Lothian NHS Board

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Date 20 October 2026
Your Ref
Our Ref 11928

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION – LC/ME/CFS SERVICE

I write in response to your request for information in relation to LC/ME/CFS Service.

Question:

1. **Line-by-Line Financial Ledger:** A detailed, itemised breakdown of all actual and projected expenditure drawn from the **£385,829** pooled fund allocated to the "Regional Model Split" for the current financial planning cycle.

Answer:

Please see table under question 2.

Question:

2. **Workforce and Staffing Expenditure:** The exact staffing models, Whole Time Equivalent (WTE) figures, and respective Agenda for Change (AfC) or medical consultant salary bands funded by this regional pool. Please specify the exact amounts allocated to the Strategic/Clinical AHP Lead, Clinical Psychologist, Programme Manager, and Administrative/Medical Secretary roles.

Answer:

REGIONAL ALLOCATION AGREEMENT.
Underspend due to initial pause to fully develop planned model of delivery and delays in recruitment. Underspend will remain in partner boards to be reallocated to local LC/ME/CFS service delivery for year 2026/27.

Profession	Band	wte	Annual Costs	Actual Costs YTD M6	Projected Full Year costs
Psychology	8B	0.5	£52,677		£13,169
Medical	Consultant	1	£193,141		£19,314
Admin	4	1	£42,771		£10,693
AHP cons	8b	1	£105,355	£52,677	£105,354
Total		3.5	£385,829	£52,677	£148,530

Question:

3. **Consortium Governance Records:** Copies of all minutes, action logs, and financial briefing papers generated by the **Regional Long Covid/ME/CFS Steering Group** and the **Regional Clinical Sub-Group** from January 2026 to the present date.

Answer:

Please see enclosed ZIP files.

Question:

4. **Inter-Board Resource Agreements:** Copies of the finalized or most recent draft versions of the Shared Service Agreements or Service Level Agreements (SLAs) governing the 29.01% financial siphon from participating boards (specifically referencing the £28,787 extracted from NHS Borders).

Answer:

The SLA will only be completed when full-service model agreed. Enclosed Memorandum of Understanding which governs agreement to date.

Question:

5. **Biomedical Prescribing Provisions:** Any service specifications, clinical triage pathways, or risk assessment matrices detailing how the siphoned regional funding provides tertiary medical authority or legal indemnity for community General Practitioners (GPs) to prescribe autonomic and cardiovascular treatments for severe neurogenic orthostatic hypotension (nOH).

Answer:

Not applicable - no such agreement in place.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: https://org.nhslothian.scot/FOI/Pages/default.aspx

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive

Regional Long Covid/ME CFS Multidisciplinary (MDT) Service

Memorandum of Understanding
between
Participating Boards

VERSION 1.1

Review History and Version Control

Version Control

Date	Version	Change Reason	Author
23.04.26	**0.1**	**Original draft**	**BW**
18.05.26	**0.2**	**Review by HC/Group**	**HC/BW**
02.06.26	**0.3**	**Minor formatting amendments**	**BW**
20.07.26	**1.0**	**Final version for signing circulated**	**BW**
08.07.26	**1.1**	**Wording change re: legal status**	**BW**

Reviewers

Name	Date
Dr Heather Camerson	18.05.26
Dr Charlie Chung	18.05.26
Regional Long Covid/ME CFS Steering Group	08.06.26

Distribution

Copy No	Name	Notes
1	Regional Long Covid ME CFS AHP Directors (NHS Borders, NHS Fife, NHS Forth Valley, NHS Lothian)	Signatory request: 24.06.26

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1. Introduction

The regional Long Covid ME CFS multidisciplinary (MDT) service will be a consortium of 4 Boards: NHS Borders; NHS Fife; NHS Forth Valley; and NHS Lothian.

This Memorandum of Understanding (MOU) (Section 6) outlines the commitment, shared aims and collaborative responsibilities for the service provision during set up and the transition period in preparation for the new Regional Long Covid/ME CFS service going live and a formal shared service agreement taking effect.

2. Background

The Scottish Government's paper "Scotland's Long Covid Service" recognised that Long COVID can be associated with a wide range of symptoms affecting both mental and physical health.
A set of approaches was therefore recommended to optimise support for those with Long Covid based on maximising and improving co-ordination of the broad range of existing services across our health and social care system and third sector that are relevant to the spectrum of symptoms that people are experiencing.

The approaches are based on four key elements:
1. Supported self-management
2. Primary care and community-based support
3. Rehabilitation support
4. Secondary care investigation and support

After 3 years of non-recurring funding SG have now indicated their intent to provide funding on a recurring basis to support delivery of services for patients with Long Covid in addition to ME/ CFS and similar Long-Term conditions.
Whilst each Health Board is responsible for delivering services for their own local population, it was recognised that for a small cohort of individuals with more complex needs, a regional approach would be preferable to ensure delivery of timely, supportive interventions that this patient group require to optimise their outcome.
The regional work will focus on services for adults*with consideration of children and young people managed through existing local arrangements.

3. Parties to the Agreement

The Regional Long Covid/ME CFS MDT service is made up of 4 boards: NHS Border; NHS Fife; NHS Forth Valley; and NHS Lothian.

4. Purpose of the Agreement

The MOU represents an agreement outlining the accountability, expectations and responsibilities of the Boards during the development and transition period through to the service going live and a shared service agreement taking effect.

The MOU provides clarity of the shared commitment to create a regional Long Covid/ME CFS MDT service.

It should be noted that this Memorandum of Understanding is not a legally enforceable contract.

5. Definition of Terms

In this agreement, the following expressions shall, unless otherwise specified have the following meaning

Term/Expression	Meaning
Boards	Shall mean NHS Borders, NHS Fife, NHS Forth Valley and NHS Lothian.
(MOU)	Shall mean this Memorandum of Understanding
Interim/transition Period	The period of time from development of the regional service, with recruitment of regional staff and the launch of the new Service going live and the Shared Service Agreement taking effect

6. Memorandum of Understanding

This document is intended to set out the mutual responsibilities, funding, governance and commitment throughout the development period and into the establishment of the live regional Long Covid/ME CFS service provision.

