

Impact of Long COVID-19

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1. Introduction

The effect of COVID-19 on people's health should not only be perceived in terms of hospitalisations and deaths. By October 2021, data from the Office for National Statistics estimated that 1.2 million people had self-reported as being affected by 'Long COVID-19' – ongoing symptoms persisting for more than 4 weeks after infection. (1) Of these, 65% reported that persisting symptoms affected their ability to carry out day-to-day activities. Long COVID-19 is an emerging phenomenon that is not yet fully understood. (1)

As per NICE/SIGN/RCGP guidance, 'Long COVID-19' is a commonly used term to describe:

- Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4 to 12 weeks.
- Post-COVID-19 syndrome: signs and symptoms that develop during or after COVID-19 and continue for more than 12 weeks and are not explained by an alternative diagnosis. (2)

Post-COVID syndrome, also known as Long COVID-19, is multi-system in nature. Occurring irrespective of age, co-morbidities, hospitalisation or severity of infection. Patients often present with clusters of symptoms, often overlapping, which may change over time. Often many people with post-COVID syndrome also experience generalised pain, fatigue, persisting high temperature and psychiatric problems. (2) Some may need specialist input from secondary care. According to the Office of National Statistics, Fatigue continued to be the most common symptom reported as part of individuals' experience of Long COVID-19 (55% of those with self-reported Long COVID-19), followed by shortness of breath (39%), loss of smell (33%), and difficulty concentrating (30%). (1)

There is still uncertainty in what is known about the long-term effects of COVID-19 and as evidence emerges we will begin to understand about the prevalence and recovery patterns following COVID-19. (1).

The Primary Care and Community Post-Covid-19 Rehabilitation Pathway service for TNW was launched on 18th January 2021. This was in response to the NHS England and NHS Improvement five-point plan that mandated Integrated Care Systems, to have in place, Long COVID-19 clinics to support patients experiencing long-term health effects following infection with Covid-19. (3)

We worked collaboratively with all key stakeholders to commission a local service that will enable patients who experience ongoing symptoms following infection with covid-19 to access a multi-disciplinary team of experts. The Multi-disciplinary team (MDT) includes physiotherapists, occupational therapists and psychologists, GPs and physicians from Barts Health, who could support aftercare/rehabilitation and, when necessary, arrange an onward referral to hospital and specialist services. (2) The Long COVID-19 provision was commissioned from East London Foundation Trust (ELFT) for the residents of Newham and Tower Hamlets, whilst North East London Foundation Trust (NELFT) provide a similar service for the community of Waltham Forest.

The model developed was set up with the view that the assessment hub would triage and assess the patient, but ongoing management would be via the provision of existing pathways. However, since mobilisation of the service, the model has gone through a number of iterative changes and has been further enhanced to meet the emerging needs of patients.

