Quality & Performance Committee

Paper title:	Post Covid & Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Services Review
Agenda item:	x
Report by:	Sponsor: Amanda Doyle – National Director for Primary Care and Community Services
Author:	[redacted] Transformation and Improvement
Paper type:	For decision
Paper classification:	Classification: Official-Sensitive

Links to:

NHS Mandate from Government	☐	Statutory item	☐
NHS Long Term Plan	☐	Governance	☒
NHS Long Term Workforce Plan	☐		

Working with people and communities:

What approaches have been used to ensure people and communities have informed this programme of work? [Please select all appropriate]

☐ Recruited Patient and Public Voice (PPV) Partners
☐ Consultation / engagement
☒ Qualitative data and insight, for example, national surveys; complaints
☒ Quantitative data and insight, for example national surveys
☐ Partnership working with voluntary, community and social enterprise organisation
☐ Other (please list below)
☐ N/A

Bespoke national survey, strategic engagement through regions; qualitative and quantitative data and insights; with Department of Health task and finish group with patient groups, charities, and people with lived experience

Action required:

The Board is asked to:

1. Consider the relative priority of Long Covid, ME and CFS services and whether further action and investment is required.

1.Background

In September 2024 Quality and Performance Committee requested ‘a more accurate in-depth overview of the position of Post Covid Services across England’.

The scope of this stocktake was extended in November 2024 to include Myalgic Encephalomyelitis (ME) / chronic fatigue syndrome (CFS) services.

This paper demonstrates the results of the Post Covid and ME/CFS stocktake.

2. Current state

To understand the current state, the Long Covid & ME/CFS stocktake interrogated available data and engaged with delivery chain via regional directors of Primary care, relevant internal and external stakeholders, and clinical leads leads.

We also worked collaboratively with the Department of Health and Social Care (DHSC) because of related work, My full reality: the interim delivery plan on ME/CFS - GOV.UK and Improving the experiences of people with ME/CFS: consultation outcome - GOV.UK and the prospective timelines to publish an ME/CFS Delivery Plan in Spring 2025.

2.1 Data visibility

The NHS England Long Covid data dashboard architecture remains in place and there is submitted activity through Post-COVID Assessment service data submissions which contribute to a long COVID registry.

This activity is seeing up to a 50% reduction in return rates, impacting the ability to draw meaningful insights. The publication of this data ceased in April 2024, creating gaps in data quality and visibility.

Annex 1 shows a data dashboard of results for Long Covid and ME/CFS services formed from available datasets.

There is no resourced analytical support for the Long Covid data collection and no plans to update or enhance its development, so quality and visibility will remain inadequate in terms of access and future improvements.

There is no national data dataset or collection for ME/CFS services.

2.2 ICB Survey and Insights

The stocktake also included an ICB survey conducted in December 2024, through regional medical directors. The survey results demonstrated an agreed view of existing regional insights; one of variation across both Post Covid Assessment services and ME/CFS services.

There was a low response rate amongst ICB’s, therefore the data only gives an indication of the current state (See Annex 2)

The survey results showed variation in service delivery from MDTs and community-based rehabilitation to tailored services addressing physical and psychological, across Adult's and Children and Young People's services.

The Clinical Post Covid Society part funded by NHS England till March 2025 conducted a survey of their members published in December 2024.

The results described an uncertain future for many Long Covid and ME/CFS services across regions with significant challenges around:

- funding
- continuity
- ME/CFS services being considered for integration with post-COVID services
- anticipation of disbanding by March 2025 if funding is not renewed
- services already being scaled back
- at least one service reported to have already closed

The Commissioning guidance for post Covid services remains valid and in line with localised services/ subsidiarity, equitable access, and risk mitigation.

Through the regional engagement and survey results we know there are gaps in service delivery and varied adoption of the Post Covid commissioning guidance.

There is no current national commissioning guidance or service delivery models in existence for ME/CFS services.

2.3 Assurance and Oversight

Funding for Post Covid Assessment services and ME/CFS services is distributed to ICBs as part of baseline funding allocations.

Regional medical directors provided valuable, accurate overviews of Post Covid and ME/CFS services describing a varied picture in terms of:

- assurance
- oversight
- challenges in systems with funding
- competing priorities
- the complex nature of the condition
- small referral numbers to some Children and Young People's services

To ensure a consistent, sustainable assurance approach from NHS England across all regions, it is recommended to use existing regional assurance mechanisms and levers for oversight of quality/safety and performance of services.

3.Considerations and Interdependencies

The NHS England National Medical Director instructed the development of a Post-Viral Long Term condition's task and finish group in December 2024. Annex 3 sets

out the terms of reference for this group.

This group will provide specialist expertise and guidance to the DHSC ME/CFS Task and Finish Group responsible for the publication of the ME/CFS Delivery plan expected in Summer 2025.

Consideration needs to be given

- to the lack of allocated funding for the ME/CFS Delivery Plan increasing risk to its implementation.
- collaboration required between NHS England and DHSC for developing actionable and evidence-based recommendations aligned to responsibilities
- to the non identification of any specific clinical conditions identified in NHS England Operational Planning guidance for systems to prioritise aligned to subsidiarity

4.Conclusion and recommendation

In summary, the stocktake found that since April 2024, national Long Covid data publication has ceased with no analysis of an open dashboard with submissions and that ME/CFS services have no national guidance or datasets.

