

Policy for the out of area assessment, diagnosis and management of Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME)

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Name of author and title:	Public Health Warwickshire & ICB Medical Directorate
Name of reviewer and title:	Dr Mike Caley, Deputy Chief Medical Director
Department:	Medical Directorate

VERSION HISTORY

Date	Version	Changes made to previous version	Consulting and Endorsing Stakeholders, Committees / Meetings / Forums etc.
25.01.2024	V2	Update to NICE reference Amended policy title to provide clarity as to policy content	Clinical Commissioning Policy Development Group – 19 December 2023

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1. Category: Not commissioned

2. Background

This commissioning policy has been produced in order to provide and ensure equity, consistency and clarity relating to the approach to the out of area assessment, diagnosis and management of chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) by the Integrated Care Board (ICB).

3. Commissioning position

The assessment, diagnosis and management of CFS and ME at out of area specialist inpatient or outpatient units is not commissioned or funded by the ICB.

The assessment, diagnosis and treatment of CFS and ME must be managed by primary care, in the community, in line with the assessment, diagnosis and treatment recommendations given in the National Institute for Health and Care Excellence (NICE) NG206 guidance. This may include referral to the commissioned local secondary care specialist service for assessment, diagnosis and management advice, if required.

4. Guidance

NICE guideline [NG206] Published: 29 October 2021 Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management - <https://www.nice.org.uk/guidance/ng206>

5. Equality and Quality Impact Assessment Tool

The following assessment screening tool will require judgement against all listed areas of risk in relation to quality. Each proposal will need to be assessed whether it will impact adversely on patients / staff / organisations.

Insert your assessment as positive (P), negative (N) or neutral (N/A) for each area.

Record your reasons for arriving at that conclusion in the comments column. If the assessment is negative, you must also calculate the score for the impact and likelihood and multiply the two to provide the overall risk score. Insert the total in the appropriate box.

Quality Impact Assessment

Quality and Equality Impact Assessment

Scheme Title:	Policy for the out of area assessment, diagnosis and management of Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME)		
Project Lead:	Lucy Dyde, IFR Team Manager	Senior Responsible Officer:	Dr Michael Caley, Deputy CMO
		Quality Sign Off:	Quality team as below
Intended impact of scheme:	<p>To provide a fair, equitable and transparent process for all patients of the NHS Coventry and Warwickshire Integrated Care Board (ICB), for which the ICB has commissioning responsibility.</p> <p>The policy for the out of area assessment, diagnosis and management of chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) supports the objective to prioritise resources and provide interventions with the greatest proven health gain, within ICB budgetary constraints. The intention is to ensure equity and fairness in respect of access to NHS funding for interventions and to ensure that interventions are provided within the context of the needs of the overall population and the evidence of clinical and cost effectiveness and desired outcomes for patients it is intended for.</p>		
How will it be achieved:	Through the process detailed in this document.		

Name of person completing assessment:	Lucy Dyde
Position:	IFR Team Manager
Date of Assessment:	28 June 2024

Quality Review by:	Petty Trowell, Michelle Gorrell, Micaela Loveridge, Anna Crane, Sarah Chamberlain, Lee Hill
Position:	Team members
Date of Review:	04 07 24

High level Quality and Equality Questions

The risk rating is only to be done for the potential negative outcomes. We are looking to assess the likelihood of the negative outcome occurring and the level of negative impact. We are also seeking detail of mitigation actions that may help reduce this likelihood and potential impact.

AREA OF ASSESSMENT		OUTCOME ASSESSMENT (Please tick one)			Evidence/Comments for answers	Risk rating (For negative outcomes)			Mitigating actions
		Positive	Negative	Neutral		Risk impact (I)	Risk likelihood (L)	Risk Score (IxL)	
Duty of Quality Could the scheme impact positively or negatively on any of the following:	Effectiveness – clinical outcome	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
	Patient experience	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB.				