Participating Boards are asked to agree as follows:

6.1 Shared Intent

The participating NHS Boards confirm their collective commitment to the development of a regional MDT Long Covid/ME CFS service. The Boards agree to work collaboratively during the design and implementation phase, including supporting early recruitment and preparatory activity, to ensure the service can transition smoothly to full operational delivery.

6.2 Development Responsibilities

The participating NHS Boards agree to work collaboratively during the development phase and commit to the following responsibilities:

- Contribute to the design and development of the regional service, including pathway development, clinical model, governance arrangements and operational processes.
- Provide timely and relevant input, data and expertise to support workforce planning, demand and capacity modelling, and service specification.
- Support early recruitment activity, including confirming funding contributions, participating in selection processes where required and ensuring appropriate hosting arrangements are in place.
- Participate in programme governance, attending meetings, reviewing proposals and contributing to decision-making to ensure the service progresses to agreed timelines.
- Ensure alignment with local operational groups, sharing updates and gathering feedback.
- Contribute to risk management, including identifying and escalating risks related to workforce, finance, governance or implementation.
- Support preparatory work for transition to live service, including agreeing the final service model, financial flows, reporting requirements and the development of the subsequent SLA.

6.3 Duration of the Agreement

The agreement shall take effect on the date of acceptance (see below) until such time as a Shared Service Agreement commences, which is subject to an agreed implementation plan and state of readiness being confirmed.

It is anticipated that all Boards will commit to and continue with the terms of the MOU subject to any agreed changes, and the MOU will apply for the interim period unless substantive changes occur.

6.4 Regional Recruitment

6.4.1 Local service activity currently carried out within existing Boards will continue to be managed by individual Boards.

6.4.2 Boards will continue to assume responsibility for operational and management support to their existing staff within their local services.

6.4.3 All Boards will agree the final workforce requirements of the staff for the regional Long Covid/ME CFS service.

6.4.4 On behalf of all Boards, NHS Lothian will carry out the recruitment process of staff to the regional service subject to agreement by all Boards.

6.4.5 For staff recruited explicitly for the regional service, the Boards will meet the requirements of the Working Time Regulations or any other such responsibilities placed on an employer by legislation and/or Scottish Government applicable to the hours of work within the regional service.

6.4.6 The Boards will assume responsibility for claims of personal injury or negligence arising from the acts of the regional service staff performing duties during the interim period.

6.5 Financial and Funding Commitments

- The participating NHS Boards agree in principle to jointly fund the development and implementation of the regional service.
- Each Board commits to contributing its agreed share of development and early-stage operational costs, with the final apportionment to be confirmed through finance colleagues as part of the detailed financial planning process. Summary details of funding allocation are outlined on the attached appendix (1).
- During the development phase, Boards will ensure that sufficient resources are in place to support recruitment, programme management and preparatory activity required to establish the service.
- The detailed funding model, including apportionment, financial flows and ongoing cost arrangements, will be set out in the SLA once the service moves to live operational delivery.

6.6 Payroll and HR Record Requirements

6.6.1 NHS Lothian will make arrangements to onboard regional staff to an appropriate payroll system and ensure all regional staff are paid on time in accordance with agreed timetables, including the issuing of accurate pay slips and any HMRC documents and in line with Scottish Government terms and conditions.

6.6.2 NHS Lothian will ensure that all necessary deductions and employer contributions are paid.

6.6.3 NHS Lothian will maintain required sickness records on receipt of information from Boards and ensure all relevant systems are updated with absence and additional hours and payments are in accordance with occupational and statutory sick pay rules.

6.6.4 NHS Lothian will ensure sufficient controls are in place to mitigate against the risk of over or under payment and ensure these controls are subject to audit through their own internal and external audit requirements.

6.6.5 NHS Lothian will provide payroll support to respond to payroll related queries, process deductions and activities related to pension services in relation to regional service staff where appropriate.

6.6.6 NHS Lothian will maintain necessary maternity, adoption, paternity, parental pay records to ensure compliance with statutory maternity, adoption, paternity, parental pay scheme rules in relation to the regional service staff where appropriate.

6.6.7 NHS Lothian will preserve historical records in line with statutory requirements.

6.6.8 NHS Lothian will respond to financial reference requests in relation to bank and building societies for regional service staff where appropriate.

6.7 Information Governance, Security, Data Protection and Freedom of Information

6.7.1 All Boards will comply with the appropriate NHS Scotland Data Security policies.

6.7.2 All Boards will comply with the Data Protection Act 2018 and any associated Data Protection Legislation.

6.7.3 Where requests are received under the Freedom of Information (Scotland) Act 2002 each Board is legally responsible for responding to FOIs relating to their own workforce. All Boards will co-operate in relation to any request for information relating to the regional staff employed by NHS Lothian.

6.7.4 Information relating to the regional services business held by NHS Lothian will only be released to a third party with the express approval of all Boards in writing, or if there is a legal requirement to disclose. NHS Lothian will meet its legal obligations to specify the purposes for which the information is used.

6.8 Confidentiality

Parties to this MOU will adhere to the requirements of confidentiality in regard to any information acquired which concerns or is deemed to concern individual identity and personal details in line with local and National policy and relevant legal framework.

6.9 Governance Structure and Timeline

- The development of the regional service will be overseen through the agreed programme governance arrangements, including the Regional Long Covid/ME CFS Steering group, Regional Clinical sub-group and any other associated operational and management groups.
- Participating Boards commit to engaging fully in these structures, contributing to decision-making, and ensuring appropriate local oversight and alignment with Board priorities.
- A detailed implementation timeline, including key development milestones and the transition to live service, will be agreed collaboratively through the programme governance structure. This timeline will be reviewed and updated as required to reflect progress, dependencies and any emerging risks. The MOU provides the framework for joint working during this period until a formal Service Level Agreement is established for operational delivery.