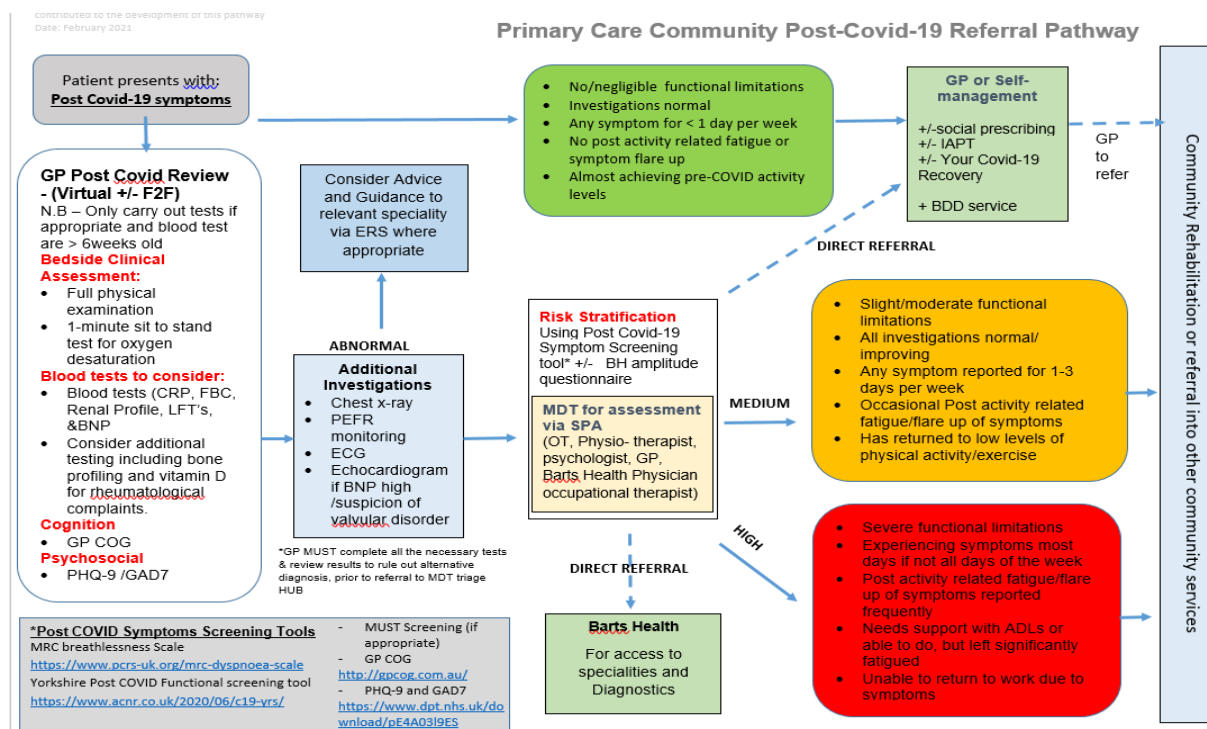


Figure 1: Primary Care Community Post Covid -19 Referral Pathway

1.1. Data

The ELFT service has now been in place for one year and has received 730 referrals from across Newham and Tower Hamlets. The data indicates that the majority of patients accessing the service are in the 35-44 age bracket and are predominantly female and white or of Asian or Asian British ethnic background. This clearly demonstrates a shift in the ethnic groups that are now accessing the service. Until July 21, the service was in the main receiving referrals for white patients. This may be an indication that the CCG has now been successful in engaging and raising awareness amongst the hard to reach and BAME communities.

Below is a detailed breakdown of the patients presenting to the service from Jan 21 to Jan 22. However, it is paramount to highlight that all the data presented in this report refers to combined data from both Newham and Tower Hamlets. Unfortunately, the mechanism of reporting does not allow activity to be broken down by the different areas.

ELFT (Jan21- Jan22)

Week ending		Total
Referrals	Accepted	395
	Rejected	335
	Total	730
Total number of patients waiting for assessment	Total	-

Table1: Breakdown of the TNW ELFT provision for the Long COVID-19 Service from Jan 21-Jan 22