					On this basis there will be a positive impact as there is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
	Patient safety	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
	Parity of esteem			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Safeguarding children or adults	✓			Usual ICB and/or Provider Safeguarding policies and mechanisms will apply.				
NHS Outcomes Framework Could the scheme impact positively or negatively on the delivery of the five domains:	Enhancing quality of life	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there is no evidence base to support commissioning,				

					therefore the ICB is not exposing patients to this service.				
	Ensuring people have a positive experience of care	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
	Preventing people from dying prematurely			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Helping people recover from episodes of ill health or following injury			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Treating and caring for people in a safe environment and protecting them from avoidable harm	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there				

					is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
Patient services Could the proposal impact positively or negatively on any of the following:	A modern model of integrated care, with key focus on multiple long-term conditions and clinical risk factors	✓			The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
	Access to the highest quality urgent and emergency care			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Convenient access for everyone			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Ensuring that citizens are fully included in all aspects of service design and change			✓	The policy reflects the NG206 guidance where engagement has already been completed at a				

					national level. Patients invited to participate in current providers National/Local staff satisfaction surveys and there is no change to previous QIA completed October 2020.				
	Patient Choice		✓		Adopting the policy does not offer choice to use specialist providers and there is no change to previous QIA completed October 2020.	3	1	3	Other services to support patients
	Patients are fully empowered in their own care		✓		Adopting the policy will impact on where patients receive support and there is no change to previous QIA completed October 2020.	3	1	3	Patients directed to local services
	Wider primary care, provided at scale			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area.				
Access Could the proposal impact positively or negatively on any of the following:	Patient choice		✓		Adopting the policy does not offer choice to use specialist providers. There is no change to previous QIA completed October 2020.	3	1	3	Other services to support patients
	Access			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB.				

					On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Integration			✓	Policy to implement NG206 guidance has an integrated care approach to ensure patients are not exposed to this service where there is no evidence base to support commissioning. There is no change to previous QIA completed October 2020.				
Compliance with NHS Constitution	Quality of care and environment			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Nationally approved treatment/drugs			✓	The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be neutral impact for this area and there is no change to previous QIA completed October 2020.				
	Respect, consent and confidentiality	✓			All usual ICB and/or Provider respect, consent and confidentiality policies and mechanisms will				

					apply.				
	Informed choice and involvement	✓			Patients will be fully involved in their care planning through shared decision-making, personalised care, and support planning for commissioned services. The policy reflects the NG206 guidance; an out of area service is not commissioned by the ICB. On this basis there will be a positive impact as there is no evidence base to support commissioning, therefore the ICB is not exposing patients to this service.				
	Complain and redress	✓			Usual ICB and/or Provider compliment, complaint and redress policies and mechanisms will apply.				

*Risk score definitions are provided in the next section.

Equality Impact Assessment

Project / Policy Details

What is the aim of the project / policy?

To provide a fair, equitable and transparent process for all patients of the NHS Coventry and Warwickshire Integrated Care Board (ICB), for which the ICB has commissioning responsibility.

The policy for the out of area assessment, diagnosis and management of chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) supports the objective to prioritise resources and provide interventions with the greatest proven health gain, within ICB budgetary constraints. The intention is to ensure equity and fairness in respect of access to NHS funding for interventions and to ensure that interventions are provided within the context of the needs of the overall population and the evidence of clinical and cost effectiveness and desired outcomes for patients it is intended for.

Who will be affected by this work? e.g staff, patients, service users, partner organisations etc.

Patients

Is a full Equality Analysis Required for this project?

Yes	Proceed to complete this form.	No	Explain why further equality analysis is not required.
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If no, explain below why further equality analysis is not required. For example, the decision concerned may not have been made by the ICB or it is very clear that it will not have any impact on patients or staff.

Equality Analysis Form

1. Evidence used

What evidence have you identified and considered? This can include national research, surveys, reports, NICE guidelines, focus groups, pilot activity evaluations, clinical experts or working groups, JSNA or other equality analyses.

<https://www.nice.org.uk/guidance/ng206>

2. Impact and Evidence:

In the following boxes detail the findings and impact identified (positive or negative) within the research detailed above; this should also include any identified health inequalities which exist in relation to this work.

Age: A person belonging to a particular age (e.g. 32 year olds) or a range of ages (e.g. 18-30 year olds)

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Disability: A person has a disability if he/she has a physical, hearing, visual or mental impairment, which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Gender reassignment (including transgender): Where a person has proposed, started or completed a process to change his or her sex.

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Marriage and civil partnership: A person who is married or in a civil partnership.

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Pregnancy and maternity: A woman is protected against discrimination on the grounds of pregnancy and maternity. With regard to employment, the woman is protected during the period of her pregnancy and any statutory maternity leave to which she is entitled. Also, it is unlawful to discriminate against women breastfeeding in a public place.

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Race: A group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Religion or belief: A group of people defined by their religious and philosophical beliefs including lack of belief (e.g. atheism). Generally a belief should affect an individual's life choices or the way in which they live.

This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.