6.10 Health and Safety

Boards where regional workforce are based, will provide a safe working environment and facilities, to look after the health, safety and wellbeing of staff to the same extent as that if they were the Board's own employees, whether that be working from their own estates or working from home in accordance with health and safety and other relevant legislation.

6.11 Mutual responsibilities

All Boards will co-operate with each other in the fulfillment of their respective obligations.

6.12 Disagreements

6.12.1 All Boards will attempt in good faith to resolve any dispute arising out of or relating to this MOU.

6.12.2 Where disagreements occur, those concerned will attempt to resolve the issues promptly through appropriate discussion.

6.12.3 Where disagreements are unable to be resolved within a 14-day period, the matter will be escalated within each relevant Board with every attempt taken to resolve issues without any undue delay.

6.12.4 If the matter cannot be resolved, the issue should be raised with the AHP Directors within the relevant Boards, where the decisions made will be binding.

6.12.5 Where the matter collectively affects all Boards, it would be appropriate to seek the view of the Regional Long Covid/ME CFS Steering Board, in terms of a resolution.

6.13 Review and Management

Given the interim nature of this MOU, reviews will be as and when requested by any participating Boards. Reviews will be carried out by all Boards collectively and brought to the regional Long Covid/ME CFS steering Board for agreement.

The Clinical Lead of the Regional Long Covid/ME CFS service in conjunction with the designated Board clinical representatives, will manage the delivery of the responsibilities in this MOU. The Directors of AHPs from all Boards will be formally accountable.

7. Appendices

Appendix 1 – Financial Contribution Summary

LC / MECFS proposed Regional split				
	Total Allocation	Split	Regional Model Split	Balance for local service
Borders	£99,208	0.07	£28,787	£70,421
Fife	£307,495	0.23	£89,226	£218,269
Lothian	£676,576	0.51	£196,322	£480,254
FV	£246,390	0.19	£71,495	£174,895
Total	£1,329,669	1	£385,829	£943,839

8. Agreement Signatures

Although this Agreement does not have legal effect, the Boards will act in accordance with the MOU.

Board	NHS Board Designated Officer	Date
NHS Borders	Signature:	
	Print Name:	
	Title:	
NHS Fife	Signature:	
	Print Name:	
	Title:	
NHS Forth Valley	Signature:	
	Print Name:	
	Title:	
	Print Name:	
	Title:	
NHS Lothian	Signature:	
	Print Name:	
	Title:	

No.	Meeting Date	Action	Owner	Due Date	Status	Updates
2	8.1.26	HC/BW to amend draft TOR & recirculate.	HC/BW	30.3.26	Complete	19.3.26 TOR accepted with amendment of Board on membership table. 4.2.26 HC/BW to update the TOR to clarify membership roles and responsibilities.
3	8.1.26	Plan additional monthly meetings in diaries.	BW	31.1.26	Complete	
4	8.1.26	All to arrange a deputy if cannot attend monthly meetings.	All	30.3.26	Complete	19.3.26 HW added for FV and 2 reps for Borders - await Fife rep for AW
6	8.1.26	BW will pick up the job description for the admin person (medical secretary with additional wider admin support).	BW	19.3.26	Complete	19.3.26 Amendments have been made to a B4 medical secretary TL role JD - this has been sent to partnership and then to JE for their decision around an addendum or if full evaluation is needed. JD is with JE team awaiting outcome.
7	8.1.26	HC will have conversation with medical consultant around supporting clinical model.	HC	19.3.26	Complete	19.3.26 HxC has met with AH for feedback and potential inclusion where possible to help develop and input to the new regional pathway.
8	8.1.26	Names to CC for Bath workshop/masterclasses & IPIC conference in Nottingham	All	19.3.26	Complete	19.3.26 - rep from FV has tied in around Nottingham conference and workshop activity is in progress - CC has received the invoicing. Any names of people will specialised interest to be sent to CC.
9	4.2.26	All to identify appropriate finance representatives.	All	30.4.26	Complete	19.3.26 2 finance reps collated so far, remaining reps from Forth Valley and Fife to be confirmed (In progress).
10	4.2.26	Clinical Sub group - Names for sub-group to be sent to CC by end of next week - 13th February 2026.	All	13.4.26	Complete	All names in - awaiting NHS Fife contact.
11	4.2.26	BW/CC to extend the planning for local group into a regional group and send information to group to be communicated within own local routes.	BW/CC	19.3.26	Complete	19.3.26 - This is currently awaiting update by eHealth. BW to share flyer with subgroup reps once complete.
13	19.3.26	HW to be added to all future meetings	BW	30.3.26	Complete	HW added to all remaining diary dates.
14	19.3.26	Change name of contact email box to LTC	BW	28.4.26	Complete	
15	19.3.26	Circulate flyer for LE group to clinical subgroup	BW	28.4.26	Complete	
16	28.4.26	•HxC will seek advice/clarity from CB around the MOU and next steps	HxC	11.5.26	Complete	
17	28.4.26	HxC will check with AHP directors around the CHSS meeting request.	HxC	11.5.26	Complete	Checked with AHP Directors and group received update from HW NHS FV. HxC will build on this and reach out to CHSS for a call. Passed to CC to set up call with CHSS which has been planned in (see action 30).
18	28.4.26	•BW will add Communication and engagement to to next meeting	HxC	11.5.26	Complete	
19	28.4.26	CC/BW will ask subgroup reps for any visual diagrams of their current services.	CC	11.5.26	Complete	CC has incorporated current services into visual slides that have been presented within the clinical sub-groups and steering group.
21	11.5.26	SBAR with proposals for medical pathway to be brought to next meeting (CC).	CC	8.6.26	Complete	CC has brought updated proposals in SBAR to group.
22	11.5.26	BW to plan in another meeting for early June	BW	8.6.26	Complete	
23	8.6.26	•CC/BW to pull together a couple of paragraphs that can be circulated to AHP Directors for psychologists' interest (for clarity - not clinical work but to support development of regional services).	BW	8.6.26	Complete	CC has received a few interested parties.
25	8.6.26	•CC will amend wording within SBAR to incorporate medical model within MDT	CC	20.7.26	Complete	
26	8.6.26	BW to draft a 1-page briefing document to support staff engagement around the regional service.	BW	20.7.26	Complete	
28	20.7.26	•CC/JF to take the psychology paragraphs to the psychology meeting for discussion and any other updates and BW will recirculate to AHP Directors for any psychologists' interest (for clarity - not clinical work but to support development of regional services).	BW	24.8.26	Complete	
29	20.7.26	CC to set up education sub-group, look for potential volunteers and Chair of group	CC	24.8.26	Complete	1st meeting planned in.
31	20.7.26	BW to liaise with HV around availability for next meeting	BW	24.8.26	Complete	
33	24.8.26	Meetings to be set up 6 weekly.	BW	6.10.26	Complete	Next set of meetings booked in 6 weekly.

