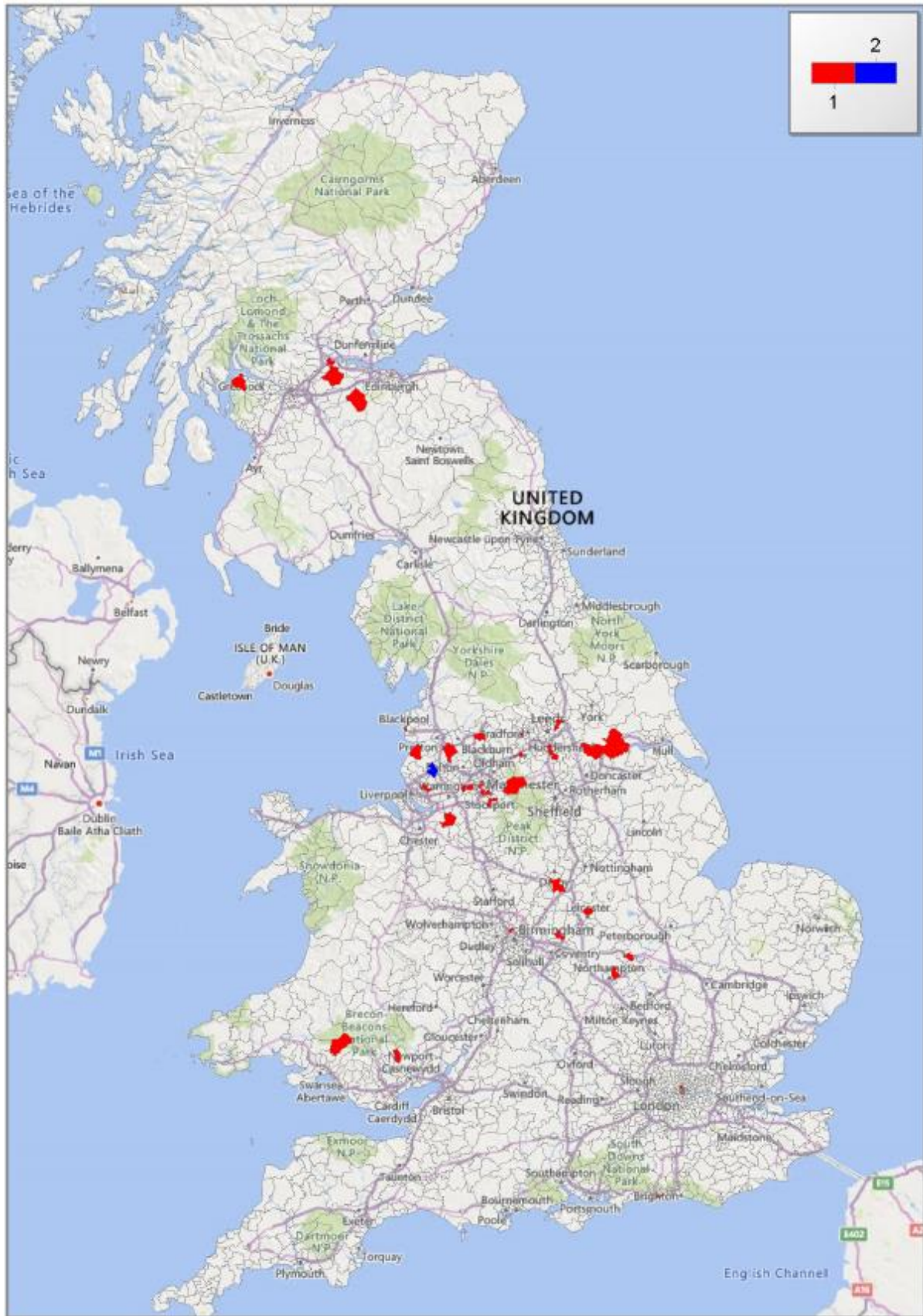
Transition patients are those that were under NAC service with a non-CPA aspergillus diagnosis that transformed into CPA
Late registration refers to patients who were inadvertently not entered into monthly figures at diagnosis

Appendix 3 Geographical location of patients attending NAC

Graph 1 All patients on NAC service March 2021



Graph 2 New patient referrals 2020-2021



Appendix 4 Discharges from service

Date of discharge	Antifungal at discharge	CPA Band	Geographical area	Reason
01/04/2020	None	3	Manchester	CPA in remission
17/04/2020	None	1	Wigan	MDT decision - not CPA
01/04/2020	None	2	London	Stable
15/05/2020	None	1	Manchester	Self discharge - stable
29/05/2020	None	2	Wigan	Stable
18/06/2020	Itraconazole	1	Derby	Stable
16/08/2019	None	2	Scotland	No CPA, post op
26/06/2020	None	2	Tyne & Wear	Stable for 6 years
18/06/2020	None	1	Crewe	No CPA
19/06/2020	None	2	Manchester	end of life care
05/06/2020	None	2	Warwickshire	Stable
26/06/2020	None	3	Manchester	No CPA
16/07/2020	None	1	Lancashire	Stable
08/06/2020	Itraconazole	1	S. Ireland	Patient declined follow up
02/06/2020	None	2	Northumbria	Stable
01/07/2020	None	1	Manchester	Patient declined treatment and follow up
03/07/2020	None	1	Bury	Stable
10/07/2020	None	3	High Peak	Stable
14/08/2020	None	1	Ashton under Lyne	Stable off therapy
27/08/2020	Ampho B nebs	3	Preston	No current CPA (SAFS)
27/08/2020	None	1	West Midlands	No current CPA (ABPA)
20/08/2020	None	2	Gloucestershire	Stable off therapy
03/09/2020	None	2	Central Lancashire	No aspergillus disease
25/09/2020	None	2	Scotland	Unable to contact
20/10/2020	None	1	Gwynedd, Wales	Stable off therapy
23/10/2020	None	2	Cheshire	Stable off therapy
23/10/2020	None	2	Cheshire	Stable off therapy
23/10/2020	None	2	West Yorkshire	Stable off therapy
25/11/2020	None	1	Hull	Stable off therapy, post surgery
25/11/2020	None	2	Stockport	Stable off therapy
25/11/2020	None	2	Bolton	No current CPA
25/11/2020	Itraconazole	1	Scotland	Stable on therapy
02/10/2020	None	1	Scotland	Stable off therapy
12/11/2020	None	2	Wolverhampton	Stable off therapy
30/10/2020	None	1	Nottingham	No current CPA
13/11/2020	None	2	Oldham	No current CPA (ABPA)
13/12/2020	None	2	St Helens	Stable off therapy
18/12/2020	None	2	Oldham	No current CPA
10/12/2020	None	2	Wolverhampton	No current CPA
01/12/2020	None	2	Wiltshire	Stable
09/12/2020	None	2	Salford	No current CPA
13/11/2020	None	2	Plymouth	Stable
09/12/2020	Amph B nebs	1	Northamptonshire	No current CPA (ABPA)
22/12/2020	None	3	Merseyside	No current CPA
08/01/2021	None	2	West Midlands	No active CPA
08/01/2021	None	1	Liverpool	No active CPA (ABPA)
28/01/2021	None	2	Scotland	No active CPA
18/12/2020	None	2	Lincoln	Stable off therapy post surgery
11/12/2020	None	2	Wigan	No current CPA
26/01/2021	None	3	Wigan	No current CPA
05/02/2021	Voriconazole	2	Scotland	Stable, no active CPA
05/02/2021	None	2	Bolton	No active CPA (ABPA), off antifungals
11/02/2021	None	2	Manchester	Stable off therapy
04/09/2021	None	2	Manchester	No active CPA
26/02/2021	None	1	Rochdale	No active CPA
26/02/2021	None	2	Cheshire	No active CPA
26/02/2021	None	1	Manchester	No active CPA
11/03/2021	None	3	Manchester	No active CPA
26/03/2021	None	2	Rochdale	No active CPA
12/03/2021	None	2	Southport	No active CPA
19/03/2021	Ampho B	2	Northamptonshire	No active CPA
12/03/2021	None	2	Manchester	No active CPA

Appendix 5 Admissions and OPAT activity

MONTH	ADMITTED	DISCHARGED	BED DAYS	TREATMENT	PROCEDURE	ANTIFUNGAL
APRIL (1)						
APRIL (2)						
May (1)	18/05/2020	22/05/2020	4	Tranexamic Acid		Isavuconazole
May (2)						
June (1)						
June (2)						
July (1)	01/07/2020	21/07/2020	20	Micafungin	OPAT	Micafungin
July (2)						
Aug (1)	10/08/2020	30/08/2020	20	Micafungin	OPAT	Micafungin
Aug (2)						
Sept (1)	15/09/2020	18/09/2020	3	Micafungin		Micafungin
Sept (2)						
Oct (1)	19/09/2020	05/10/2020	16	Micafungin	OPAT	Micafungin
Oct (2)						
Nov (1)						
Nov (2)						
Dec (1)	27/11/2020	06/12/2020	9	IV antibiotics		None
	10/12/2020	18/12/2020	8	Surgery	LUL lobectomy	Posaconazole
Dec (2)	10/12/2020	30/12/2020	20	Tranexamic acid		None
Jan (1)						
Jan (2)						
Feb (1)	30/01/2021	25/02/2021	26	AmBisome	Embolisation x 2	AmBisome
Feb (2)	05/02/2021	19/02/2021	14	IV antibiotics	OPAT	Posaconazole
	18/02/2021	27/02/2021	9	IV antibiotics		
March (1)	25/03/2021	26/03/2021	1		Embolisation	Voriconazole
March (2)						

Appendix 6 Clinical data for new patients 2019-2020

NCG Report for SGRO/MRC/IgG/Weight																
2019-2020																
1st visit	MRC	IgG test 1	SGRQ	Weight	2nd visit	MRC	IgG test 2	SGRQ	Weight	3rd visit	MRC	IgG test 3	SGRQ	Weight	Radiology at 1 year	Clinical Outcome at 1 year
03/10/2019	2	170		94.9	06/12/2019	1	145		94.5	29/05/2020	NR	169		NR	stable CT	Stable
17/10/2019	4	177		77.9	17/04/2020	NR	NR		NR	18/09/2020 discharged					Stable CT	Stable
11/10/2019	1	23	44.59	65.4	22/11/2019	1	NR	44.05	43.3	03/01/2020	1	18	45.63	64.8	stable CT	Stable
11/10/2019	5	97		39.2	13/12/19 cancelled		NR									Died
11/10/2019	1	176	7.95	72.8	06/12/2019	1	183		69.3	15/05/2020	2	114		NR	Improved CT	Improving
18/10/2019	4	74	38.25	54.6	17/01/2020	1	61		56.9	24/04/2020	NR	72		NR	Improved CT	Improving
28/11/2019	NR	160		78.6	28/02/2020	3	121		78.8	29/05/2020	NR	136		NR	Stable CT	Improving
20/11/2019	4	77		65.4	10/01/2020	5	NR	81.25	61.6	07/02/2020	2	104		64.3	Stable	Stable
15/11/2019	4	102		76.9	10/01/2020	4/5	NR		80.7	17/04/2021 discharged					Improved CT	Improving
29/11/2019	2	112	68.1	49.7	24/01/2020	4	NR		49	24/04/2020	NR	NR		NR	Improved CT	Stable
29/11/2019	4	708	71.9	50.8	03/01/2020	4	NR		49.8	01/05/20 dna					Improved CT	Improving
29/11/2019	4	152		37	03/01/2020	5	107		36.3	14/02/2020	3	71		33.9	Improved CT	Improving
08/11/2019	3	668	78.31	51.2	06/12/2019	3	679		53.4	13/03/2020	NR	NR		NR	Stable CT	Stable
22/11/2019	5	150		58.2	17/01/2020	NR	134		NR	20/03/2020	NR	NR		NR	Improved CT	Improving (Died July 2020 at lung transplant)
01/11/2019	1	1070		70.7	31/01/2020	1	628		71.8	15/05/2020	1	145		NR	Improved CT	Improving
12/12/2019	4	102		51.7	17/01/2020	4	139		50.5	17/04/2020	4	NR		NR	Stable CT	Stable
06/12/2019	4	184	48.2	54.9	10/01/2020	3/4	NR		54.5	27/03/2020	NR	168		NR	Stable CT	Stable
13/12/2019	1	110	35.34	52.1	07/02/2020	2	169		49.1	03/04/2020	NR	NR		NR	NR	Died Sept 2020
13/09/2019	1	NR	9.26	50.2	20/12/2019	1	176		53.6	17/04/2020	NR	NR		NR	Worsening CT	Deteriorated - therapy changed
08/11/2019	4	77	58.64	51.8	20/12/2019	4	NR		52	10/07/2020	4	NR	26.4	51.4	Stable CT	Stable
20/11/2019	NR	199		NR	03/01/2020	5	989		76.1							Died March 2020
17/01/2020	3/4	134		60.2	24/07/2020	NR	NR		NR	04/09/2020	4	133		59	Worsening CT	Deteriorated - referred surgery
03/01/2020	3	598	51.51	64.4	14/02/2020	4	532		62.8	13/03/2020	4	396		65.2	Improved CT	Improving
03/01/2020	1	NR	73.11	35	14/02/2020	2	87	82.91	31.5	20/03/2020	2	65		31.4	Improved CT	Improving
03/01/2020	2	1756	55.49	44.5	31/01/2020	NR	1716		44.9	19/03/2020	1	>200		49	Stable CT	Improving
10/01/2020	2	61	38.42	60.4	07/02/2020	3	NR		61.7	17/07/2020	2	NR		58		Surgical resection Dec 2020
17/01/2020	4	65		49.1	14/02/2020	4	80		59.3	20/03/2020	5	66		49.8	Improved CT	Improving
17/01/2020	2	109	78.89	66.5	31/07/2020	3	NR	63.17	62	06/11/2020	NR	60		61.5	Improved CXR	Improving
24/01/2020	2	80		66.5	6/3/20 dna					24/04/2020	NR	NR		NR	Stable CT	Stable
25/10/2019	2	35		83.6	03/04/2020	NR	NR			11/09/2020	2	NR	49.16	77.5	Resolution on CT	Surgical resection Dec 2019
25/10/2019	3	98	39.55	88.4												Died Feb 2020