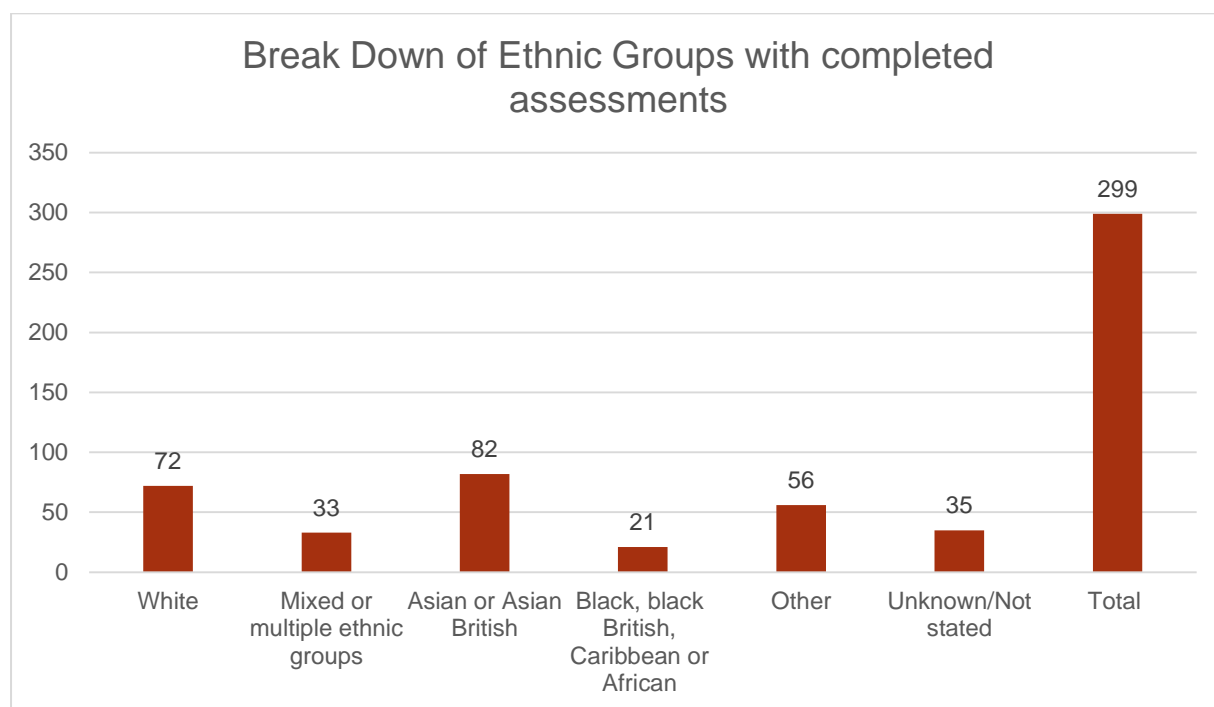


Figure 1: Ethnic Breakdown

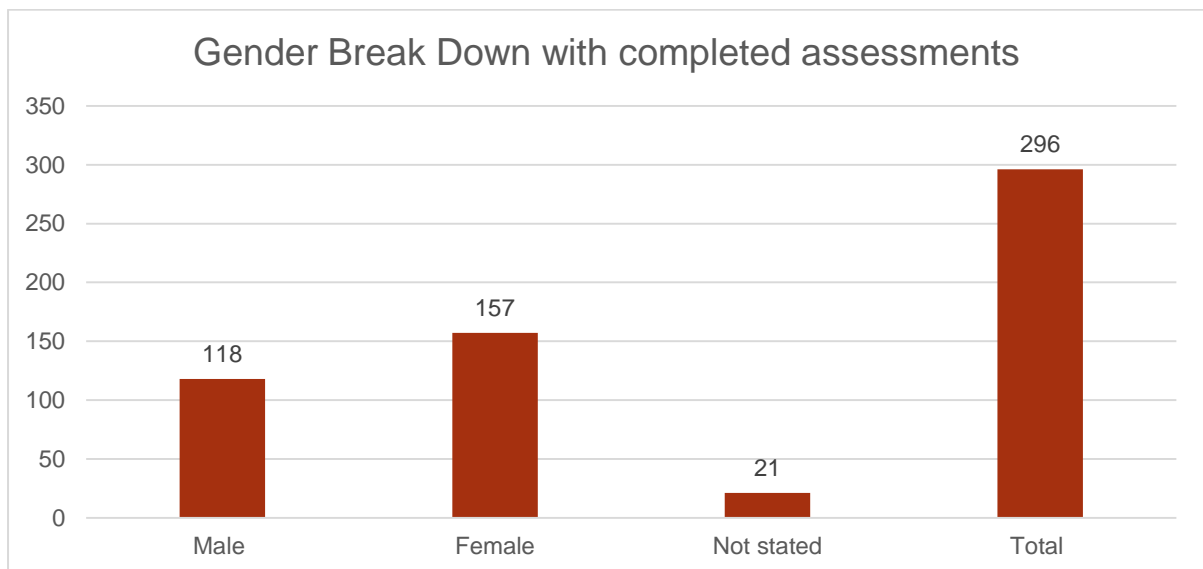


Figure 2: Gender Breakdown

Age breakdown or patients with completed assessments	0-15 years	0
	16-24 years	3
	16-18 years	1
	19-24 years	3
	25-34 years	36
	35-44 years	139
	45-54 years	10
	55-64 years	42
	65-74 years	12
	75-84 years	4
	85+ years	0
	Unknown or not recorded	35