Regional Long COVID/ME/CFS Steering Group

Summary Notes and Actions

Thursday 8th January 2026 11-12.30

Attendees: Heather Cameron (HC) (NHSL), Charlie Chung, (CC) (NHSL), Belinda Wilson (BW)(NHSL), Colin Briggs, (CB) (NHSL), Amanda Wong (AW)(NHSF), Paul Cameron (PC)(NHSFV), Paul Williams (PW) (NHSB), Paul McMenamin (PM)(NHSB).

Apologies: None

No.	Item
1.	**Introductions and Apologies** HC led introductions for the group.
2.	**Background** HC recapped Boards had received non-recurring funding for the last 3 years and that earlier this year, Scottish Government (SG) had committed to recurring funding from April 2026, slightly expanding the remit from Long COVID to ME/CFS/other longer-term conditions. HC confirmed the Lothian bid paper had been shared and thought it would be useful for all Boards to share their bids. HC confirmed early conversations have already taken place (before and after funding news) around a regional service, recognising support for a subset of patients with complex and challenging needs. Discussions included proposal around what the staffing model might look like and job descriptions. HC proposed that CC is seconded for the first 12 months to lead and progress the regional service work and there is currently a process to fill CC's substantive post, expected to be in post in March. PC added he was happy with CC looking at what would be ideal but was not sure about whether a full-time rehabilitation consultant would be required with no nurse offering. HC confirmed we need to have a clear debate around what the split might look like around the requirement for a full-time consultant and no final decisions had been made, adding it would be useful to talk to a clinical lead for psychology and finance at a later stage. AW asked what the medical consultant post will look like, for example, will it specialise in renal, cardio as there is none of that locally and this will need considered under the umbrella other than just the rehab aspect. HC advised that there needs to be a level of realism with this as well, recognising that with ME/CFS services there is a risk unearthing unmet need. HC recognises that in developing the clinical pathways this is likely to come up and it would be worth mapping what current Boards current offer at a local level. PC added that not all Boards have ME/CFs and that there would be a very long list of involved professions and that it would be difficult for a regional service to be that specialised, instead looking at a consistent and co-ordinated regional service would be the overarching view. CC advised that while building the medical rehab role in Lothian, it was not clear what professionals would be involved, for example, for POTS but that diagnostics are met before it

No.	Item
	arrives at consultant level making it easier for them to have conversations with other services. **Action**: All Boards to share SG bid papers – send to BW, who will collate and share with the group.
3.	**Draft Terms of Reference (TOR)** HC advised a draft TOR had been drawn up and took the group through the paper. ***(Aims)*** PW if one of the aims could be explicit about the group establishing the model of pathway and workforce. PW also asked whether the regional service would cover children and adults? HC confirmed we would add in more explicit wording around the workforce and staffing model. PC advised that including children and young people (CYP) was not an ask from the SG and that it would involve multiple different sets of specialists and any inclusion of CYP may not sit comfortably with paediatricians as specific elements are dealt by them as experts. CB added that if SG did not highlight CYP to be included, then leave out just now however make this explicit in the TOR along with definitions of the age of a child. CB agreed other bullet points were fine but could add clarity around overseeing/scoping of education and relevant definitions, for example, is this for undergraduates, and be specific about experienced professionals. HC clarified for education, it would be post graduate, looking at what the regional specialist core team could offer and it could cover patient education but not pre-registration. PW confirmed with the allocation of funding, there was no intention to invest in children's paediatric services regionally as these were managed locally. HC advised that SG had not been as explicit as we would have liked, although they have asked about CYP. In Lothian, some money has been given locally to CYP but earlier conversations with paediatricians highlighted that they were not seeing a lot of children with Long COVID, although there was increasing withdrawal from school/education and in young people's functional presentation. There is also clear overlap clinically with neurodevelopmental symptoms. Also clear that whilst consideration of support for CYP, this was not part of the regional proposal which is for adults only but that did not preclude informal collaboration on a case by case basis. CC added that locally, Lothian has had conversations with Borders, for a young person who needed help as we had built up a resource that could be shared. This was initially open to young people with Long COVID, then fatigue conditions and we have collated valuable information for other Boards. HC summarised that the additions to the TOR: workforce/staffing model; clarity around development of the regional model; clarify adults; clarify education point. ***(Membership)*** PW suggested Psychology as the local lead was very interested in this work and raised that having all AHPs might be an issue. HC added medical input might be useful and suggested that both psychology and medical input need not come only from Lothian. HC confirmed that these areas might fit in a subgroup that will be driving the clinical model. PC advised we could add lots of people but to what end, adding this group was just to get this going and then we would get experts in the room.