05/07/2019	2	98		43	03/01/2020	1	84	20.51	45	05/06/2020	1	80		NR	Improved CT	Improving	
27/09/2019	4	170	66.66	55	24/01/2020	4	139		56	04/09/2020	4	111	66.66	55	Stable CT	Stable	
14/02/2020	3	103		50.4	27/03/2020	NR	NR		NR	24/07/2020	3	59		NR	Stable CT	Stable	
21/02/2020	5	31	83.4	51.9	03/07/20 discharged										Improved CT	Improving	
07/02/2020	2	79	53.04	41.6	12/06/2020	NR	NR		NR	16/10/2020	NR	37		NR	Resolution on CT	Improving	
07/02/2020	5	174		81.7	15/05/2020	5	NR		NR	25/09/2020	NR	NR		NR	Resolution on CT	Improving	
14/02/2020	3	62	85.1	43.1	17/04/2020	NR	NR		NR	09/10/2020	3/4	NR		NR	Stable CT	Stable	
13/02/2020	1	17		65.5	22/05/2020	1	NR		NR	27/11/20 discharged					Stable CT	Stable	
13/02/2020	3	124		75	14/08/2020	3	NR		NR	04/12/2020	3	132		65	Stable CT	Stable	
17/01/2020	1	82	27.19	57	24/04/20 Rescheduled					18/09/2020	1	70		NR	stable CT	Stable	
13/12/2019	3	99		62.15	14/02/2020	3	117		57.5	Died 17/03/20						Died March 2020	
06/03/2020	4	510	86.37	60.7	03/04/2020	NR	NR		NR	04/09/2020	3	147		61	Stable CT	Improving	
06/03/2020	2	111		61.3	05/06/2020	NR	140		NR	09/10/20 dna		136			Improved CT	Improving	
13/03/2020	1	112		64.6	03/04/2020	NR	108		NR	14/08/2020	NR	49		NR	Improved CT	Improving	
13/03/2020	2	135		61.2	17/07/2020	NR	171		NR	29/01/2021	NR	NR		NR	Stable CT	Stable	
20/03/2020	5	134		60.6	10/07/2020	NR	NR		58	15/01/2021	5	105		61	Stable CT	Died Feb 2021	
06/03/2020	1	120		91.3	05/06/2020	NR	NR		NR	16/10/2020	4	NR		NR	Stable CT	Stable	
2020-2021																	
20/03/2020	NR	107			24/07/2020	NR	88			13/11/2020	NR	47			Improved CT	Improving	
06/03/2020	2	178	72.78	47.7	15/05/2020	NR	NR			30/10/2020	NR	123			Improved CT	Improving	
Late Reg	NR	40			27/03/2020	NR	33			21/08/2020	NR	35		73	Stable CXR	Died Nov 2020	
19/06/2020	4	56	98.74	63	14/08/2020	5	62	100	65	15/01/2021	5	41	92.93	63.5	Stable CT	Improving	
22/05/2020	NR	50			11/12/2020	NR	12			f/u Dec 21					Stable CXR	Stable	
15/05/2020	187	NR			Died 26/10/20											Died Oct 2020	
26/06/2020	2	11			08/01/2021	2	8	38.26	58.2	f/u July 21					Stable CXR	Stable	
16/07/2020	3	76		64.4	06/11/2020	3	NR	75.41	63.5	21/05/2021		76			Stable CT	Stable	
23/07/2020	3	13	62.83	76.04	04/12/20 dna					15/01/2021	4	NR		76.2		pending data	
10/07/2020	1	154	11.8	69.1	27/11/2020	1	NR			26/03/2021	1	NR				pending data	
10/07/2020	4	736	84.85	56.6	21/08/2020	NR	171			19/02/2021 dna						pending data	
17/07/2020	4	150	94.63	47.6	25/09/2020	NR	NR			14/01/2021	5	101				pending data	
06/08/2020	2	75	31.76	69.6	09/10/2020	NR	NR			f/u April 21						pending data	
07/08/2020	5	>200	98.59	68.4	30/10/2020	NR	NR			11/12/2020	4	NR				pending data	
21/08/2020	4	>200	82.43	42	09/10/2020	NR	NR		42	18/12/2020	5	NR	75.58	39.5		pending data	
13/02/2020	4	53			27/11/2020	NR	NR			f/u May 21		28				pending data	
04/09/2020	4	>200	59.74	57.4	20/11/20 dna					12/02/2021	4	NR				pending data	
04/09/2020	3	192	42.5	60	08/12/2020	3	NR	40.05	56.8	26/02/2021	NR	NR				pending data	

18/09/2020	5	NR	83.14	54.2													Died Oct 2020
25/09/2020	2	145		63.2	02/10/2020	2	NR	25.23	63.2	24/03/2021	2	NR	41.27	55.7			pending data
03/09/2020	4	102	87.15	50.8	18/12/2020	4	170			19/03/2021	5	175	NR	NR	Stable CXR		Died May 2021
23/10/2020	4	>200	74	71	27/11/20 rescheduled												Died Dec 2020
25/09/2020	3	932	79.47	54.6	20/11/2020	4	NR		55	05/02/2021	4	1018		55			pending data
06/11/2020	4	NR	58.8	45	29/01/2021	4	NR	73.55	45	f/u April 21							pending data
13/11/2020	3	90	71.89	50.8	12/02/2021	NR	NR			f/u April 21							pending data
13/11/2020	3	NR	33.62	73.02	19/02/2021	NR	NR			f/u April 21							pending data
27/11/2020	4	NR	71.37	60.4	12/02/2021	NR	NR			12/03/2021	NR	110					pending data
27/11/2020	NR	NR			f/u May 21												pending data
04/12/2020	4	190	90.49	51.5	15/01/2021	NR	NR			f/u May 21							pending data
04/12/2020	5	117	72.3	54	26/02/2021	NR	NR			f/u April 21							pending data
11/12/2020	4	132	88.21	66.2	f/u April 21												pending data
18/12/2020	2	87	32.26	50.1	f/u April 21												pending data
08/01/2021	5	109	92.09	69.4	f/u April 21												pending data
15/01/2021	1	>200		46	f/u April 21												pending data
22/01/2021	5	>200	88.63	48	19/03/2021	5	NR			f/u May 21							pending data
26/02/2021	4	>200	91.19	52.15	f/u April 21												pending data
05/02/2021	4	>200	67.92	69.8	f/u June 21												pending data
15/01/2021	3	126	44.23	45.8	26/02/2021	3	NR		44.9	f/u May 21							pending data
19/03/2021	1	48	3	52.7	f/u June 21												pending data

Appendix 7 Antifungal Trial Data

POSACONAZOLE DRUG TRIALS 2020-2021					
Trial start date	4 month review	6 month review	Continue	Trial Outcome	Comments
22/10/2019	Feb-20	Apr-20	Yes	Continue	Achieved targets at 4/12 and 6/12
01/11/2019	Mar-20	May-20	Yes	Continue	Achieved targets at 4/12 and 6/12
07/02/2020	Jun-20	Aug-20	No	Failed	weight loss and worsening SQRQ, no serology/radiology due to Covid 19. Died Sept 2020
09/03/2020	Jul-20	Sep-20	No	Failed (ADR)	Stopped April 20 due to dry mouth and lethargy
29/11/2019	Mar-20	May-20	Yes	Failed	CT progression, worsening SGRQ, changed to Isavuconazole
25/10/2019	Feb-20	Apr-20	Yes	Continue	Achieved targets at 4/12 and 6/12
07/02/2020	Jun-20	Aug-20	Yes	Continue	Achieved targets at 4/12 and 6/12
02/12/2019	Apr-20	Jun-20	Yes	Continue	Achieved targets at 4/12 and 6/12
03/01/2020	May-20	Jul-20	Yes	Continue	Achieved targets at 4/12 and 6/12
24/01/2020	May-20	Jul-20	Yes	Continue	Achieved targets at 4/12 and 6/12
08/11/2019	Mar-20	May-20	Yes	Continue	Achieved targets at 4/12 and 6/12
20/11/2020	Mar-21	May-21	No	Failed (ADR)	Stopped after 1 week due liver toxicity
25/03/2021	Jul-21	Sep-21			
09/10/2020	Feb-21	Apr-21			Achieved targets at 4/12
24/07/2020	Nov-20	Jan-21	No	Failed	switched to Isavu Nov by local team
28/11/2020	Mar-21	May-21			started 25/9/20, stopped 27/10/20 due high drug levels and ADR. Re-started 28/11/20
26/02/2021	Jun-21	Aug-21			
08/12/2020	Apr-21	Jun-21			
31/07/2020	Nov-20	Jan-21	Yes	Continue	Achieved targets at 4/12 and 6/12
Success					
Failure					
Pend to 21/22					

ISAVUCONAZOLE DRUG TRIALS 2020-2021					
Trial start date	4 month review	6 month review	Continue	Trial outcome	Comments
08/11/2019	Mar-20	May-20	Yes	Continue	Achieved targets at 4/12 and 6/12
01/03/2020	Jul-20	Sep-20	Yes	Continue	Achieved targets at 4/12 and 6/12
03/01/2020	May-20	Jul-20	Yes	Continue	Achieved targets at 4/12 and 6/12
15/11/2019	Mar-20	May-20	Yes	Continue	Achieved targets at 4/12 and 6/12
26/11/2020	Mar-21	May-21			
Feb-21	Jun-21	Aug-21			
01/05/2020	Sep-20	Nov-20	Yes	Continue	Achieved targets at 4/12 and 6/12
10/07/2020	Nov-20	Jan-21	No	Failed	No improvement
09/10/2020	Feb-21	Apr-21	No	Failed (ADR)	stopped October due to deranged LFT's
01/11/2020	Mar-21	May-21	No	Failed	Patient choice to stop therapy Dec 2020 - do not include
Success					
Failure					
Pend to 21/22					

VORICONAZOLE DRUG TRIALS 2020-2021					
Trial start date	4 month review	6 month review	Continue	Trial outcome	Comments
11/12/2020	Apr-21	Jun-21	Yes	Continue	Achieved targets at 4/12. Patient chose to stop.
21/08/2020	Dec-20	Feb-21	Yes	Continue	Achieved targets at 4/12 and 6/12
28/08/2020	Dec-20	Feb-21	Yes	Continue	Achieved targets at 4/12 and 6/12
13/11/2020	Mar-21	May-21			Achieved targets at 4/12
07/08/2020	Dec-20	Feb-21	Yes	Continue	Achieved targets at 4/12 and 6/12
01/11/2020	Mar-21	May-21			Achieved targets at 4/12
27/11/2020	Mar-21	May-21			Achieved targets at 4/12
15/01/2021	May-21	Jul-21			
24/06/2020	Oct-20	Dec-20	Yes	Continue	Achieved targets at 4/12 and 6/12
25/06/2020	Oct-20	Dec-20	Yes	Continue	Achieved targets at 4/12 and 6/12
08/01/2021	May-21	Jul-21			
08/01/2021	May-21	Jul-21			
10/07/2020	Nov-20	Jan-21	Yes	Continue	Achieved targets at 4/12 and 6/12
Jun-20					Died July 20
14/09/2020	Jan-21	Mar-21	Yes	Continue	Achieved targets at 4/12 and 6/12
Success					
Failure					
Pend to 21/22					

Clinical data for Drug Trials 2020-2021

Drug Trial	Date trial started	Weight			MRC			SGRQ			IgG			Baseline	6 months	Outcome
		Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months			
Posaconazole	22/10/2019	54.1	52.8	51.6	4	2	4	86.78	49.29	NR	1300	1071	1723	Extensive right lung cavitation	CXR sig improvent RLL changes	Success
Posaconazole	01/11/2019	53.9	NR	55	2	NR	2	36.92	NR	20.28	38	33	ND	RUL thick cavity and aspergilloma	Thin walled cavity, no aspergilloma	Success
Posaconazole	07/02/2020	49	48	40	2	2	4	NR	60.87	81.09	169	ND	ND	RUL cavity wuth aspergilloma	Nil due to Covid-19 (pt did not want)	Failed
Posaconazole	29/11/2019	59.6	NR	45.21	5	NR	5	63.47	NR	80.33	887	798	ND	Bilateral cavities and aspergilloma	Worsening left disease	Failed
Posaconazole	25/10/2019	66.1	66.8	ND	NR	3	2	NR	49.78	51.83	33	27	ND	Bilateral upper lobe cavities	Stable	Success
Posaconazole	07/02/2020	60.4	NR	57.15	2	NR	4	38.42	NR	80.64	61	ND	48	Left upper cavity and aspergilloma	Stable CT findings	Success
Posaconazole	02/12/2019	43.8	44.5	44.4	4	4	5	85.92	NR	77.68	168	111	ND	Bilateral cavities and aspergilloma	Stable right, improved left aspergilloma	Success
Posaconazole	03/01/2020	64.8	NR	65.5	1	NR	2	45.63	NR	30.62	18	14	15	Bilateral cavities	Sig improvement, no residual cavitation	Success
Posaconazole	24/02/2020	51.5	52.4	54.6	4	NR	3	82.57	NR	87.88	92	170	ND	Large RUL aspergilloma	Stable CT findings	Success
Posaconazole	08/11/2019	43.3	64.8	65.5	3	1	2	44.05	45.63	30.62	197	146	138	Multiple cavitating lesions with aspergilloma	Reduction in size of both aspergilloma	Success
Posaconazole	31/07/2020	65	63.5	63.5	5	5	5	100	83.97	92.93	62	60	ND	Left upper cavity and aspergilloma	Cavity wall thinner, reduced aspergilloma	Success
Posaconazole	09/03/2020	69.4	NR	68	5	NR	4	73.9	NR	80.9	849	ND	ND	Right aspergilloma		ADR
Posaconazole	20/11/2020	50.8			4			87.15			170			Right upper cavitory disease on BG severe ILD		ADR
Posaconazole	24/07/2020	NR	59	NR	NR	NR	NR	NR	NR	NR	134	ND	ND	Extensive left lung cavitation		Failed
Isavuconazole	08/11/2019	54.1	52.4	54.1	5	5	1	56.96	NR	25.46	694	190	152	RUL cavity with aspergilloma	Stable, some reduction in cavity size	Success
Isavuconazole	01/03/2020	49	NR	50	1	NR	3	20.51	NR	9.17	>200	135	117	RUL fibrocavitary disease with aspergilloma	Stable disease	Success
Isavuconazole	03/01/2020	54.8	NR	54	4	NR	3	83.6	NR	66.82	169	146	112	Bilateral upper lobe cavities, prob LUL aspergilloma	Sig improvement cystic changes, Aspergilloma stable	Success
Isavuconazole	15/11/2019	58.2	NR	63.2	4	NR	3	63.2	NR	56.2	98	101	ND	RUL cavitating mass	Stable disease	Success
Isavuconazole	01/05/2020	44.4	49.2	44.45	4	5	4	81.71	84.59	82.47	83	63	ND	Bilateral cavitory disease, right aspergilloma	Left improved, right stable	Success
Isavuconazole	10/07/2020	63.5	60.32	63.5	4	4	4	60.46	57.48	83.8	178	113	196	Lung nodules (biopsy hyphae)	Right nodule improved, new left nodule	Failed
Isavuconazole	09/10/2020	57.7			5						156			Left upper lobe cavity		Failed
Voriconazole	21/08/2020	42.8	39.5	40.4	4	5	4	82.43	75.48	NR	>200	ND	>200	Complete left hemithorax cavitation	Stable disease	Success
Voriconazole	28/08/2020	58	NR	58	2	NR	2	NR	NR	30.47	458	ND	158	Right upper lobe cavitation and aspergilloma	Stable aspergilloma, reduced cavitation	Success
Voriconazole	07/08/2020	68.4	NR	69.85	5	4	5	98.59	NR	95.88	>200	ND	159	RUL cavity with aspergilloma	Reduced size of aspergilloma	Success
Voriconazole	25/06/2020	47.6	NR	47.6	4	5	5	94.63	NR	NR	150	ND	101	LUL cavitating lesion with intracavitary material	Marked improvement	Success
Voriconazole	10/07/2020	56.6	NR	DNA	4	NR	DNA	84.85	NR	DNA	736	171	ND	LUL cavity and aspergilloma	No imaging	Success
Voriconazole	11/12/2020	63.5	NR	NR	4	NR	NR	NR	NR	NR	116	99	ND	RUL cavity with aspergilloma	Reduced size of aspergilloma	Success
Voriconazole	14/09/2020	50.8	NR	44.4	4	NR	5	87.15	NR	86.38	ND	170	175	Right upper cavitory disease on BG severe ILD	No imaging	Success