Table 2: Age Breakdown

NHS England (NHSE) developed a modelling assumption to estimate how many of these patients may require follow up in a Long COVID-19 service. (4) There was clinical consensus that provisionally around 2.9% of people who had COVID-19 will go on to need NHS support. (4) According to this model, it was suggested that patients would fall into three levels of treatment intensity, following an initial assessment as highlighted below:

Treatment Intensity	Estimated % population	Treatment
(Tier 1)	30-50%	Appropriate for supported self-management
(Tier 2)	18-30%	Treatment in primary and community care
(Tier 3)	20-50%	Follow up in specialist services and rehabilitation pathways

Table 3: NHSE modelling assumption indicating expected distribution of cases according (4) to treatment intensity

According to modelling above, it was estimated that 4404 people would require some level of support across Newham and Tower Hamlets and that between 2,202-2,995 patients

would require level 2-3 support. However, the NHSE modelled activity indicates a large variance from the number of referrals actually received by the service. The CCG therefore undertook a local modelling exercise based on ONS reported figures on actual numbers of patients reported as having covid to the actual numbers seen by the service. Using this methodology, we were able to project expected activity, which equates to 748 referrals annually. Although this is not far from the actual activity, it is important to highlight that just under a half of referrals were rejected by ELFT. This can be attributed to the following reasons:

- Vital clinical information absent from the referral form
- Evidence that the referrer has not undertaken the necessary tests to rule out an organic medical disease
- Evidence that an existing medical condition has not been optimised prior to referral
- Clinical information is out of date.

To mitigate the number of rejected referrals, we have recently introduced a standardised North East London Wide referral form. This has been embedded across all GP systems to streamline the referral process and make it is easier for clinicians to refer into the service. The form requires mandatory fields to be completed and the necessary tests to be performed prior to referral. The aim is that the referring clinician will rule out any underlying organic causes prior to referral. Furthermore, this will allow the Long-Covid-19 service to have to hand, up to date, relevant information to make an informed decision with regards to the patients' management plans, which in turn will result in an efficient service for patients.

From the number of referrals received by the service, it is reasonable to conclude that not all patients are seeking support for the management of their Long COVID-19 symptoms or it may be that the patient has attributed their symptoms to other causes or are self-managing. There is also a possibility that the service is not yet know to patients and hence they have not come forward to seek assistance.

1.2. Funding

Financial Allocation Breakdown Dec 20-March 21

NHS England, NHS Improvement (London) provided funding of £10million nationally to support the establishment and operationalising of Post COVID-19 Syndrome Assessment Clinics services. NEL received £365,560. This was further supplemented with £145k from an ICS local Ageing Well funding stream. Tower Hamlets, Newham and Waltham Forest (TNW) received £190,811 of this overall funding.

Financial Allocation Breakdown 2021-2022

The total funding allocation for TNW equates to £920,441, which includes both funding from NHSE and the local NEL funding contribution. The table below indicates the total funding made available for the ELFT service.

ICP	NEL ICS fund	NHSE Q1-Q2	NHSE Q3-Q4	Total Funds
ELFT	£101,074	£176,592	£281,605	£559,271

Table 4: ELFT Funding Allocation for 21-22

1.3. Next Steps

A full review of the service has instigated the need for a business case for further funding to support expansion and sustainability of the service. The providers have worked tirelessly to ensure the service fully meets the need of the local residents and therefore have developed a treatment pathway as an add on to their current offer of assessment only. This will allow patients to be assessed and offered treatment in line with the patient needs and level of acuity. Additionally, the service has now included in their plans provision for face to face consultations which previously, due to high rates of circulating Covid-19, were only virtual. This will help to address the issue of excluding those who may not be digitally literate.