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	CC suggested someone from SCI might be useful to prevent IT tripping points in future. CB suggested that finance might be part of the group and there was a rep here, but we can contact other people to add in as required. ***(Frequency)*** HC confirmed monthly would be useful to start then a short life working group would be set up, likely chaired by CC, to lead the clinical pathway work. ***(Programme governance)*** HC asked the group if they were happy reporting back within their local processes and there were no objections. PC confirmed he was happy with the frequency but would like advance notice of meetings. HC added it would be essential for members to have a deputy, to keep the monthly progress **Actions: HC/BW to amend draft TOR; plan additional monthly meetings in diaries. All to consider a deputy if cannot attend monthly meetings.**
4.	**Finance/Staffing Model** HC confirmed a document with finance outlines had been included with the papers. HC confirmed the AHP consultant seconded post for 12 months to develop the model and that what the medical input will look like is to be determined. There will be a psychology post and admin support. PW confirmed this was a pragmatic approach and the admin post will be useful from the outset. HC advised professional advice was psychology post should be at 8B rather than 8A. It was felt this level of seniority was required; financial difference is minimal. HC advised that in Lothian ME/CFS, there is a supporting infrastructure, and a psychology job description could be ready to go within weeks if agreeable for Lothian to lead. All agreed and HC confirmed she would ask the Lothian psychology lead to start the progress on this and contact other Board's psychology contacts. HC asked for both PC and PW to provide contacts so she could ask Chris to start recruitment for clinical posts to be in place for April. HC advised that from a medical perspective, there is interest publicly and FOI's have already come in, with scrutiny and interest so keen to progress conversation. HC suggested in the short term; it would be useful for medical input to work with CC to develop the model as a first step. PW advised this was a sensible approach. HC advised she would check what support could be provided as the medical consultant is currently working for three different organisations so may have limited capacity. PC highlighted that there were no medical rehab concerns but 10 minutes of conversation creates additional hours of rehab from other staff, so it would be unlikely the medical post should be full time. HC acknowledged this was a reasonable health warning but emphasised that a true multi-disciplinary service should save time and shouldn't generate additional work. CC added that these were also risks considered within Lothian's service, but with diagnostics and referral criteria, especially seen within ME/CFS which was already tight, this could be managed. CC added that it would be useful to have the evaluation conclusions before the National Long COVID meeting steps down to inform the medical model going forward. **Actions: HC will ask CH to link with psychology leads in other Boards to progress recruitment; BW will pick up the job description for the admin person which will likely be a medical secretary with additional wider admin support. HC will have conversation with medical consultant around supporting development of clinical model.** (Psychology Contacts supplied in meeting chat: Caroline Cochrane in NHS Borders susie.porteous@nhs.scot Interim Director of Psychology FV)

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5. **Recruitment** – as discussed in agenda item 4.

6. **Next Steps**

HC confirmed CC would look at the subgroup and BW would look at dates for the monthly meetings.

7. **AOCB**

HC raised the topic of lived experience group and asked re-setting this up and expanding the membership. PC confirmed they already had a large group and PW advised there was nothing specific in Borders. HC asked if a group for the region could be challenging and complex. PW advised it would be great if Borders residents had access to that but with different local services it could lead to questions around inequity.

CC advised that there was a group facilitated by CHSS, where other Boards joined and it had found value in smaller groups where people were more comfortable to express views but the group were valuable in shaping services. HC advised that there is benefit in looking at this. PC added that people like having their own identity and the groups help keep this, which can feel lost with "long term condition". HC added it was helpful to say LTC as widening this gives an opportunity to think differently, but acknowledged we do need to be mindful of language.

HC advised that CC had liaised with colleagues in Bath to provide an in-person workshop (utilising small in year underspend) for Lothian team. CC added that this was a great opportunity, looking at therapy models and neurodivergent population and almost ready to be booked. HC indicated that would make sense to widen to regional colleagues and interested names could be sent to CC. CC added that there was date coming out at end of March, likely focused on at the Nottingham conference and was hugely valuable and a networking opportunity if regionally we were to send reps.

Action: Names to CC for Bath workshop.

Summary of Actions:

	Actions	**Owner**
1	Boards to share SG bid papers – send to BW, who will collate and share with the group.	All
2	HC/BW to amend draft TOR & recirculate.	HC/BW
3	Plan additional monthly meetings in diaries.	BW
4	All to arrange a deputy if cannot attend monthly meetings.	All
5	HC will ask CH to link with psychology leads in other Boards to progress psychology recruitment.	HC
6	BW will pick up the job description for the admin person (medical secretary with additional wider admin support).	BW
7	HC will have conversation with medical consultant around supporting clinical model.	HC
8	Names to CC for Bath workshop.	All

Regional Long COVID/ME/CFS Steering Group

Summary Notes and Actions

Wednesday 4th February 2026 9-10.00

Attendees: Heather Cameron (HC) (NHSL), Charlie Chung, (CC) (NHSL), Belinda Wilson (BW)(NHSL), Amanda Wong (AW)(NHSF), Paul Williams (PW) (NHSB), Hazel Webb (HW) (NHS Forth Valley)

Apologies: Colin Briggs, (CB) (NHSL), Paul Cameron (PC)(NHSFV), Paul McMenamin (PM)(NHSB).

No.	Item
1.	**Introductions and Apologies** Hazel Webb is a new member attending on behalf of Paul Cameron - HC led introductions for the group.
2.	**Previous Minutes/Actions**

- **SG Bid papers - Boards to share SG bid papers with BW, who will collate and share with the group (All).**
  Papers not yet received – action for all to share bid papers (In Progress)
- **Terms of Reference - HC/BW to amend draft TOR & recirculate. (HC/BW)**
  Amendments completed and on agenda for review. (In Progress).
- **Future Meeting Plan - add monthly meetings in diaries (BW).**
  Dates in diary for next 5 months. **(Completed)**
- **Meeting Attendance - All to arrange a deputy if cannot attend monthly meetings. (All)**
  Incorporated in TOR. (Completed)
- **Psychology post-HC will ask CH to link with psychology leads in other Boards to progress psychology recruitment (HC).**
  Heather has linked with CH who has linked with Board leads and this is being taken forward, hopefully advertised soon. AW confirmed the NHS Fife contact is Jackie Fearn. (In Progress).
- **Admin post-BW will pick up the job description for the admin person (medical secretary with additional wider admin support) (BW).**
  BW has gathered in medical secretary role however this does not exclusively meet the requirements therefore other roles will be considered or an amended role will need to be submitted to job evaluation (In Progress).
- **Clinical model - HC will have conversation with medical consultant around supporting clinical model. (HC)**
  HC has call booked in 4.2.26 to discuss and will provide an update at next meeting. (In Progress)
- **Bath Specialist Service workshop - Names to CC for Bath workshop. (All)**
  CC advised remit has changed slightly and there is opportunity to be involved in the planning and content development of specialist workshops or sessions to meet any possible unmet needs.