Appendix 8 Publications

NAC/MRCM Journal publications 2020/2021

1. Moazam S, Eades CP, Muldoon EG, Moore CB, Richardson MD, Rautemaa-Richardson R. Positive *Aspergillus* PCR as a marker of azole resistance or sub-therapeutic antifungal therapy in patients with chronic pulmonary aspergillosis. *Mycoses*. 2020;63(4):376-381 [10.1111/myc.13052](https://doi.org/10.1111/myc.13052)
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Appendix 9 Patient Survey Results

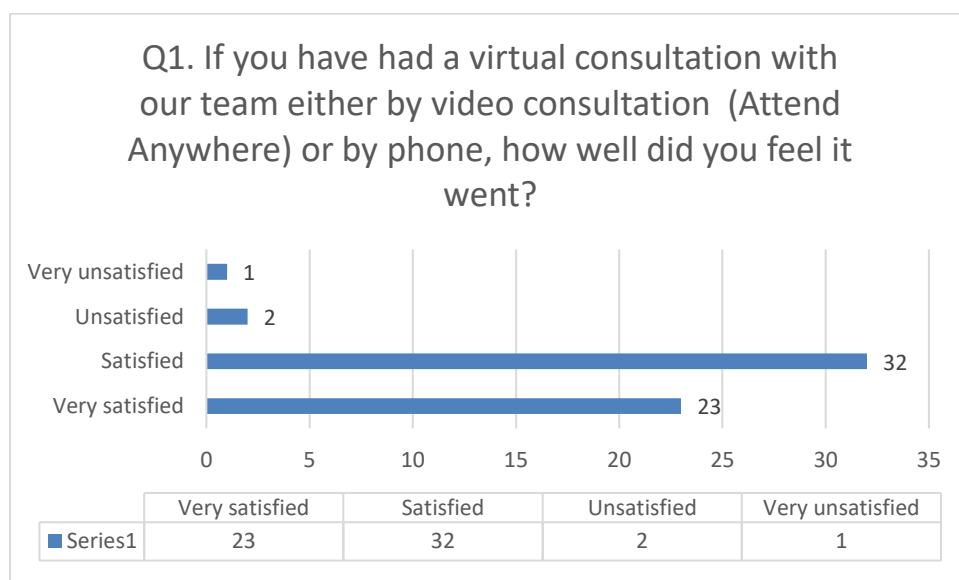
Patients survey 2021

Detailed analysis (2021 figure boxed in grey)

The National Aspergillosis Patients Survey is undertaken annually for 4 weeks in February/March and is intended to provide patient feedback on a range of NAC services. We can usually detect improvement or deterioration year on year by comparing answers from earlier years. However, 2020 and 2021 have been heavily impacted by the SARS-CoV-2 pandemic, which has exerted highly unusual pressures on NAC services and staff. These years are therefore not likely to be completely comparable to earlier surveys as changes noted could be the result of those extra pressures. We will include figures for 2019 (boxed in yellow) and 2020 (boxed in light blue) for reference.

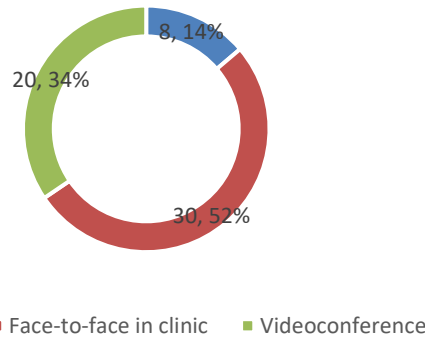
- 2019 – a routine year
- 2020 – pandemic lockdown began on 26th March, only 31 surveys completed
- 2021- The survey was offered to patients in three ways:
 1. A link to the online survey was offered to patients attending clinic via Attend Anywhere from mid-March to mid-April 2021
 2. We posted out paper copies of the questionnaire to 218 CPA patients
 3. We posted out links to an online version of the questionnaire to the same CPA group who received postal copies.

62 questionnaires were returned. 33 online and 29 by post. This is less than in 2019 when there were 86 questionnaires completed. This was at a time when patients would be offered the survey to complete while waiting for a face-to-face appointment in clinic.



2021: 55/58 (95%) who voted were satisfied or better with virtual consultation, so it seems that we have successfully adapted to the new remote way of seeing patients.

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



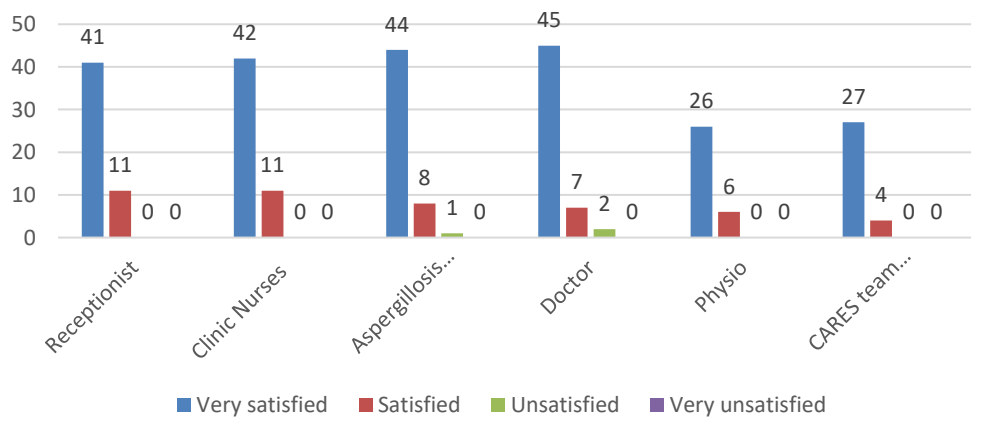
2021: Of those who voted, 30/58 (52%) preferred a face-to-face clinic in future. 8/58 (9%) preferred using the phone and the rest (39%) would be happy with videoconference. This result is perhaps not too surprising for a national centre as many patients (nearly half) will find travel to NAC quite difficult and remote consultations may bring benefit to the patient.

Q3. Is this your first visit to the National Aspergillosis Centre?

Of the people who answered the survey, 5/61 (8%) were visiting the NAC clinic for the first time.

- 2020 8%
- 2019 5%

Q4. How satisfied are you with the courtesy shown to you by our: -



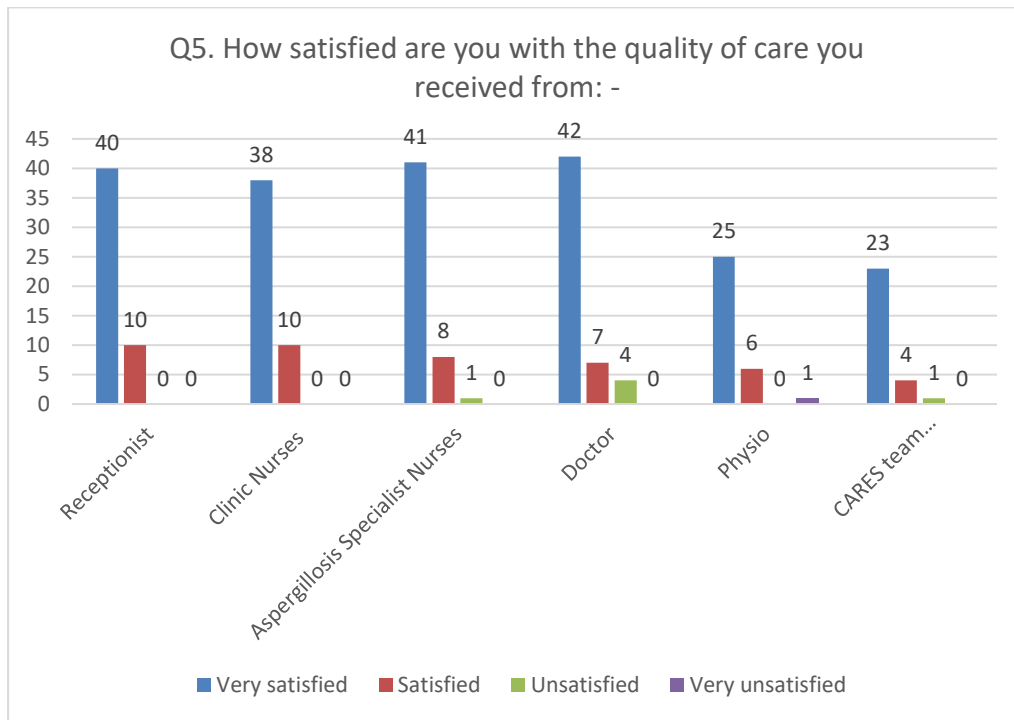
2021: 100% of patients were satisfied or better with the courtesy shown to them by Receptionists, Clinic Nurses, Physio and CARES team (Comms). One individual out of 55 (2%) was unsatisfied with the courtesy shown by Aspergillosis Nurses (98% satisfied) and

two individuals out of 54 (4%) were unsatisfied with the courtesy shown by the Doctors (96% satisfied).

It is noteworthy that overall, these approval figures have improved over the last year which is a remarkable achievement by the NAC team.

2020: Receptionist 94%, Clinic Nurses 97%, Aspergillus specialist nurse 96%, Doctor 96%, Comms team 100% and Physio 100%.

2019: Receptionist 98%, Clinic Nurses 98%, Aspergillus specialist nurse 99%, Doctor 98% and Physio 97%.



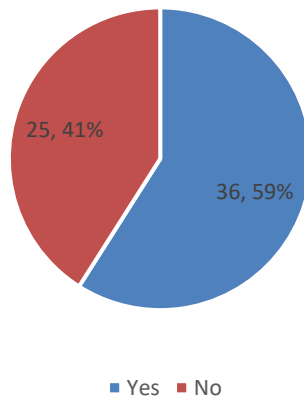
2021: 100% of patients were satisfied or better with the care shown to them by Receptionists and Clinic Nurses. One individual out of 50 (2%) was unsatisfied with the care shown by Aspergillois Nurses, four individuals out of 53 (8%) were unsatisfied with the care shown by the Doctors (92% satisfied), one individual out of 28 (4%) was unsatisfied with the care shown by the CARES Team (Comms – 96% satisfied) and one out of 32 (3%) was very unsatisfied with the care shown by the Physio’s (97% satisfied).

Standards of care have clearly been maintained or improved on in most cases. Considering this has been a year of great change in how we have had to manage patient care that is an achievement.

2020: Receptionist 94%, Clinic Nurses 97%, Aspergillus specialist nurse 96%, Doctor 96%, Comms team 100% and Physio 100%.

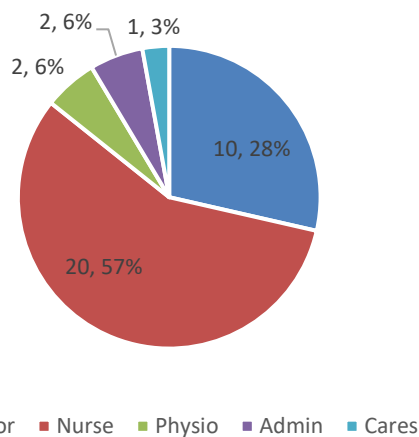
2019: Receptionist 98%, Clinic Nurses 98%, Aspergillus specialist nurse 99%, Doctor 98% and Physio 97%.

Q6. Have you been contacted by a member of the NAC team, after or in between clinic visits?



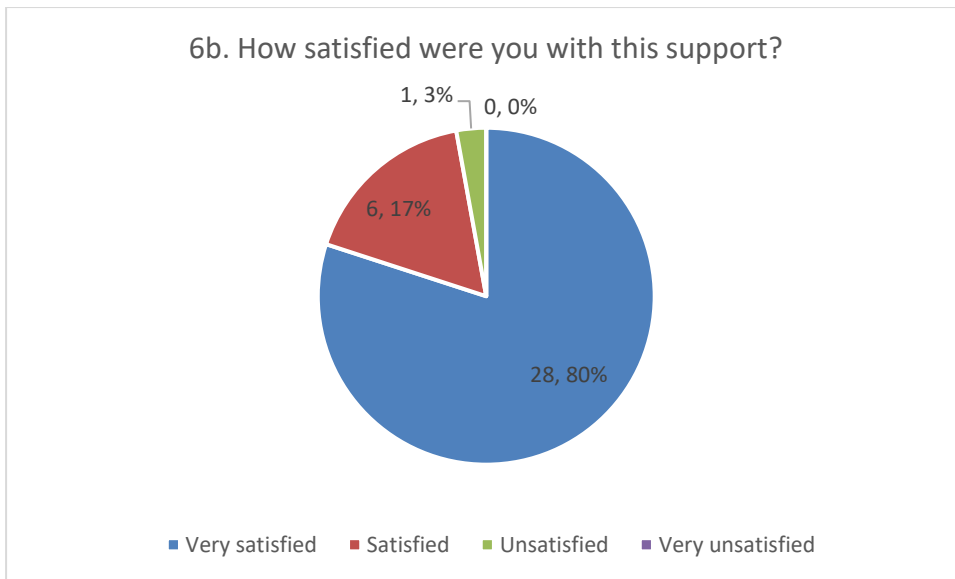
2021: 59% of patients had been contacted by a member of NAC between clinic consults.

6a. Which team was it: Nurse, Doctor, CARES team, Physio, Admin?



2021: there has been a noticeable shift in which team is making patient contacts between clinic consults from nurses to doctors, physio and CARES teams.