Sex: A man or a woman		
This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.		
Sexual orientation: Whether a person feels generally attracted to people of the same gender, people of a different gender, or to more than one gender (whether someone is heterosexual, lesbian, gay or bisexual).		
This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.		
Carers: A person who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support		
This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.		
Other disadvantaged groups:		
This policy does not contain any statements which may exclude clinicians of the NHS Coventry and Warwickshire Integrated Care Board from applying this policy.		
3. Human Rights		
FREDA Principles / Human Rights	Question	Response
Fairness – Fair and equal access to services	How will this respect a person's entitlement to access this service?	<p>To provide a fair, equitable and transparent process for all patients of the NHS Coventry and Warwickshire Integrated Care Board (ICB), for which the ICB has commissioning responsibility.</p> <p>The policy for the out of area assessment, diagnosis and management of chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) supports the objective to prioritise resources and provide interventions with the greatest proven health gain, within ICB budgetary constraints. The intention is to ensure equity and fairness</p>

		in respect of access to NHS funding for interventions and to ensure that interventions are provided within the context of the needs of the overall population and the evidence of clinical and cost effectiveness.
Respect – right to have private and family life respected	How will the person’s right to respect for private and family life, confidentiality and consent be upheld?	The patient will not be contacted by the ICB. If the patient contacts the ICB of their own accord then all communication, written or verbal, will be provided in a confidential, clear, understandable, format.
Equality – right not to be discriminated against based on your protected characteristics	How will this process ensure that people are not discriminated against and have their needs met and identified?	This policy is applied to all patients of the NHS Coventry and Warwickshire Integrated Care Board to prioritise resources and provide interventions with the greatest proven health gain, within ICB budgetary constraints. The intention is to ensure equity and fairness in respect of access to NHS funding for interventions and to ensure that interventions are provided within the context of the needs of the overall population and the evidence of clinical and cost effectiveness.
Dignity – the right not to be treated in a degrading way	How will you ensure that individuals are not being treated in an inhuman or degrading way?	All communication, written or verbal, will be provided in a confidential, clear, understandable, format.
Autonomy – right to respect for private & family life; being able to make informed decisions and choices	How will individuals have the opportunity to be involved in discussions and decisions about their own healthcare?	Individuals will have the opportunity to discuss their healthcare with the requesting clinician.

		If the patient contacts the ICB of their own accord then all communication, written or verbal, will be provided in a confidential, clear, understandable, format.
Right to Life	Will or could it affect someone's right to life? How?	No
Right to Liberty	Will or could someone be deprived of their liberty? How?	No

4. Engagement, Involvement and Consultation

If relevant, please state what engagement activity has been undertaken and the date and with which protected groups:

Engagement Activity	Protected Characteristic/ Group/ Community	Date
N/A	N/A	N/A

For each engagement activity, please state the key feedback and how this will shape policy / service decisions (E.g. patient told us So we will):

N/A

5. Mitigations and Changes

Please give an outline of what you are going to do, based on the gaps, challenges and opportunities you have identified in the summary of analysis section. This might include action(s) to mitigate against any actual or potential adverse impacts, reduce health inequalities, or promote social value. Identify the **recommendations** and any **changes** to the proposal arising from the equality analysis.

N/A

6. How will you measure how the proposal impacts health inequalities?

e.g Patients with a learning disability were accessing cancer screening in substantially lower numbers than other patients. By revising the pathway the ICB is able to show increased take up from this group, this is a positive impact on health inequalities.

You can also detail how and when the service will be monitored and what key equality performance indicators or reporting requirements will be included within the contract.

Activity is monitored through Acute Contracting/Business Intelligence. This is a policy where the intervention is not commissioned and therefore any activity would be investigated and challenged through the appropriate ICB channels.

7. Is further work required to complete this assessment?

Please state what work is required and to what section. e.g additional consultation or engagement is required to fully understand the impact on a particular protected group (e.g

disability).			
Work needed	Section	When	Date completed
N/A	N/A	N/A	N/A

8. Sign off

The Equality Analysis will need to go through a process of **quality assurance** by a Senior Manager within the department responsible for the service concerned before being submitted to the Policy, Procedure and Strategy Assurance Group for approval. Committee approval of the policy / project can only be sought once approval has been received from the Policy, Procedure and Strategy Assurance Group.

Requirement	Name	Date
Senior Manager Signoff	Dr Michael Caley, Deputy CMO	01.07.2024
Which committee will be considering the findings and signing off the EA?	F&P	06.11.2024
Approved by the Policy Procedure and Strategy Assurance Group.		

Once complete, please send to the ICB's Governance Team.