All to nominate a contact for anyone interested in this to CC. (In Progress)

3. **Draft Terms of Reference (TOR)**

All happy with changes. PW asked for additional clarification for membership and whether people are attending in their capacity to represent the Board, profession or region and who they are feeding back to, acknowledging that this group may not need a huge range of wider stakeholders.

HC clarified that AHP directors would be representing their respective Boards, with Colin Briggs representing regional planning and Paul leading the finance while linking in with other Boards finance reps. Wider stakeholders will likely be represented in the clinical group. AHP directors would be able to update the relevant people and those who need to know within their local Boards. HC added that those in CC's clinical sub-group would include wider representation from all clinical professions and would report into this group, the steering group.

Action: All to identify appropriate finance representatives.

Action: HC/BW to update the TOR to clarify membership roles and responsibilities.

4. **Finance**

There was no update however HC clarified there were no expectations around cross-charging for this financial year and we will pick up finance at the next meeting.

5. **Recruitment**

HC confirmed that in addition to the roles discussed earlier in the meeting, CC's backfill role request had been submitted for approval and would be advertised shortly which would free up CC's time. HC added that the medical post needed further conversations around what that looks like.

6. **Clinical Sub-group**

CC advised he would be setting up the sub-group with clinical leadership and is looking for names of people who know what the local offering is. HC added people should also be able to clearly articulate what the hopes and ambitions with clinicals who are interested and have expertise. This could include wider clinical representation, such as psychology and nursing.

PW asked if this where the model would be developed along with looking at local gaps and opportunities. HC confirmed this was the case and once the admin person is recruited they can support this group & CC can do a TOR for the group.

Action: Names for sub-group to be sent to CC by end of next week - 13th February 2026.

7. **Service User Engagement**

BW updated the group that a framework for a small local group was ready to be launched, pending review from public engagement and this included a patient information sheet, promotional flyer and risk assessment. BW advised we still had the Lothian Long Covid email box and the plans were to collate patient interest within this email box. HC asked how we were planning to gain patients for the group. BW advised there were a few groups including patients of the clinicians in CC's clinical forum group, there was the Get Involved route within Lothian for public engagement if needed and BW had an action to link in with wider organisations such as the Alliance. HC asked the group for thoughts around expanding this to a regional group. PW advised there are groups in place but not dedicated groups and this would be great for Borders. HW advised it was similar in Forth Valley with larger user groups

No.	Item
	and local groups led by people but not by Board and people would be interested. AW added that Fife was similar and do not have a specific Board led group. AW highlighted that we would need to be clear around the scope and include ME/CFS and wider post infection patients therefore the email box title of Long Covid may not be appropriate. HC added we can look at changing the email title. **Action: BW/CC to extend the planning for local group into a regional group and send information to group to be communicated within own local routes.** **Action: BW will look to change the name of the email box.**
8.	**Conference/Networking** CC updated the group around the IPIC conference in Nottingham on 25th March which is a valuable event and would be a great opportunity for any interested parties from other Boards to travel to for networking purposes. CC has emailed the group with details of the conference. Link: IPIC-Conference-Programme-2026-2.pdf **Action: All to provide interested names to CC.**
9.	**National strategic Long Covid network event - Evaluation presentation** CC updated that group that the National group were running a concluding evaluation event in in Glasgow on 20th March. Boards are invited to present 3-minute updates. HC added that it would be a good event to attend even though we are at the beginning of the regional model, and a useful platform to share ambitions. CC added that an email had recently been circulated from the National network for a POTS masterclass, which CC would be also attending and can provide an update on. **Action: Any interested parties to attend/present to link in with CC.**
10	**AOCB**

Summary of Actions:

	Action Area	Action details	Owner	Due Date
1	**Bath Specialist Service workshop**	Planning and development opportunity to shape content **-** a*ll to nominate a contact for anyone interested in supporting this to CC.*	CC	19.03.26
2	**Board Finance representatives**	All to identify appropriate finance representatives (with exception of Borders).	All	19.03.26
3	**Terms of Reference**	HC/BW to update the TOR with a column clarifying membership roles and responsibilities.	HC/BW	19.03.26
4	**Clinical Sub-group**	Names for clinical sub-group to be sent to CC by end of next week.	All	13.02.26
5	**Regional Service User Engagement – lived experience group.**	Extend the planning for local group into a regional group and send information to group to be communicated within own local routes.	BW/CC BW	27.02.26 19.03.26

		BW will look to change the name of the email box.		
6	**Conference/Networking**	All to provide CC with any interested names to attend: LC Conference in Nottingham 25th March IPIC-Conference-Programme-2026-2.pdf National LC strategic network event (conclusion) Glasgow 20th March Link: Long COVID Strategic Network Day Tickets, Fri 20 Mar 2026 at 10:30 | Eventbrite	All	13.02.26

Next Meeting: 19th March, 11-12.30

Regional Long COVID/ME/CFS Steering Group

Summary notes and Actions

Thursday 19th March 2026 11.00-12.30

Attendees: Heather Cameron (HC) (NHSL), Charlie Chung, (CC) (NHSL), Belinda Wilson (BW)(NHSL), Paul Williams (PW) (NHSB), Hazel Webb (HW) (NHS Forth Valley)

Apologies: Colin Briggs, (CB) (NHSL), Paul Cameron (PC)(NHSFV), Paul McMenamin (PM)(NHSB), Amanda Wong (AW) (NHSF).