2020: 52% Yes. 79% of these contacts were from a nurse, 14% from a doctor and 7% admin.



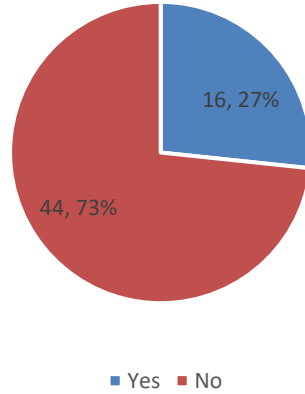
2021: One person was unsatisfied with the contact they received from a nurse which relates to the comment “Called and spoke to my next of kin despite having all my contact details“.

2020: 100% satisfied or better.

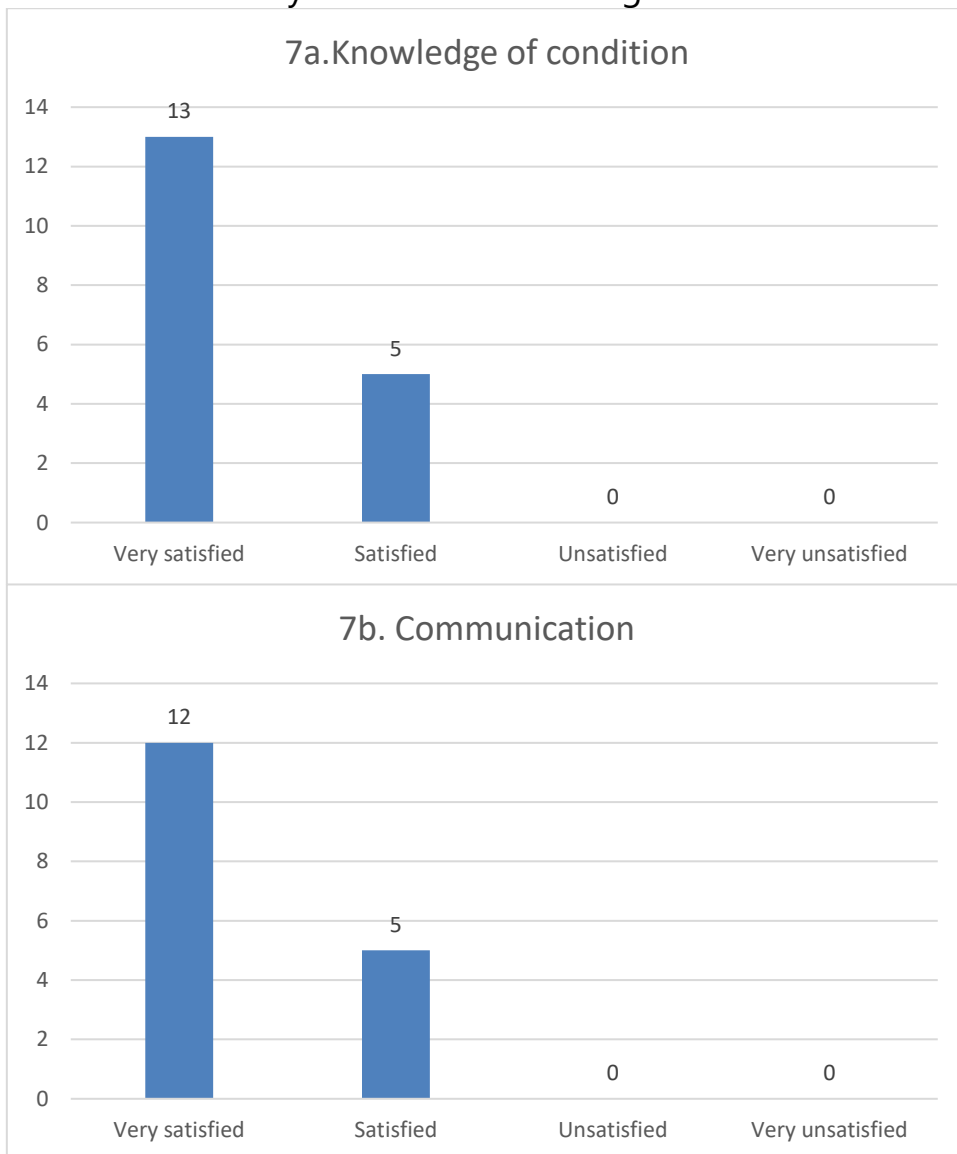
All other comments:

- I have not had a follow up letter as before after my consultation and not been given a date for a future consultation or been given any advice as to whether I should be still having blood tests for liver etc.
- Generally overwhelmed by the support from NAC, I would like to ask more questions than I’ve been able to and hope that when covid allows I will be able to do so (Nurse, admin, and twice by doctors).
- Communicated results of a discussion about me in MDT really clearly (CNS)
- It is always possible to speak, email, message. (Dr, cares team and physio)
- Regarding a mix up with blood results (Nurse)
- the Dr and the Bronchoscopy team were fantastic and helped me so very much (Doctor re: having a Bronchoscopy)
- Prompt call back and clear advice. Brilliant. (Nurse)
- At clinic I rarely see a nurse or clinical nurse specialist
- She was a big help as I have had no contact with your team for some time. She says that I will be getting a test tube soon now 29th April 2021 (Nurse)
- In difficult times well done (All Doctors & nurses)
- My condition is chronic so to receive a call in-between clinic appointments was reassuring (Doctor)
- Any letters to show the dates of any previous visits etc. It’s a long time between calls etc. and easy to keep losing track of things
- Rochelle has been fantastic (Nurse)
- This was by phone once between 2020-2021 (Doctor)

Q7. Have you had a consultation with a Specialist Nurse (Aspergillosis Nurse) at your last visit/remote call?



If yes, how satisfied were you with the following:



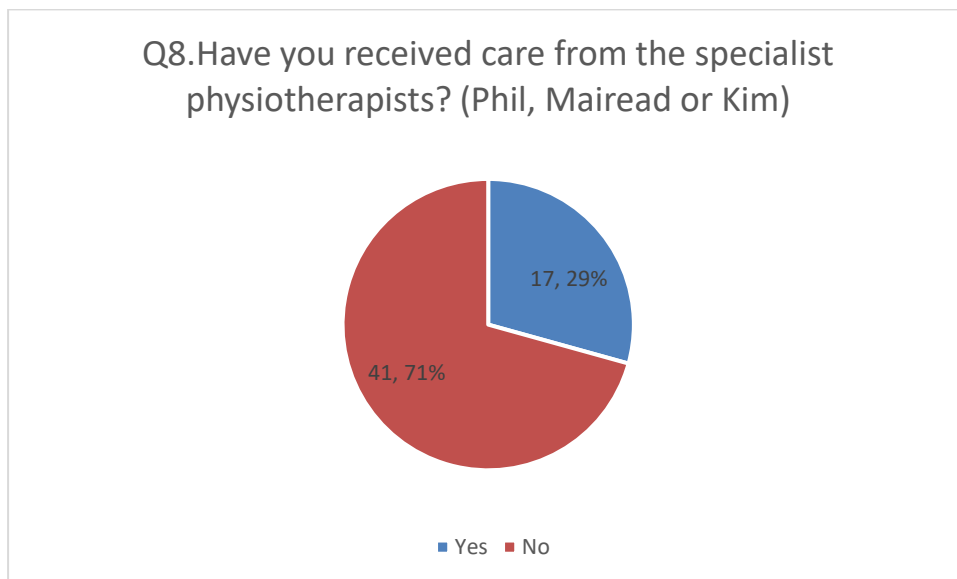
2021: Specialist Nurses continue to increase this activity with very high patient satisfaction.
2020: 24% had consulted with a nurse, all were 100% satisfied or better with their knowledge and communication. All positive comments.

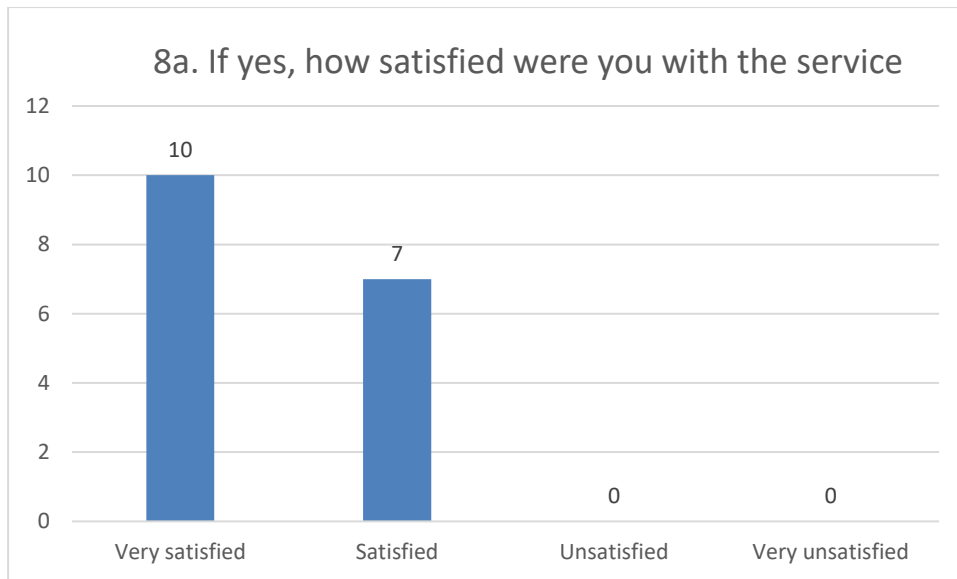
2019: 6% had consulted with a nurse, all were 100% satisfied or better with their knowledge and communication.

Comments:

- The Drs at Lincoln County Hospital said they couldn't get hold of team
- **I only have met 1 of the specialist nurses, I have no idea who they are anymore. It would be helpful to put names to faces. I haven't managed contact with a 'specialist nurse' since Covid. I have left messages but always get answered by whoever finds my call and have no idea who I'm speaking to.****
- As above, appointment missed due to Nurse stating they didn't have my contact details.
- Very occasional call to nurse when I could not access Dept admin
- Would contact only re test results
- It took place on 29th April. (Phone) It was nice to hear from your team.
- It's extremely useful discussing my cpa with the nurses when I call in

****Action point – the team have now all had photographs taken to post on the patient website and newsletters to help address this important point**





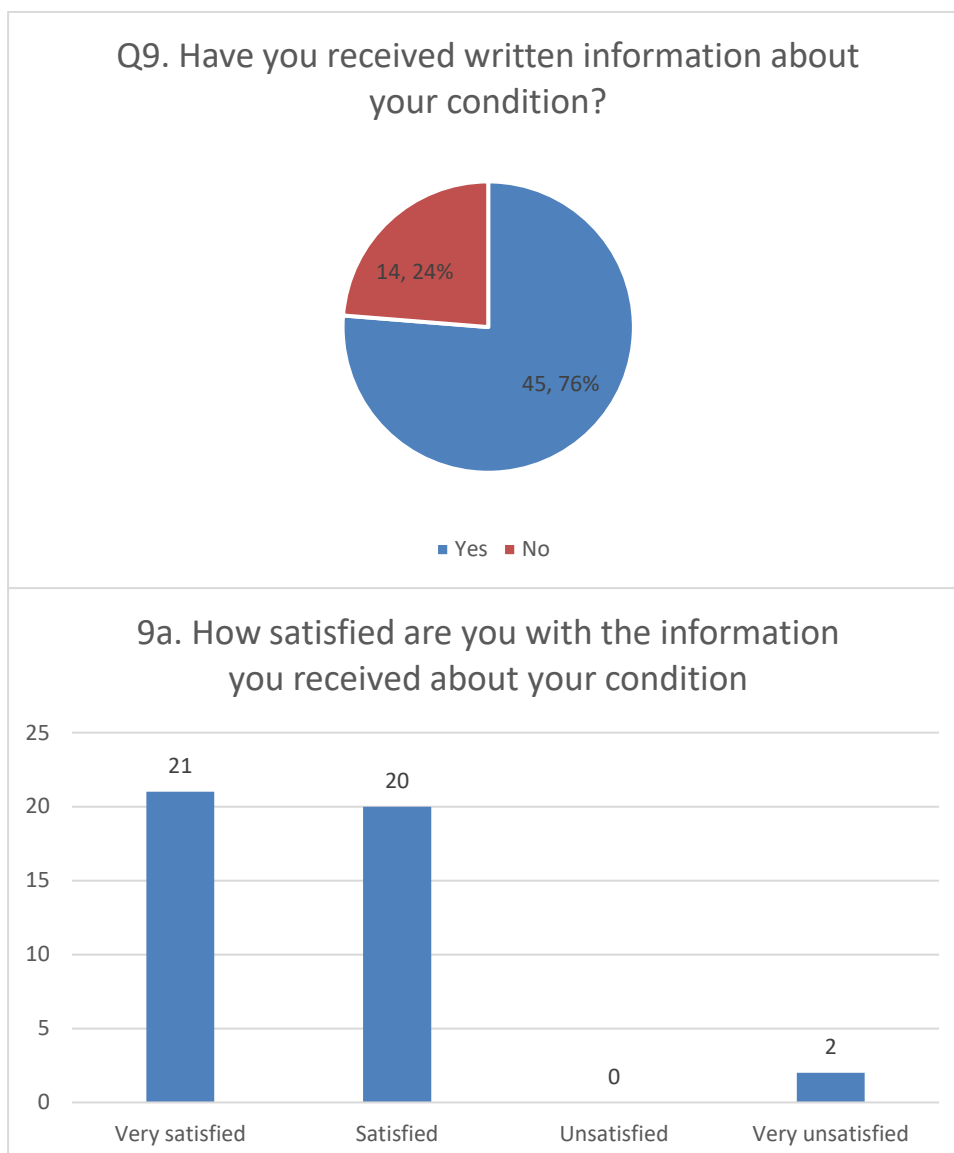
2021: Physio's continue to increase this activity with very high patient satisfaction. The comments (below) are also highly complementary to Phil and his team.

2020: 24% had received care from Physio, all were 100% satisfied or better. There were 3 comments, two were positive and one 'Not sure who they are'

2019: 15% had received care from Physio, all were 100% satisfied or better.

Comments

- How do you thank people who have had such a positive impact upon your life. My initial contact was with Phil and his gentle humour and knowledgeable approach helped me to put things into perspective and feel like I had a future. Mairead helped to get me started on Amphotericin B nebulisers and her patience, compassion and approach made me feel safe and enabled me to establish using the nebulisers, which I understand not everyone can. I think this was mainly to Mairead supporting me in the early days. I haven't met Kim but I am sure she is wonderful too. I can only say thank you for helping me to get my life back.
- Phil has been part of my care at NAC for a long time. He is always cheerful and is a real help when I have problems with my medication and nebulising equipment.
- Only contact with Phil was the nebuliser trial of 2019
- Phil took the time to listen to our concerns regarding my fathers illness and guided us to provide him with the best possible care. Phil is always professional and helpful and his understanding of the illness is exceptional. He always goes the extra mile to help his patients.
- I have had care from Phil at clinic but this has only occurred when I attended clinic and was unwell
- Sending me some sample tubes out
- Thoroughly went through the issues I was having re chest physio etc., Phil telephoned after I had mentioned my queries to one of the nurses and Phil followed up with a lengthy phone call and advised me, he also sent me links to a couple of videos he had made so that I can use them as part of my regime.