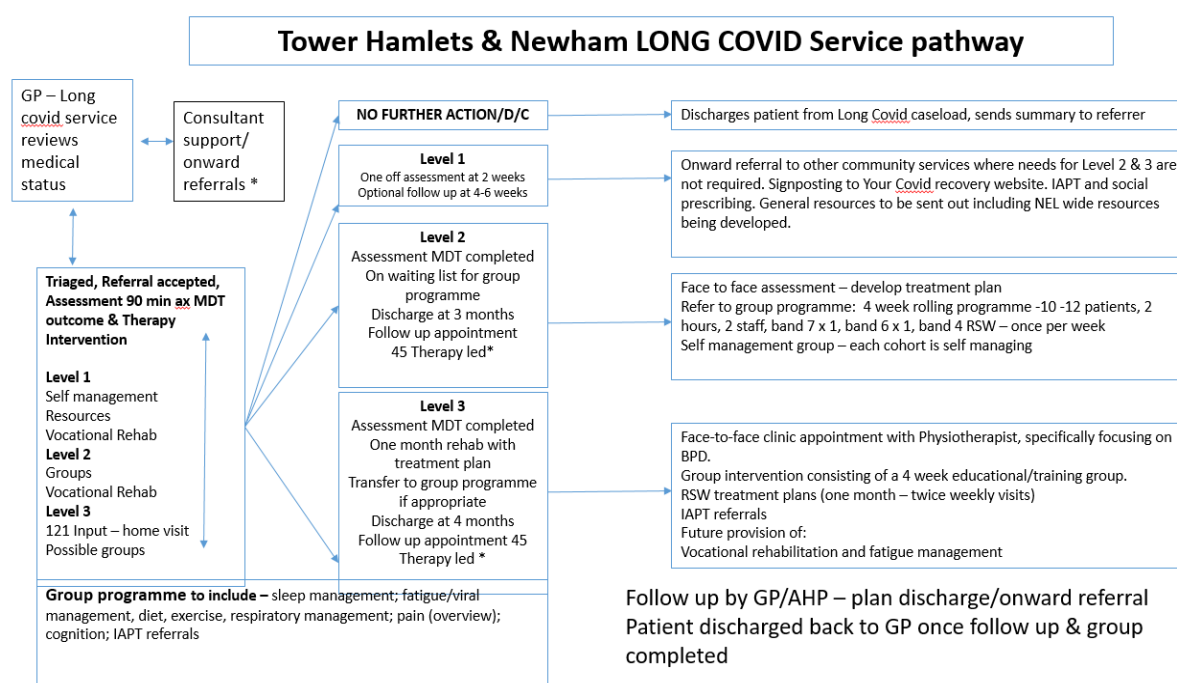


Figure 3: Enhance ELFT offer for patients with Long COVID-19-19

The new model now includes treatment that can support patients beyond self-management, which although remains an essential component of the pathway, cannot replace professional interventions.

1.4. Role of Primary Care

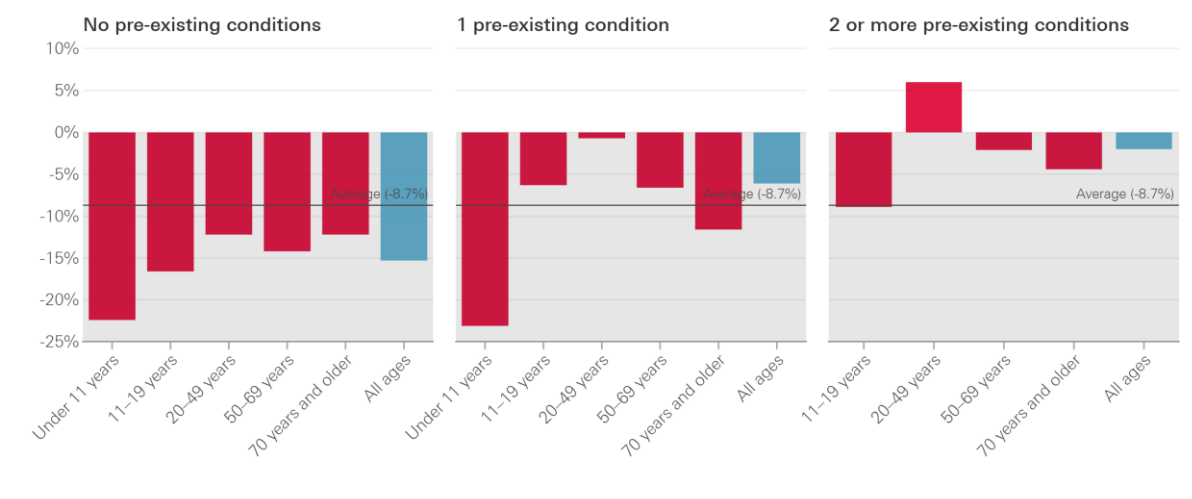
Long COVID-19 is a new and complex condition. To manage this effectively in Primary Care, it will require professional education, consistent coding of patients, planning of practice clinical pathways to assess and support patients and consideration of measures to reduce the risk of inequity of access to support.