No.	Item
1.	**Introductions & Apologies**
2.	**Previous meetings notes/actions** HC noted that the draft minutes from the previous meeting had not been shared with the papers. HC reviewed the minutes with the group virtually with no amendments however the minutes will be shared electronically. **Previous Actions** • **All to share Board finance representatives (All)** 2 finance reps collated so far, remaining reps from Forth Valley and Fife to be confirmed (In progress). • **Terms of Reference - HC/BW to amend draft TOR with membership and role table (HC/BW)** • Table completed with minor Board amendments. (Complete).
3.	**Recruitment** HC advised that while clarity around the regional model is still needed, in Lothian services there has been a medical rehabilitation consultant for the last 12 months. The current consultant however is leaving the role, with another consultant covering during the interim period while the regional model is developed. HC took the opportunity to speak to the outgoing rehab consultant to gain feedback to help inform the new pathway development. Feedback included essential consideration to being part of a team to avoid feeling isolated. There are options being explored with the new medic with potentially two medics doing 1 session each and that would mitigate the isolation of one medic and might be more sustainable. HC is taking these conversations forward. PW agreed on the need for a sustainable and resilient option and pragmatism around what is achievable with an element of flexibility but is supportive of HC having those further conversations.

No.	Item
	HW asked for a recap around what the regional service recruitment would look like. HC confirmed that the initial financial calculations and proposal included: 1 full time medic; 1 AHP lead; 0.5 psychology' and 1 full time medical secretary. HC added that the psychology post had changed from 8a to 8b and the AHP consultant position might change over time. There was a proposal to release CC into the AHP lead role and backfilling his position and that more discussion is needed around what the medical input looks like as there are other options witnessed in other Boards such as a GP with special interest or neuropsychiatry. HC advised that conversations are taking place with the new interim medic within Lothian services around the role which could be neuro or neuro-rehab, GP or senior level trainee post and that rehab consultants taking 1 session each also provides options. CC highlighted the guidelines around medical input, particularly around the benefits of more than 1 doctor for cross cover and that testing of MDT working adds value. CC suggested this links in with Dublin infectious diseases neurology services and the value of working together with a whole team approach and more that 1 doctor strengthens services. HC added we have the opportunity to move quickly without a permanent solution and will sense check with the new interim medic when they are back from leave and bring CC into the conversation. HC advised that we will invite AH into the clinical reference group as she will have very clear views from a medical need around what has been challenging and what is needed from a public perception. CC added in terms of visibility of services, CC, BW had an earlier meeting with the relevant refhelp team around adding a video to the Lothian pages to build on the information around medical input and to promote clear messaging. One of the additional questions discussed was around the regional services and they confirmed they would be happy to update if this was agreed. CC asked for thoughts on the information on the regional service, if this would be on own Boards refhelp or we expand on a regional page and what that messaging should be. HC advised that it will depend on how the regional service will work as GP's already refer into services and it could be that referrals are escalated from local services. HC highlighted that we might not yet have the answer but there could be a risk if the service was wide open for direct referral. CC added we will be able to protect direct routes with the development of good information. PW advised that the clinical group will need to work through this with a clear position on access and sees most benefit with escalation from people who have accessed services rather than open access, with a regional MDT approach addressing complex needs. HW agreed that referring to local services in first instances and then if issues arise, escalating to regional model as we want complex patients going there. CC added this reinforces the need for clear messaging to avoid the risk of people just wanting the medical part of it as it won't be a diagnostic service and recognises the risk of direct pathways. HC advised this will emerge through the clinical subgroup and that with Long Covid there are different variations and not a single point of contact and that services might look different within other Boards. CC added that a script will be written around the video and shared so everyone is happy with it. BW advised that an update had been received from the Lothian psychology lead who had liaised with other Boards psychology leads, and a draft job description had been developed. Points were raised around transparency of the population that the post will serve and the need to quantify what severe and complex look like as the 0.5 post could be easily overwhelmed if these were not clear. The risk of isolation was also raised and it is important that the post holder have access to regular support and supervision.

No.	Item
	BW added a job description for the medical secretary role had been sourced and BW was liaising with the job evaluation team around this, anticipating the job might be ready to recruit to in May. HC advised that in terms of local Lothian recruitment arrangements, a number of people have been made substantive and everyone is in post now with a remaining question around a 0.5 post and asked where other Boards were. PW advised there was 1 post in Borders, an advance OT role that have been made substantive. HW advised that similarly, within Forth Valley, there was 1 nurse, 0.7 physio, and a 0.4 physio that were now all substantive.
4.	**Clinical Sub-group** CC advised he has met with Forth Valley and Borders reps to gain the lay of the land. BW has created a proforma ready to capture current services and it will be useful to get the wider perspective on what is within current services and what is missing. CC added that conversations had opened around the more complex bed bound patients and what we could do and it was noted that while we see a lot of these patients within Lothian, other services haven't yet come across those in similar numbers. It was good to note agreement around services being different but working together to create a regional pathway with strong connections, training and education resources. CC noted we still need to make contact with Fife's rep and CC will make contact with AW to source the best person to join the group. HC suggested that we need to highlight that it would be useful for alternative reps to attend meetings, so we always have appropriate nominees to keep things progressing. HC added we may identify unmet needs and education can then come to the fore with education support from the wider team to avoid fatigue which will also help other colleagues. CC highlighted the psychology pyramid model which was supported by education. PW agreed that education needs agreement around where it sits into existing pathways to add to the support and to be able to refer accordingly. PW raised the question around where the regional service will sit within the sub national planning as Forth Valley sits in a different clinical area. HC advised she had chatted to CB around this and there were already many cross-Board services and no current appetite to immediately unpick these but it's something to be mindful of. There is a push on collaborative services and we are already embracing a collaborative MDT approach. CC reflected that a few local services offered digital or online group sessions and there is an opportunity to consider opening up groups regionally for efficiency purposes. HC added looking at the central pot of money and finding ways to work collaboratively, for example in digital spaces, provides the opportunity to do something different, particularly with the widening scope of long-term conditions with less emphasis on being diagnosis specific.
5.	**Service User Engagement – Regional LE group** BW advised that the attached papers were amended to promote a regional lived experience group but we were currently waiting on a contact email box being changed to widen the offering to LC/ME CFS and get this correct from the outset. The proposal is for the email contact box to be LTC (long term conditions). Once the email box is amended by the local eHealth department then the flyer will be circulated to Board contacts. We already have interested names from the ME Action group. **Action: BW to circulate flyer for LE group to clinical sub group reps.**