2021: The number of patients receiving information has increased significantly. The comments (below) are quite mixed with some praising the information given out, others say it is too general, others praise specific leaflets or the Aspergillus website, several seem to misunderstand the question. **

2020: 62% (18) had received information. There were 2 comments which were neutral or positive

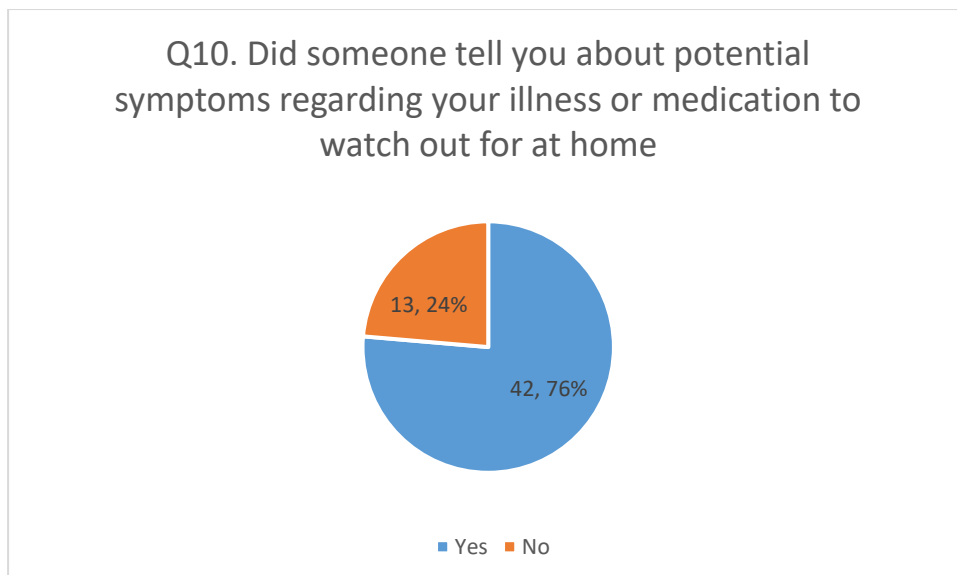
2019: 67% (48) had received information. There were 6 comments which were neutral or positive, one praised a letter by Prof Denning in particular. One was a concern "I never have any feedback after appointments like my other clinic visits at different hospital

**Action point – re-word question for next year's survey

Any comments?

- Not sure what you mean. I receive written reports of consultations and these are good
- As mentioned I have not had recent written correspondence
- Just at initial consultation I received a patient information booklet from nurse.

- Not always accurate information
- Mairead gave me tailored information about breathing exercises which I found really helpful.
- The Aspergillus website has so much information that I can always find useful. The Cares team always keep us up to date through the Facebook support group and zoom sessions
- But the communication is only the summery of my condition in medical terminology not personalise for patients
- I receive a copy of the Consultant's notes to my GP after my Clinic Consultation
- It's been slow turning up after a consultation
- This took place some years ago, not up to date.
- Very thorough
- Got all info we need from docs
- Don't recall getting any
- Some information, I understand new information is being worked on at NAC



2021: We do well at this but several comments (below) are asking for more information. Perhaps this needs a leaflet & webpage?

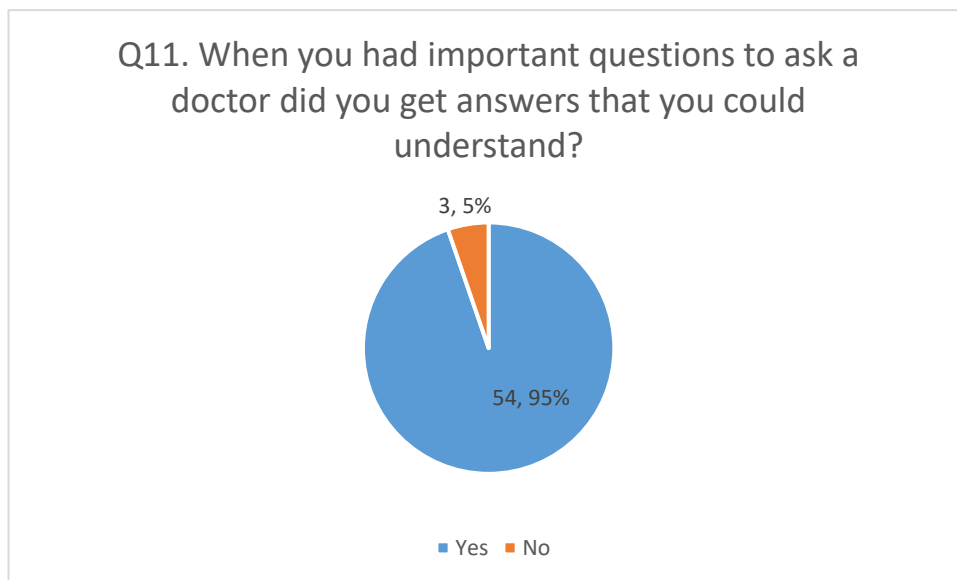
2020: 80% Yes.

2019: 74% Yes.

Any comments?

- Several. Coughing up blood was a big one
- I would very much appreciate and welcome this information because I am struggling to recognise and differentiate symptoms on Aspergillosis and COPD
- Prof Denning was always very good at explains things at a higher than usual level
- Yes e.g potential bronchospasm with AB nebs
- But not in depth
- Don't know can't remember

- Sorry not sure what you mean?
- I've had the condition for 35 years so knew what to watch out for
- Don't recall any conversation
- Could do with more knowledge
- I really would appreciate this information



2020: 100% yes

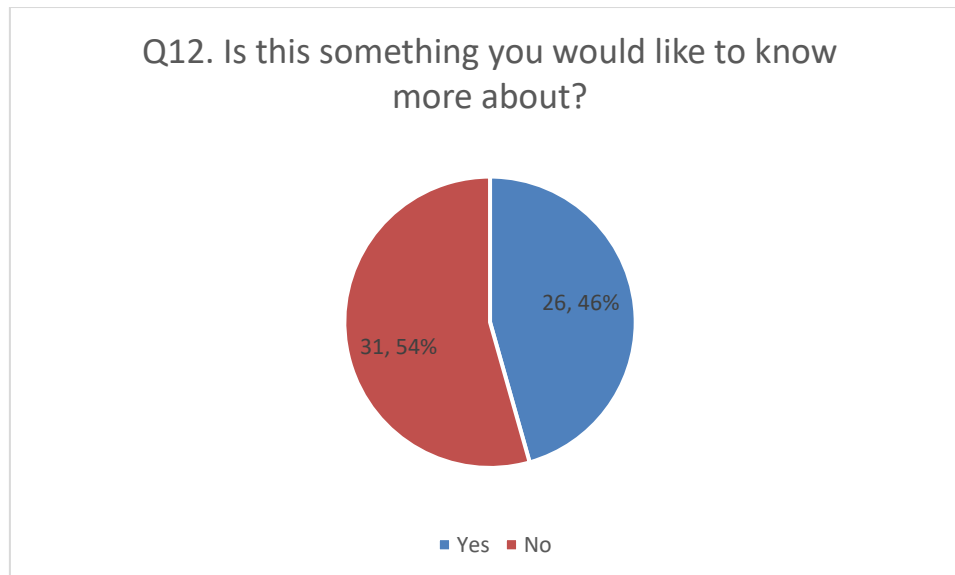
2019: 100% yes

Any comments?

- All docs been exceptional in this. Always seem to make time to answer questions.
- **I'd like to know what what questions I can put to doctors or nurses, whose the best person to ask really, I do feel in the dark about this illness, partly because it has taken so long for my local respiratory team to diagnose and also covid restrictions and massive strain on nhs staff at all levels****
- Dr Barrera was very kind and courteous and really took time to explain things to me
- On the whole I have but there have been times in clinic when Drs have been in a rush to move on.
- There were times during a low platelet period when I had support so I could record historic blood results
- No comments
- Don't recall any conversation
- Kind of

**Action point – to be addressed under roles on the website

For some patients treatment options can become limited and for others, despite adequate treatment, they have on-going severe symptoms such as breathlessness. Local palliative care teams can support you with additional interventions designed to increase your quality of life and improve symptoms, and we sometimes suggest that we work in partnership with them and yourself.



2021: This year we slightly reworded this question and now there has been a large increase in request for this information. Needs a leaflet & webpage.

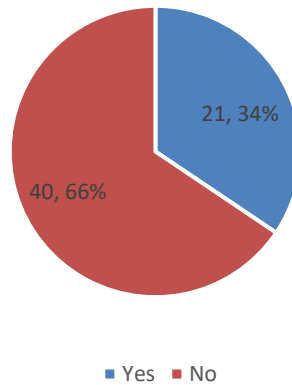
2020: Around 90% did not want to discuss, with slight difference in preference about who the conversation should be with (doctor rather than nurse).

2019: 90%

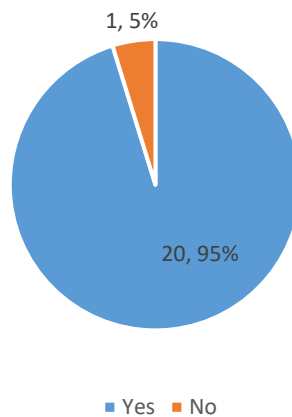
Any comments?

- I would think you would know to whom and when this is appropriate
- Would like to know more about this
- Phages as a possibility for infection management
- Fortunately, for me I have gone back up to doing at least 10,000 steps per day from not being able to walk across a room. However, if I were to need these services in the future I would gladly welcome them.
- Sometimes when I feel ill continuously it can be hard physically and mentally. I already grow azole resistant Aspergillus in my lungs and sinus. I don't do well on steroids. It would be great to have extra support when necessary.
- Because it is not relevant at the moment
- Presently not on medication
- Don't think this applies to me
- I thought palliative care was end of life care? I don't think I am at this stage yet.
- Not at the moment
- Yes Please

Q13. Have you ever had an in-patient stay here at Wythenshawe Hospital?



13a. If yes did you feel you were treated with respect and dignity while you were in hospital?



2021: Numbers spending time as in-patient has increased in 2021. 95% of these were satisfied with how they were treated and comments (below) are universally positive.

2020: 23% yes, of which 100% felt that they had been treated with respect and dignity.

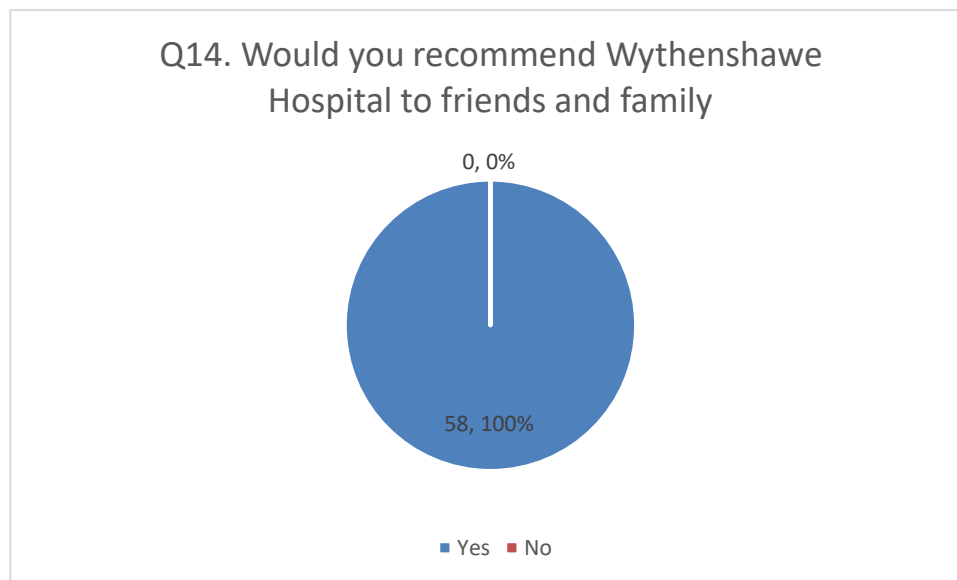
Comment: Very well looked after

2019: 32% yes, of which 96% felt that they had been treated with respect and dignity. One individual answered no.

Any comments?

- All staff I meet / encounter through Wythenshawe are so kind, friendly and knowledgeable. I would be in a much worse state if it wasn't for being referred more than 6 years ago. Thank you all.

- I have stayed several times, not only for Aspergillus but also infections and had a stay in intensive care.
- Really friendly, helpful and cheery staff
- Not for NAC , X was treated like a king
- Nothing to do with this - prostate problem
- My stay was happy and comfortable



2021: 100% yes and Comments (below) are universally approving.

2020: 100% yes

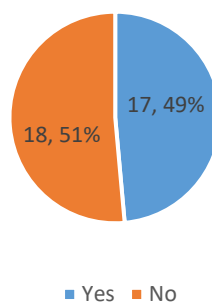
2019: 99% yes

If you can, please give us a few details why.

- Because you seem to know what you are doing and everyone is so caring and competent.
- Brilliant service, NHS is good, but NAC is excellent
- For the Aspelligosis care
- I don't have enough words of praise or gratitude for everything Wythenshawe are doing for me, I feel as though I'm being listened to and the help is there for me even though I live a couple of hundred miles away, I join the zoom meetings and pick up useful information, I've just joined hospify and I'm finding that very useful too, also the support groups on Facebook
- Excellent service Thankyou
- Because I feel safe in your hands and I felt like I was treated like an individual where my own life skills and knowledge were also respected too.
- If anyone of my family got this disease I wouldn't think twice. Sadly I live in Northamptonshire which on a good day is 3 hours each way. It's worth the journey for me as I would be dead by now if I had never bumped into Professor Denning online.
- But I only know about the Aspergillois dept.