It is recognised that General practice plays a key role in supporting patients, both adults and children, with long term symptoms of COVID-19. This includes assessing, diagnosing, referring where necessary and providing longer term holistic support for patients.

Long COVID-19 has undoubtedly had an impact on Primary Care and the full impact of this reduction in routine NHS care in general practice is only now emerging. Primary Care now faces a huge backlog of unmet patient need, with patients facing long waits for treatment. Some of this backlog can be attributed to Long COVID-19 as this cohort of patients has displaced those patients who normally access Primary Care for routine appointments. Patients have also missed vital opportunities to receive initial assessment and diagnosis for health problems due to slots been taken up by patients with Long COVID-19.

Health Foundation analysis shows that all regions across England saw a 30% drop in GP consultations per patient between March and May 2020. (5) This was despite the efforts to enable online and telephone consultations. An unintended consequence of this service shift has meant that access has been more challenging for those digitally excluded or people more reliant on face-to-face services. (5) The greatest reduction in consultations has been for patients without a pre-existing condition, as shown in Figure 4 (15% versus 6% for those with one pre-existing condition and 2% for those with two or more pre-existing conditions). The size of the reduction in consultations, however, suggests that there will be a high number of people with undiagnosed conditions coming into contact with the health system at a more advanced stage of their condition.

Percentage change in consultation rate in 2020 compared to 2019, by number of pre-existing conditions and age: England



The Health Foundation © 2021 Source: Clinical Practice Research Datalink (CPRD), Aurum database, Analysis from CPRD protocol number 20_143 • Note: Data for under 11 year olds with two or more pre-existing conditions are not available. For the number of patients with two or more conditions, the conditions are: Asthma, Atrial Fibrillation, Cancer, Coronary Heart Disease, COPD, Depression, Anxiety or other, Diabetes (Types I & II), Heart Failure, Stroke or TIA.

Figure 4: Percentage change in consultation rate (2020) compared to 2019 by number of pre-existing conditions and Age

It is important to note that not all patients are referred into the Long COVID-19 service and the effects of Long COVID-19 may manifest in exacerbations of underlying health conditions. It is therefore difficult to quantify the true impact of Long COVID-19 on Primary Care.

In order to support Primary Care Clinicians to be able to refer patients in to the Long COVID-19 service with ease, North East London CCG has worked collaboratively to standardise and simplify the referral form. This will reduce the GP workload and ensure good quality referrals are made to the service which will enable the service to provide timely care.

During this recovery phase, there is an opportunity to create a healthier, more resilient society, by ensuring patients are provided with the tools to be able manage their long term conditions better. Part of the wider strategy to assist recovery aims to enable Primary Care to be furnished with tools that will allow risk stratification of their patients with long term conditions. (6) This approach will allow practices to prioritise patients who are at the highest risk of an exacerbation and intervene in a proactive way. In order for Primary Care to rise to the challenge and provide a consistent standard of care to all patients, it is essential there is a step change in the way patients with long term conditions are supported and their care managed. There is now a greater emphasis on workforce and allowing skill mix in general practice to help address the backlog that Primary Care is now facing. (6) This approach will allow patients to be seen quickly, efficiently and by the most appropriate healthcare clinician.