There is variable and inadequate oversight and assurance of Long Covid and ME/CFS services. Through regional insights and national survey, we have demonstrated variation in update of the Long COVID commissioning guidance and significant challenges in terms of data quality, visibility, and assurance.

The Post Covid and ME/CFS services stocktake has not been able to demonstrate an ‘in depth accurate overview’ as commissioned.

There is opportunity and potential to address these challenges and/or to consider further review with improved data, assurance and oversight.

Annex 4 shows a range of scenarios through an options appraisal that could be utilised to improve data quality, visibility, and assurance both cost neutral and with investment that require committee review and decision.

5. Recommendations for Committee Approval:

Consider whether these services should be an organisational priority. If so, the committee should consider the following recommendations:

1. Re-opening to publication of the Long Covid dashboard to optimise data visibility and quality.

2. Maximising assurance and oversight through regional assurance mechanism (RAMs) for Long Covid datasets to ensure sustainable and consistent assurance approach.

3. For NHS England to engage and align with DHSC on ME/CFS Delivery Plan to work collaboratively to produce a plan that is aligned to NHS England's operational framework and meets the needs of people living with ME/CFS

4. Agree to complete a further review in 6-12 months post recommendation implementation, returning to Quality and Performance Committee with 'an accurate in-depth review of Post Covid services and ME/CFS services'.

Annex

Annex 1 – Data Dashboard – Long Covid ME/CFS Stock take December 2024

Data	Data source	Regions						
		North West	North East and Yorkshire	Midlands	East of England	London	South East	South West
Population estimates 2023	ONS	7,400,000	8,100,000	10,900,000	6,300,000	9,000,000	9,200,000	5,900,000
Prevalence - Long Covid	University of Manchester 2022	5%	5%	4.8%	4%	4.5%	3.6%	3.4%
Prevalence – ME/CFS	2011 Study	n/a	0.26%	n/a	0.23%	0.19%	n/a	n/a
Total Referrals for Long Covid (Dec 2024)	Long Covid Dashboard FDP NHS England (not quality assured)	141	66	223	108	75	112	72
Total Referrals for ME/CFS (Dec 2024)	No data source	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Waiting times initial assessment (days) Dec 2024	Long Covid Dashboard FDP NHS England (not quality assured)	46.3	56.5	40.7	28.3	119.2	64	47

Annex 2 Long Covid & ME/CFS Stock take Survey Results

Long Covid & ME/CFS Stocktake Survey Results	Long Covid		ME/CFS	
	Numbers	**%**	**Numbers**	**%**
Regional Responses	5/7 North West North East & Yorkshire East of England Midlands London	**71%**	4/7 North West North East & Yorkshire East of England Midlands	**57%**
ICB Responses	14/42 Cambridgeshire & Derbyshire ICB South East London ICB NHS Surrey Heartlands Derby and Derbyshire ICB Leicester, Leicestershire and Rutland ICB Lincolnshire ICB Hereford and Worcestershire ICB West Yorkshire ICB North East and North Cumbria ICB Humber and North Yorkshire ICB Lancashire & South Cumbria Cheshire and Merseyside ICB Greater Manchester ICB NHS South Yorkshire ICB	**33%**	8/42 Cambridge and Peterborough ICB Leicestershire ICB South Yorkshire ICB West Yorkshire ICB North East and North Cumbria ICB Cheshire and Merseyside ICB Greater Manchester ICB	**19%**
ICB with Named Clinical Lead	13/14 Cambridgeshire & Derbyshire ICB South East London ICB NHS Surrey Heartlands Derby and Derbyshire ICB Leicester, Leicestershire and Rutland ICB Lincolnshire ICB Hereford and Worcestershire ICB West Yorkshire ICB North East and North Cumbria ICB Humber and North Yorkshire	**92%**	4/8 North East and North Cumbria ICB Cheshire and Merseyside ICB Greater Manchester ICB Cambridge and Peterborough ICB	**50%**

	ICB Cheshire and Merseyside ICB Greater Manchester ICB NHS South Yorkshire ICB			

Annex 3 – Post Viral Task and Finish Group Terms of Reference

DRAFT%20ToR%20fo
r%20post-viral%20ta

Annex 4 – Options Appraisal Data Improvement

	Detail	Cost	Advantages	Disadvantages
Scenario 1 – Do Nothing		£0		
Scenario 2 – Regional Assurance Mechanism (RAM) only	Start process of regional assurance in April 2025	£0	Improve assurance and oversight	Based on non-robust data Long Covid only No ME/CFS focus
Scenario 3 – Open Publication to Long Covid dashboard only	Reopen publication in April 2025	£0 non-staff costs 2 x wte data analysts	Improve data quality and visibility	Long Covid only No ME/CFS focus No regional assurance or oversight
Scenario 4 – RAMs & Open Long Covid Dashboard	Start data publication and sequence process of regional assurance	£0 non-staff costs 2 x wte data analysts	Improve assurance and oversight Improve data quality and visibility	Long Covid only No ME/CFS focus
Scenario 5 – RAMs & Open Long Covid Dashboard & Post Viral Reform	Start data publication and sequence process of regional assurance and scope plans for post viral reform; clinical policy, commissioning	£0 non-staff costs 2 x wte data analysts Resource for staffing to reform	Improve assurance and oversight Improve data quality and visibility Delivers comprehensive Post viral approach addressing lack of focus on ME/CFS	