- helped to get diagnosis and treatment to worked for me
- I would recommend the Lung clinic and associated departments, I haven't used any other service at Wythenshawe hospital
- Great people, very helpful and very good knowledge of your illness
- Not sure clinics are over booked appointments run very late generally up to 2 hours. Inadequate staffing for the blood taking procedures have long waiting times .
- They are world experts in aspergillosis treatment
- All round treatment, by staff was and is wonderful.
- Full attention when required
- Very helpful
- I can only speak about the NAC. The aspergillosis unit is a unit I now depend on the guide my medical treatment in Edinburgh
- For aspergillosis yes, otherwise long travel time
- Received good care & concern
- All ways well looked after
- You give the best care
- All the staff and Drs are quite helpful
- Absolutely yes, I was seen for the first time during a lockdown period, after being told by my local respiratory team for years my condition was copd emphysema etc., then when eventually being diagnosed with CPA I was told absolutely nothing about the disease by local team and then I wasn't encouraged to get an appointment with NAC which I'm so glad I followed through with as my doctors, nurses and GP have no other Aspergillosis patients, also I find when I do go the local hospital now for appointments I am receiving more thorough questions and monitoring it has made an enormous difference to my care I receive from the local hospital, though I do wonder if the sputum tests they carry out are looking for the same bugs and carry out the same tests as say Wythenshawe . Wythenshawe has the knowledge and expertise to treat aspergillosis patients, plus they are my lifeline for information, advice, support and I would think hospitals and general practitioners all over the world.
- They are world experts in aspergillosis treatment

Q15. We provide a postal service for drug levels and sputum samples. If you have used this service have you any comments or ideas on how this can be improved?



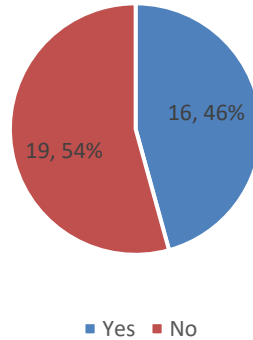
2021: The problem with fitting postal packs into postal boxes seems to have carried over from 2020.

2020: No complaints. Very good, Very good, Very good service, Smaller pots to fit in postal boxes, Packaging doesn't fit well (container cover doesn't close properly once jar is inside), Ensure return label enclosed, Local surgery seems to struggle with the concept.

Comments

- Needed to train my GP practice, but now it works smoothly
- To be advised if this is to continue or not
- Would it be possible for patients to have sputum jars and drug level jars and envelopes at home ready for any tests you may require the patient to provide samples for? I have started to have my blood tests carried out at home and I am happy to post samples back guaranteed next day delivery, I personally would prefer Wythenshawe to do my sputum's and bloods because I get no feedback about results locally and also none of my GPs. Or COPD nurses have experience with Aspergillosis patients. If possible, it would be great if I had a set of bloods, sputum jars, and test pots here ready to send if an emergency occurred and I could request replacements to be posted out to me.
- Postal packs are great; I think they should be used all of the time so that results are up to date ready for appointment, as this makes more sense.
- As I live 30 mins away i have done both but to be honest found it better to drop samples off.
- If it was someone's job to note if there is a problem and contact you.
- I have struggled to get appts locally for my blood sampling. When I used the postal pack my samples weren't processed or ? received.
- it was a good service
- The sputum pots in the protective package do not fit into a letterbox and have to be posted over the counter.
- Very good
- Always worked OK for me
- I have used it. It's OK for me
- It has worked OK for me thanks
- No improvement needed (fine)
- Any faults with this service are with Royal Mail not hospital
- Very satisfied
- I find the plastic case too small for the sputum sample bottle+ too big for the post box! I tried 4 post boxes before I found one I could jam the sample through. Our post offices are shut at local level.
- Could have post boxes at doctors, Clinics, hospitals
- Satisfactory
- None, always been ok.
- Never used
- System worked very well
- Proper fitting postal packs, some post boxes are not fitting.
- It has always worked well for me

Q16. We have commissioned a company to deliver anti fungal drugs to patient's home. If you have had this service do you have any comments



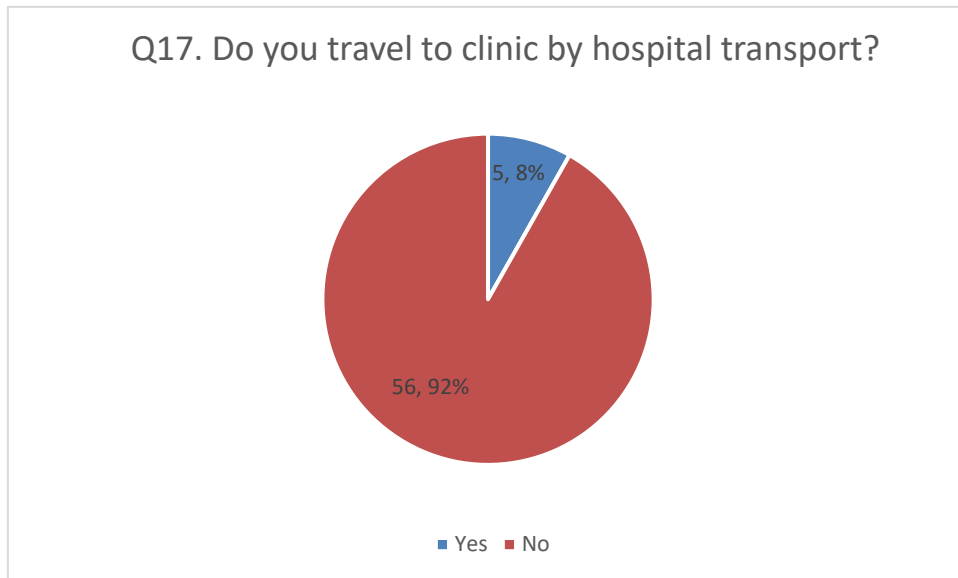
2021: This service seems to work universally well.

2020: Comments: Reliable service, Excellent, Been fine, Very good, Its very useful, Our last order was short and I had to call the company several times to chase up our order. I was disappointed at the lack of communication, Great service, Very good service, Very good services

Comments

- Works faultlessly
- This was amazing particularly as I was shielding so it cut my risk down by not having to go into the hospital
- It has worked so far and the couriers are polite.
- it is brilliant!
- it was delivered to my door
- Always turned up on time but I never received the promised text message telling me the 2 hour delivery window
- it works really well
- Fantastic service
- It's very efficient
- Always been OK as a service for me. Been good.
- No
- Satisfactory
- Prompt
- Good service
- The delivery company are very good
- All is going OK (Good service)
- Usually delivered on time
- Some delivery problems at the moment, Dose change
- I found healthcare at home superb.
- Satisfactory
- Very good

- Not used this for several years
- Very good
- Always on time
- They were always on the ball and told you day & time of delivery
- I have received them very regularly
- To date I'm really pleased with the service I receive
- It's very efficient



2020: 7% Yes. No-one commented about the quality of the service

2019: 10%



b. Could you please provide us with the first part of your postcode e.g. M23?

2021:

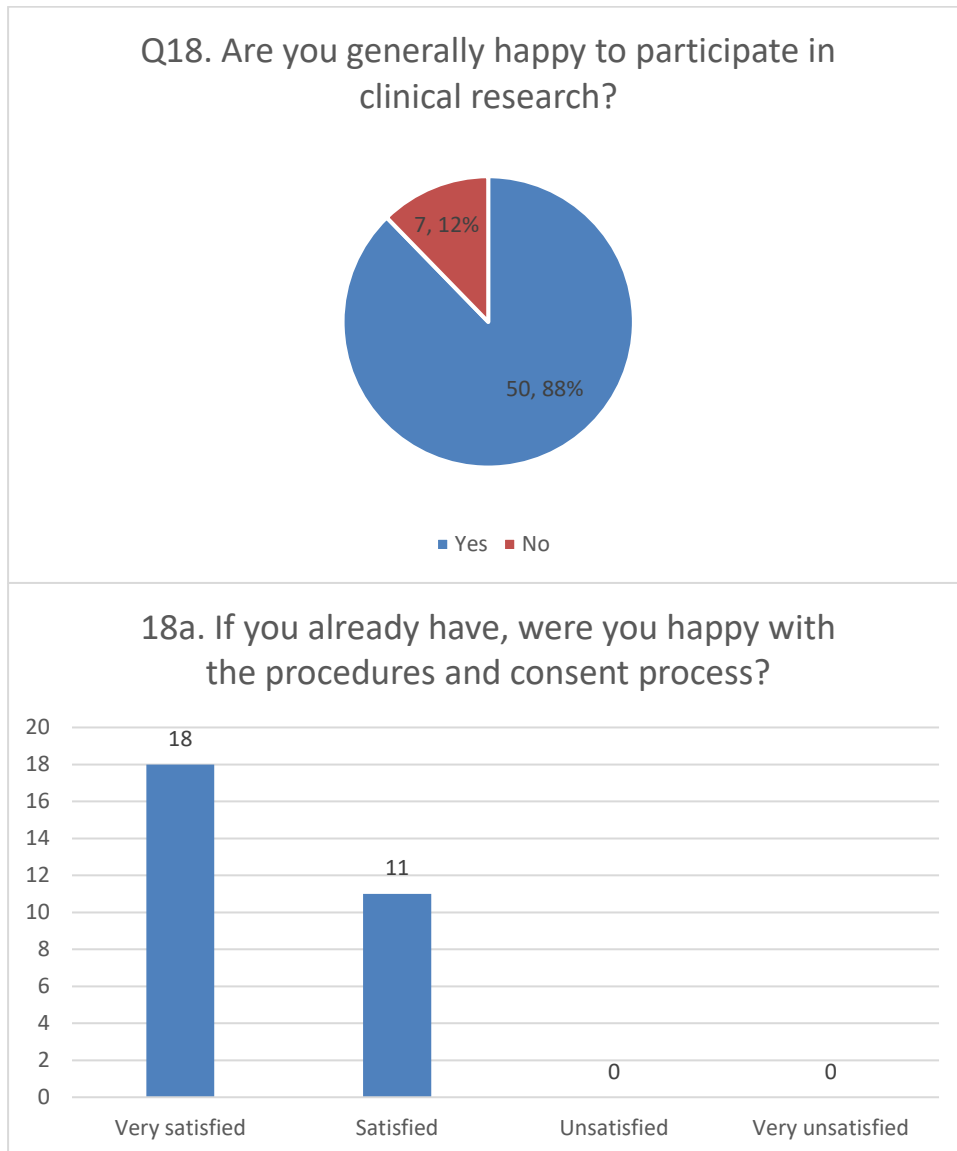
M28 (Worsley 9.2 miles)

ST10 (Cheadle (Stoke) 31.5 miles)

WF2 (Wakefield 37.4 miles)

LA8 (Lancaster 67.1 miles)

DN14 (Goole 59.9 miles)



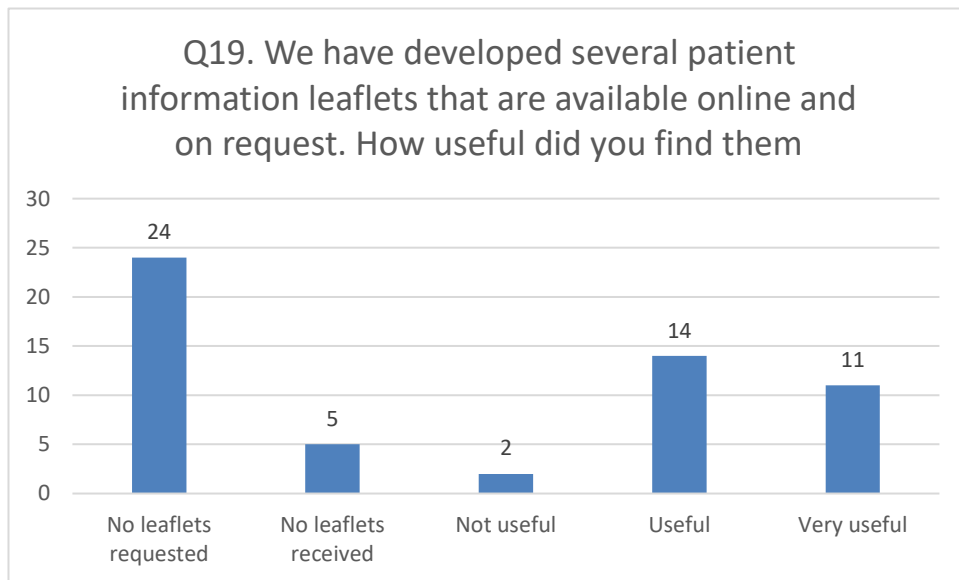
2021: The proportion of people happy to participate in clinical research rose to 88%. Comments suggest that there is interest in more involvement in our clinical trials, in more information on what we are doing and on what progress has been made. There are some queries on not being approached to participate.

2020: 77% Yes, of these 100% happy with procedures and consent process.

2019: 78%

Any comments?

- More feedback would be appreciated, although I know it's not easy
- Regarding clinical trials I live alone have family nearby but travel is very difficult to arrange but I am still interested to help in any way I can
- I would gladly enter into any appropriate research for ABPA/SAFS and bronchiectasis
- When I first came to Wythenshawe, we were asked almost every appointment to consent to trials on one thing or another. It seems to have stopped over the last 5+ years.
- I took part in a DNA study at the very start of my Clinic visits. Nothing else



2021: The proportion of people who thought our leaflets were useful was 93%, which is a marked increase on 2020 (74%).

Of the people who had not received a leaflet, 17% requested but did not receive one.

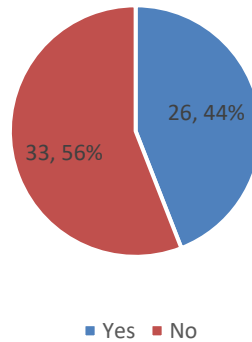
2020: 74% thought our leaflets were useful. Of the remaining people (26%) none had received a leaflet.

Is there any other information that you would like to receive information about?

- I would like to know more about this service
- No
- **Signs of pending aspergillosis related flare up****

**Action point – develop information

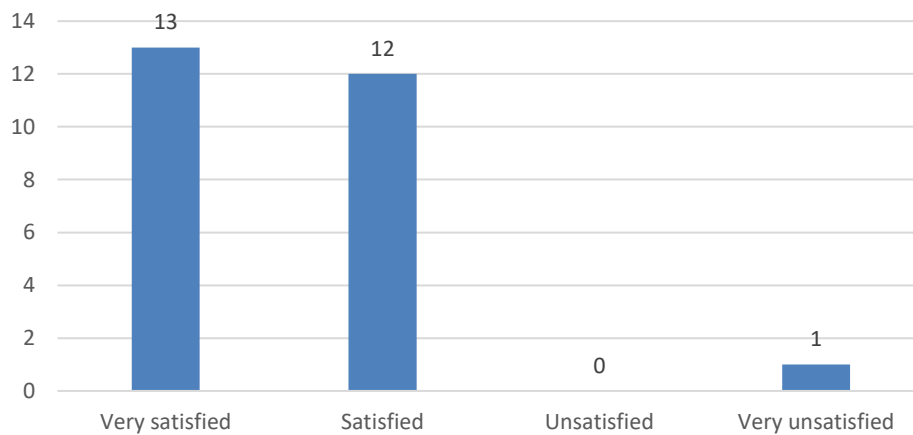
Q20. Have you visited the new Aspergillosis patient's and carers website?
(<https://aspergillosis.org/>)



2021: there is a big increase to 44% (16% in 2020) in the proportion of people who have visited the Aspergillosis website aspergillosis.org. This probably reflects increasing awareness of the website, propagated by the CARES team promoting it on social media and during meetings.