1.5. Communication and Engagement Strategy

The impact of Long COVID-19 has forced the realignment of resources within the organisation to ensure we have in place a comprehensive communication and engagement strategy. There is increasing evidence that COVID-19 has had a disproportionate impact on those in deprived populations and people in black and ethnic minority groups and that it exacerbates existing health inequalities. (7) Across North East London we have worked with our key partners to develop a complete offer with the aim of raising awareness of Long COVID-19 in our local communities.

The offer includes the following:

- Issuing regular communication to GPs in relation to the NEL referral form, training, community of practice and local services. Offering training, resources and information on the referral process so that they can provide the best possible service to patients coming forward with symptoms. We have launched the community of practice, training schedule, online resource hub, referral form and the OneContact patient survey that will allow patients to grade their symptoms.
- Working with local partners to ensure community outreach. TNW are in the process of finalising our local homelessness pathway to ensure there is equity of access and this cohort of patients is able to seek support in the light of ongoing symptoms following infection with COVID-19.
- Creating a Long COVID-19 patient video to help our residents understand the common symptoms and to provide information on where seek help. As part of this, we are working with local faith and community groups to cascade the video message to our diverse communities in north east London.
- Developing a comprehensive patient leaflet, including an easy-read version, and creating web pages with further information
here: <https://www.eastlondonhcp.nhs.uk/ourplans/long-covid-2.htm>
- Working with local community groups to understand their needs around Long COVID-19 with a view to providing translated versions of the leaflets as appropriate. Local information on both medical and non-medical services (including information on issues such as housing, finance and employment support) is being added to relevant public web pages too.
- Working with local Healthwatch to create a survey for local residents to understand whether patients are experiencing symptoms of Long COVID-19 and whether they have tried to access any support. This will help inform future communications.

- Collaborating with our colleagues in Public Health to deliver a webinar to teachers and parents in schools to raise awareness of Long COVID-19.
- Working with local engagement officers in order to identify the best strategies to adopt in order to raise awareness in communities that have not yet presented to the service.

1.6. Summary

- The COVID-19 outbreak has had a huge impact on core NHS services and the full impact of it is only now emerging. Although some uncertainty about the longevity of Long COVID-19 remains, it is clear that populations and the NHS will face a significant burden of additional morbidity and long-term conditions as a result of COVID-19
- Long COVID-19 will limit people's ability to return to work to varying degrees that will undoubtedly have a personal and social impact.
- The Long COVID-19 Service is under continuous scrutiny to ensure patients are offered a comprehensive, holistic service that will enable them to support their own recovery where appropriate.
- TNW CCGs have undertaken a modelling exercise to ensure the service can meet demand and that national indicators are met by the service
- A business case has been submitted to the CCG for additional funding to support expansion of the Long COVID-19 service
- A North East London standardised referral form has been embedded in to all GP systems across Primary Care in attempt to ensure referrals are of consistent good quality and assure the receiving provider that a holistic review of the patient has been undertaken to rule out any organic cause
- TNW CCGs have implemented a comprehensive communications and engagement plan to help raise awareness of the service and ensure hard to reach groups can access the service. The aim is to include as part of the plan a series of education and training webinars, regular communication via local bulletins, focussed intranet sites and peer review. Additionally produce support material for patients access
- The National GP enhanced service to be implemented across Primary Care to help further strengthen equity of access and adopt a more proactive case finding approach in primary care to target those populations who may typically be less likely to access healthcare
- TNW CCGs continue to gather and analyse data to inform future resource planning to maximise resources and service resilience, but also reduce unwarranted variation in the management and subsequent outcomes of patients with post-COVID syndrome
- Finalised the pathway for homeless patients to support proactive case finding of those experiencing the effects of Long COVID-19 in Primary Care

- Reinforced referral pathways directly in to secondary care to improve the patient journey and provide seamless provision across the different healthcare sectors
- Delivered several learning events across Primary Care raising awareness of the tools to support patients with Long COVID-19 in the community
- Developing a patient education programme, which encompasses a series of webinars and group sessions to cover some of the main symptoms of Long COVID-19 and how patients can help themselves to recover from these symptoms.
- Draft a patient satisfaction survey to measure success of the service and identify areas where the service can be further improved.

1.7. References

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