2020: 16%
2019: 19%

20a. If you have, how satisfied are you with the Aspergillosis website



2021: 95% satisfied or better.

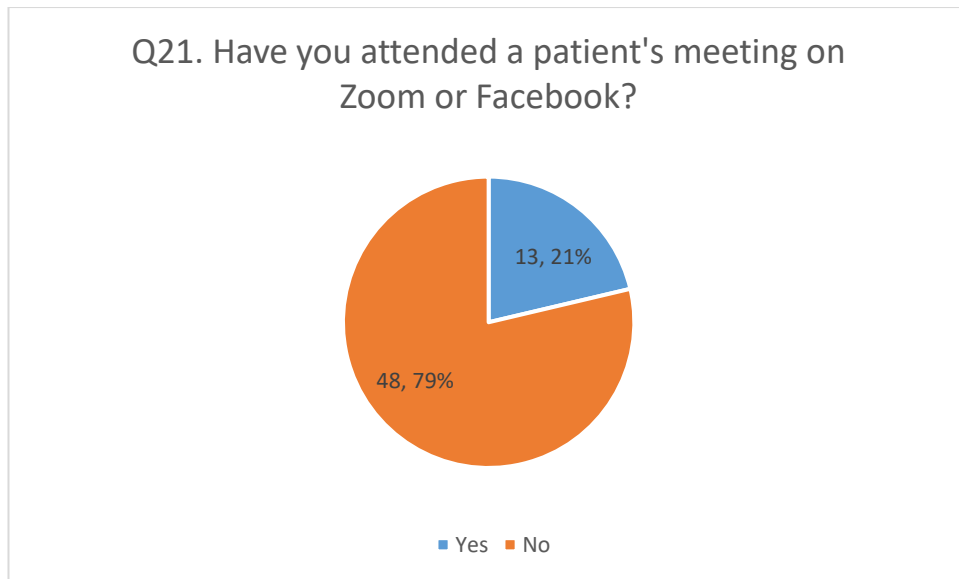
Of the people who left a comment, 3/19 (16%) did not want more information, 7/19 (37%) did not know we provide leaflets and 9/19 (47%) cannot access leaflets online.

There is room for improvement in us sending out leaflets to people who cannot access them online, and informing those who do not know about them.

2020: Of those that had visited, 100% were satisfied or better.

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

- One I wasn't aware of it but I also don't want to live constantly living Asperg.
- Probably I was hoping the various drug regimens would do the trick?
- I get all the information I require when I visit the clinic
- Didn't know about it.
- Not aware of it
- I didn't know about it
- I am not on the internet
- No computer
- Didn't know about it
- I cannot go online
- Not online
- I didn't know about it. I will look at it from now.
- Not clued up on internet
- No computer
- No computer
- No internet
- No internet
- Good information and patient stories
- I didn't know about it



2021: We have been unable to provide face-to-face meetings for patients in 2021, but it seems we reach far more patients by holding meetings on Facebook & Zoom – there has been a large increase in the number of people responding that they have attended a meeting in 2021, from 0% in 2019, to 3% in 2020, to 21% in 2021.

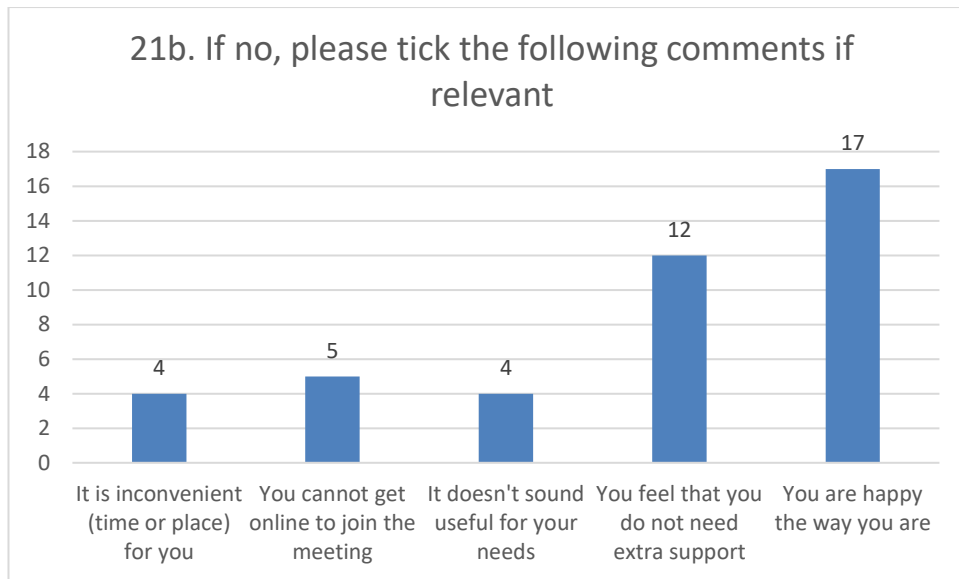
2020: 3% Yes

2019 0%

21a. If yes, have you any comments about the patient meeting/s?

- **I sometimes feel that it's always the same people that do all the talking and many people don't get to ask questions.****
- They are very informative and helpful.
- **No but would like to try on Facebook but don't know how.****
- Always informative and enjoyable
- Really like the way the meetings are run the format of introductionpresentation first and questions.....after is excellent, gives all those attending the opportunity to ask questions in an organised way without one or two who may monopolise the meeting or say something derogatory or offensive remarks

**Action points



2021: Only 4/42 (10%) did not attend because it was inconvenient (time or place) compared with 50% on 2020. It is clear that we reach far more NAC patients by presenting meetings on Facebook & Zoom.

5/42 (12%) need help or equipment to get online and join us.

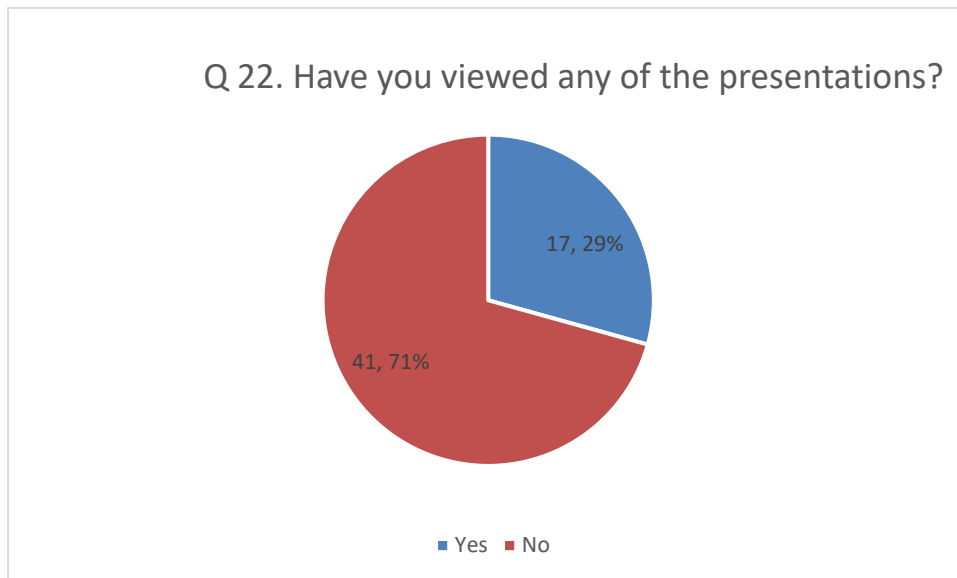
Comments suggest that some who do not attend do not fully understand what the meetings are for.

2020: Further questions revealed that nearly 50% did not attend because it was inconvenient or too far to travel. The remainder were not interested in attending the meeting as they were 'happy as they are'.

Any comments?

- A lovely idea and I may join in future.
- But not ruling out future possibilities
- I ticked 4 on the basis of my current condition, but I appreciate I am unlikely to experience a total cure. Maybe I should "test the water"
- I attended a session a few years ago but found the End of life subject depressing
- Doesn't come across my head
- I assume that it is for patients to talk about their symptoms, I find this depressing
- I live too far

Q 22. Over the last year the presentations from the patient's meetings have been recorded and put on the Aspergillosis patient's website (aspergillosis.org) and in our Aspergillosis Support Facebook group.



2021: 29% of patients have viewed the presentations, which is a large increase compared with 2020 (7%). This increase is consistent with the large increase in use of the website overall.

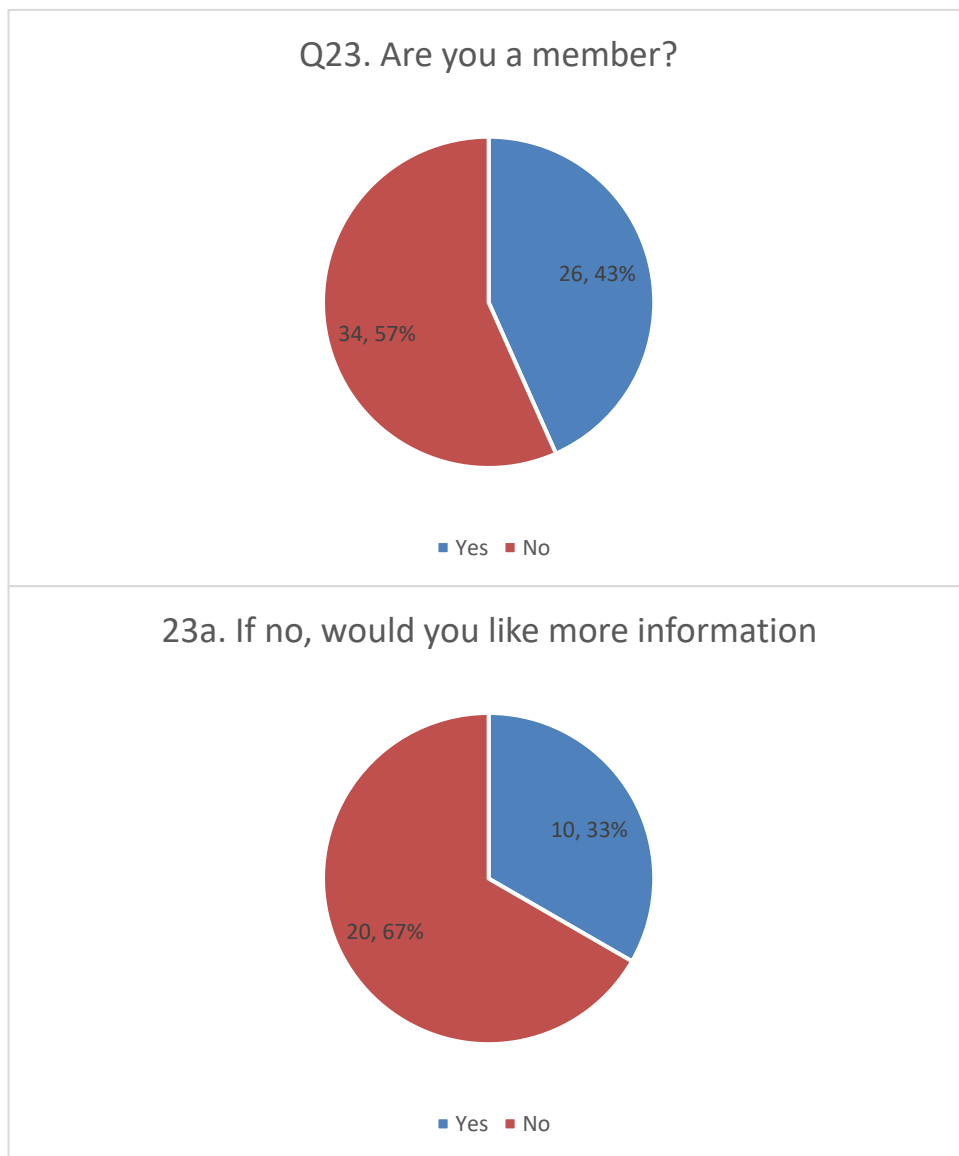
2020: 7% of patients have viewed presentations. These are loaded onto our website at aspergillosis.org and get lots of interest online, not necessarily from NAC patients.

2019: 4%

If yes, comments

- A bit long winded (need editing) and not always relevant
- Really informative, interesting and educational.
- My laptop has broken and my phone is not up to zoom.
- It has been useful and informative
- I think they're a great idea
- Learning a lot
- Not aware of this information
- It is extremely useful having the videos put online I often re-watch some of them in order to catch something I may have missed. I imagine it's extremely useful for people out at work and a must for overseas aspergillosis patients who are on different time zones.

23. We have a very active Aspergillosis Support group (>2300 members) on Facebook (<https://www.facebook.com/groups/aspergillusupport/>).



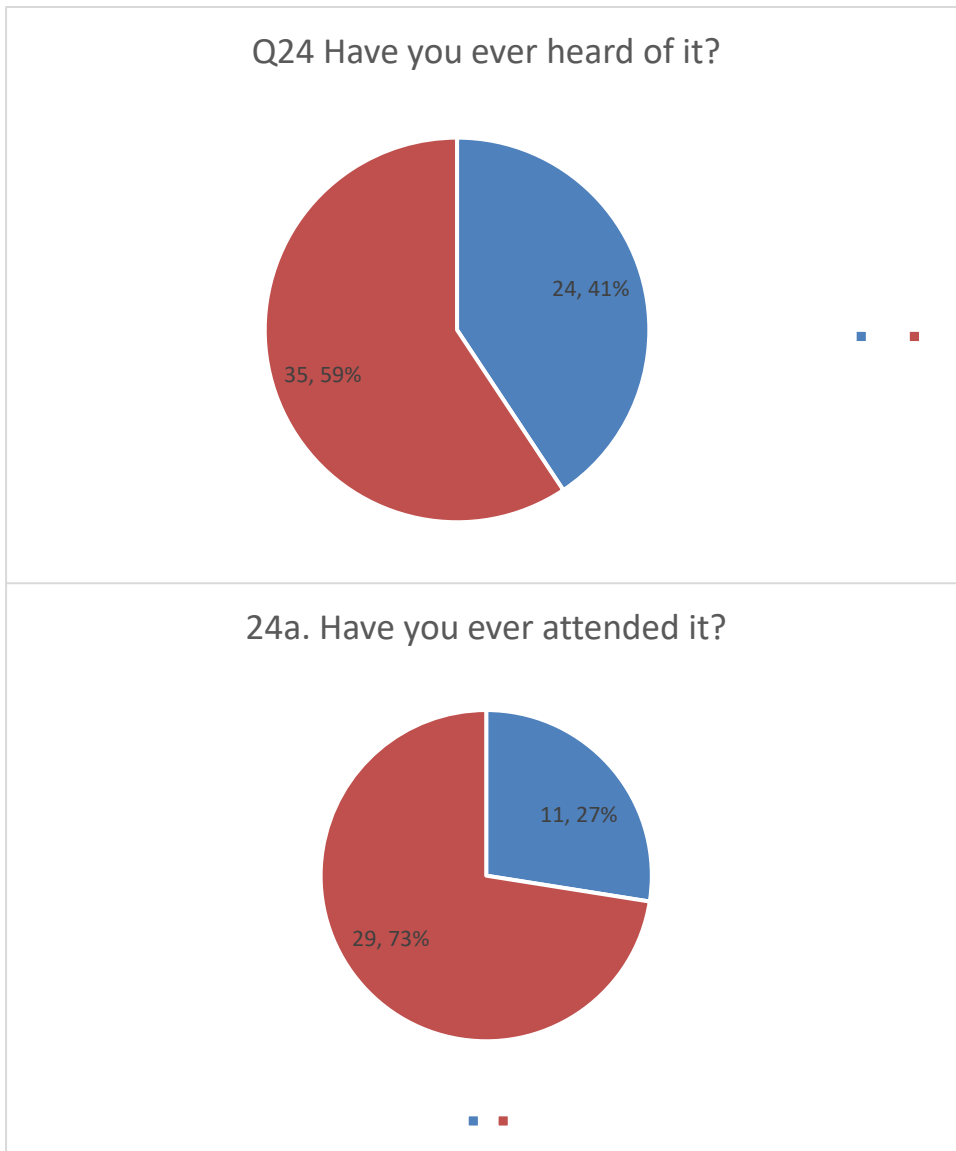
2021: This is a large increase in numbers of NAC patients who are members of our Facebook support groups from 14% in 2020 to 43% in 2021. One explanation could be that many more have joined looking for COVID information and advice during the pandemic.

2020: 14% are currently members. 30% want more information.

Your contact details

Removed for confidentiality

Q24. There is a weekly online social chat for patients & carers on Thursday at 10.00am, currently using Zoom software. You can attend using your phone or any computer. Have you ever heard of it?



2021: 41% have heard of our Thursday meeting on Zoom and 27% have attended it which is a large increase on figures for 2020 (11% and 12% respectively). This meeting switched to a daily meeting during much of 2020 and was very popular during lockdowns, so this large increase probably reflects NAC patients need for COVID support & information. 5 more NAC patients want to hear more about these meetings.

2020: 11% heard of it, 12% have attended

2019: 3%

Would you like to know more? Please enter your contact details below.

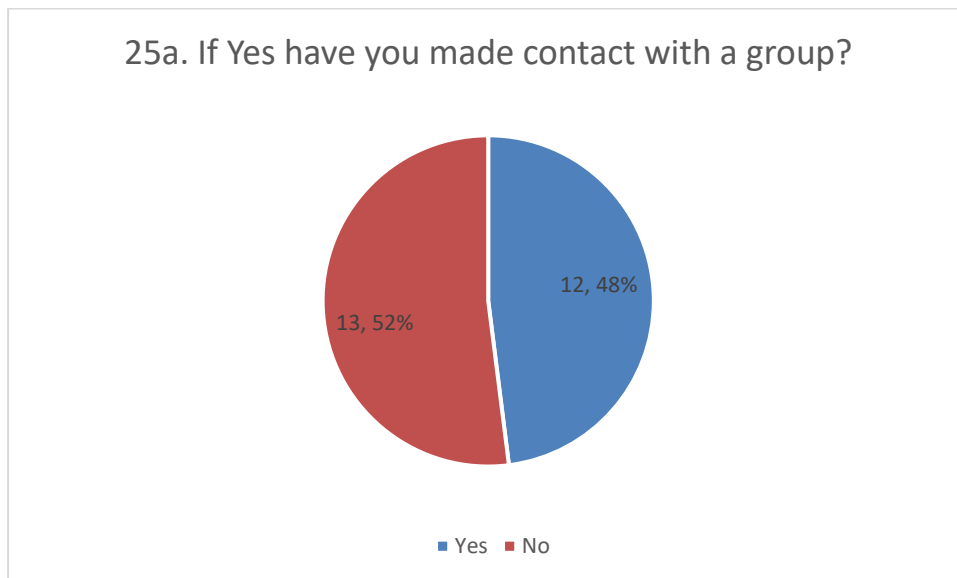
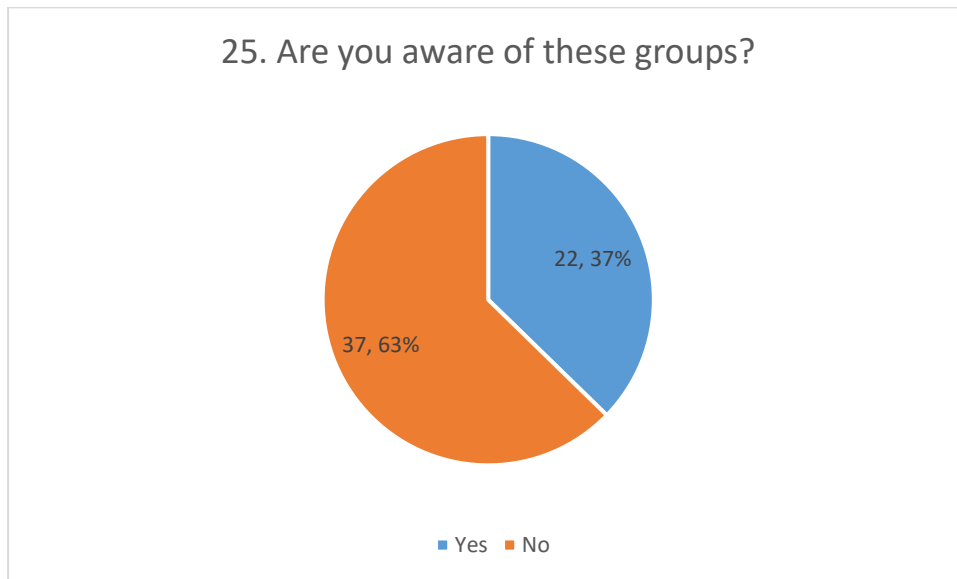
Addresses removed for confidentiality

- **Yes, it was particularly informative when we were able to ask questions or recently topics were chosen, more structured , less opportunities for the meeting to wander off into grey areas , it possibly could attract more attendees, socially its nice to see the regular faces and see familiar knowledgeable faces, but on occasions it can become all social is there any way we could split half social and half question time? Also is there a code of conduct for us as**

participants should be made aware of please. Just a question, I'm not trying to make more work for the Comms staff.**

**Action point

Q25. There have been several patient-led support groups set up around the UK, each of which has its own Facebook page; West Yorkshire. West Midlands, East Midlands, Liverpool, London, Bristol, Scotland, South Wales, East Anglia.



2021: 37% are aware of these groups and 48% (12 NAC patients) have made contact. This is a large increase from 2020.

In Comments for why no contact had been made 'none in my area' was the reason for 8/20 (40%) of NAC patients, 'Not interested' was the reason given by 4/20 (20%) and 'no access to information/didn't know about them' accounted for 10/20 (50%) of NAC patients. We

could conclude that **80% might be interested in joining a regional support group if they knew how to access them and had access to the internet.****

2020: 26% Yes. Of those who replied 1 (3%) had made contact.

In Comments for why no contact had been made, 7 replies (55%) not interested/inconvenient. 6 replies (45%) did not know and some presumably might like to join but it heavily depends on the group being in their area

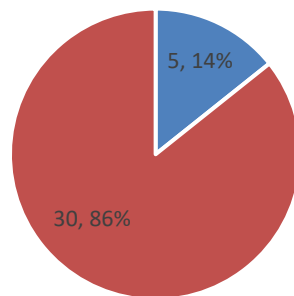
2019: 30% Of those who replied 1 (4%) had made contact.

** Action point

If No can you tell us why have you not made contact, is there anything we can do to help you make contact?

- There isn't one in my area
- No one there
- they don't cover my area
- Meetings are a long way from where I live. I do not enjoy that sort of get-together.
- There is nothing local to me
- I haven't got a computer
- I was not aware of them and none of them are in my area, in any case it would not be of interest
- Can't do it
- Not on facebook
- Didn't know about them
- Not sure what to do
- Not got facebook
- Do not have computer
- I wasn't aware there was a patient-led support group on FB in Scotland. Ill have a look into this.
- Not interested
- No computer
- Attend Manchester monthly meeting
- Not interested
- No internet
- There is nothing local to me

25b. Would you like information about setting up one in your area ?



■ Yes ■ No

(if yes please give us your contact details)
Your contact details

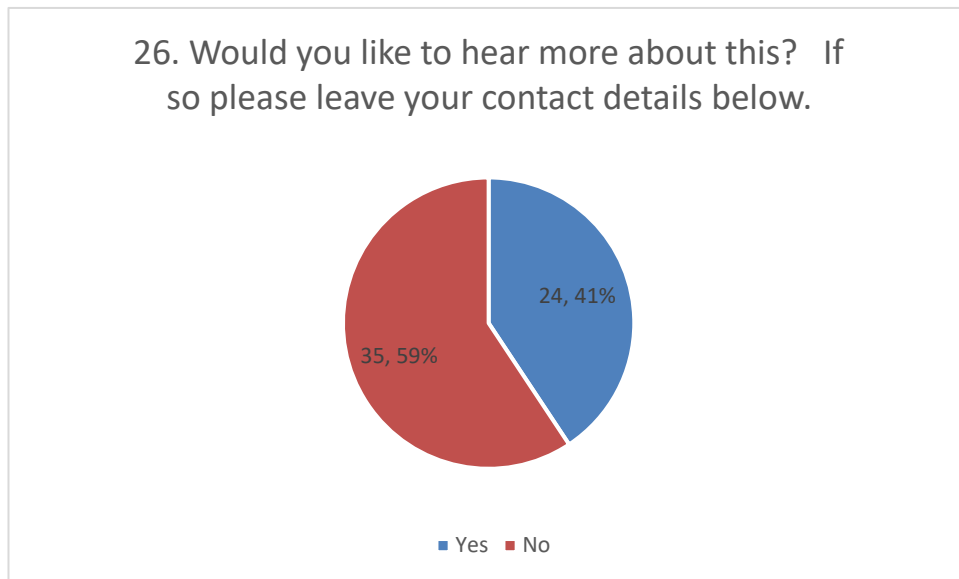
2021: 3x NAC patients would like to hear about setting up their own regional group**

2020: No replies to this question. Presumably no-one wants to run a group.

** Action point

Q26. The CARES team here at NAC have set up the Hospify App for your smartphone to enable you to contact the NAC CARES team completely privately and securely. This is useful for you to ask the team about any issues

that you make be concerned about relating to NAC and enables us to send you information too.



2021: 20 NAC patients (33% of those who completed the survey) want access to more information and support provided to them privately and securely by the NAC CARES team.

2020: This App was not available

Contact details

Removed for confidentiality

Q27. Do you have any other general comments about the NAC service?

2021: 33 NAC patients provided comments in this section, which is a big increase on the number who did so in 2020 (which was 2). 29/33 (87%) comments are highly positive and complementary to NAC staff.

- Keep up the good work. I'm only alive today because of you. Happy to help in return
- You mention that the Hospify app is completely private yet I get notifications when somebody eg a patient posts something so I am able to view this?
- Yes A great big thank you to everyone.
- Excellent doctors and nurses and very grateful for the support I receive
- The NAC service is a wonderful help and full of wonderful, supportive people who are very approachable and caring. This means the world when you have a horrid affliction like Aspergillosis.
- Very grateful for all the help from Wythenshawe, especially the nurses who are incredibly informative. Thank you so much. I don't think the hospify app is very good.
If I need help I'll ring the nurses.

- Your service has changed my life can't say it more simply than that. Not sure where I would be without you. The care and specialist knowledge I have received is second to none. I am fortunate as I realise my condition is moderate to many of your other patients, however the impact on my life has been huge. I have been shocked by the lack of knowledge about Aspergillus by the wider healthcare system. For example I diagnosed myself and found you via Google and with my previous experience of nursing immuno-compromised patients with fungal infections. So I had to ask my chest consultant to test me for a fungal infection, which he reluctantly did. So thank you so much you are a brilliant service and I hope you continue to spread the knowledge in supporting others. Kind regards, happy to be contacted if needed.
- You're all doing a brilliant job. I have been coming since 2006 and have seen many changes. I have received great care overall. Many thanks.
- A great service overall, just teething problems for myself with getting my bloods done locally. I prefer a face to face appt so I can be seen in the clinic for consultation and blood sampling etc
- I think NAC do a great job.
- Always find everyone friendly and helpful. Very thorough whenever I've visited the hospital. Waiting times are sometimes not great so video calls are much better and have helped to cut down the wait.
- I have been a patient of the NAC since 2008. The treatment I have received has always been top quality. It saved my life. The large aspergilloma that I had when I became a patient has gone and the condition is generally benign now, controlled by the drug therapy. Long may it remain so.
- I wish to thank all the staff at the NAC for the commitment and help provided for my father.
- I have to travel a distance and the round trip can take up to two and a half hours. With the long delays in clinic and possible delays on the motorway this makes it a full day out. I would suggest that the clinic and blood room appears chaotic on some visits.
- I really appreciate the NAC, live a long distance from Wythenshawe the video has not been working for the last two appointments and they have been call only, but they have been really good for me at the moment as my condition is stable, not just the travelling but being in the hospital I find stressful. I would still like the option of attending, having the nurses available if there is a problem has been invaluable in the past, as has the reassurance of a same day xray. For my first remote appointment my teen daughter was at home I felt it could have been difficult if I had received news that I wanted to keep confidential
- The last 2 times I have a telephone conversation with a doctor they have suggested taking me off my medication without checking the state of my lungs and whether or not the fungus is growing. This is rather silly. Every time I have been to the actual clinic I have been very satisfied with my care.
- Used to get all info from Dr or 3 monthly visits
- It was nice to hear from you (Denning Team) after so long.
- I am almost 70 years old. Prof Denning is very much in favour of my heavy gym work. I have been told that I have the fitness level of an average 55 year old

man. Everybody should join a gym & have a healthy diet. An SAE would have been nice!

- Many of the question not applicable during covid 19
- I have been happy with the treatment (antifungal) and life has become much better with posaconazole medicine.
- All positive ones stay safe everyone