No.	Item
6.	**Conference/Networking Masterclass** CC advised that the planned Long Covid evaluation conference had been cancelled but there was an ask for posters for the new date (still to be decided). The masterclass invoice has been sent in and preparations are underway and this is open to anyone within the wider teams. It would be useful to identify people with a specialised interest who might like to attend the workshop. National network for Long Covid presentation CC confirmed this was in Nottingham next week and quite a few people from Lothian were attending. FW confirmed reps from Forth Valley would also be attending. **Action: All to identify any interested people with specialised interest to attend/help develop masterclasses. Names to CC.**
7.	**AOCB** HC advised that the National Long Covid network meetings were closing but there had been an ask for Boards to contribute towards the final evaluation report. To date only feedback from 3 Boards had been included in the report but the date for all Boards to contribute lessons learned has been extended and a template has been shared for completion. CC and BW are pulling together Lothian's brief but it would be useful to highlight the future medical pathway in the recommendations section. HW raised a question around finance received from SG. HC advised that the finance has been received in different allocations and the latest amount was part of the last 30% of the 1st allocation in addition to the 2nd allocation. HW asked to be added as a representative to the meetings going forward. **Action: HW to be added to future meetings.**

Actions:

- **C/F - All to share Board finance representatives (All)**
  2 finance reps collated so far, remaining reps from Forth Valley and Fife to be confirmed (In progress).
- **BW to circulate flyer for LE group to clinical subgroup reps**
- **LC/ME CFS Masterclasses – All to identify anyone with specialised interest - names to CC**
- **HW to be added to future meetings**

Regional Long COVID/ME/CFS Steering Group

Summary notes and Actions

Thursday 28th April 2026 11.00-12.00

Attendees: Heather Cameron (HxC) (NHSL), Charlie Chung, (CC) (NHSL), Belinda Wilson (BW)(NHSL), Paul Williams (PW) (NHSB), Hazel Webb (HW) (NHS Forth Valley)

Apologies: Colin Briggs, (CB) (NHSL), Paul Cameron (PC)(NHSFV), Paul McMenamin (PM)(NHSB), Amanda Wong (AW) (NHSF).

No.	Item
1.	**Introductions & Apologies**
2.	**Previous meetings notes/actions** HxC noted that there were no changes at this point to the minutes of the last meeting. Any changes identified, post meeting, can be sent to BW. **Previous Actions** • **All to share Board finance representatives (All)** 3 finance reps collated so far, 1 remaining rep – BW will follow up with NHS Fife around this. (In progress). • **BW to circulate flyer for LE group to clinical subgroup reps.** BW confirmed the flyer had been shared (Completed) • **LC/ME CFS Masterclasses – All to identify anyone with specialised interest - names to CC.** CC confirmed he had received 5 names to date. (Completed) • **HW to be added to future meetings** (Completed)
3.	**Clinical Sub-group Update** CC confirmed the subgroup with clinical reps met last Monday and CC has had individual conversations with everyone. CC noted that the Fife rep was head of the pain service and they were just starting up but had met recently around plans going forward. CC noted that it was useful to have collective thinking about what models or different services are currently in place and obtaining thoughts on the medical and psychology input. The group discussed the outcomes of the advisory group 5 paper and the recommendations around involved professions and medical input and it was useful to look at future developing pathways, particularly in the occupational therapy/community OT space where gaps were noted. It was recognised that this work sits within the AHP directors portfolio which offers opportunities to link with other useful therapies and expertise in line with the psychology pyramid. For example, at a recent local discussion, SLT advised they have months of waiting time for patients with cough but there are potentially other services that could support this and an action has been taken away to look at this.

No.	Item
	From the subgroup meeting it was clear an MDT approach was valuable for complex and specialist involvement and that symptoms that are everyone's business could potentially be managed by other areas. The subgroup agreed that there was a special appreciation of medical input. In a separate local meeting with medical and psychiatry colleagues, it was also highlighted that the medical input could lead to isolation for 1 medic and it would be useful for at least 2 medics that could potentially be combined with psychiatry input. There was discussion around the medical model, prescribing medication and managing mood factors and this discussion and feedback will be useful to inform the subgroup conversations as they develop the regional pathway. PW advised that it sounded as if the right topics were being discussed and focusing on baseline services would help look at the unique and specialist function of the regional service and what that could offer. CC highlighted that it was evident in conversations with Borders and others, that there are differences in the patient cohorts seeing some less severe cases compared with Lothian who has seen quite a few bedbound and photosensitive patients who can only meet online. It was discussed that potentially floodgates could be opened with the uncertainty of why the same patient cohort are not being seen in other Boards. It was also noted that it would be useful to consider what other professions might offer in a pyramid model. PW offered insight that Borders are a rural population and there are challenges with significant needs potentially being hidden due to environment, smaller hamlets as factors but does not think floodgates would open due to the size of the population. HW added that in FV they have also not see patients at that extreme end within their small cohort of patients. HxC reflected that Lothian will have a higher percentage of the population than smaller Boards and while there might be slight anxiety around floodgates opening there is a need to develop services fully and the medical discussion and feedback is very useful, highlighting that the psychiatric colleagues offer a different perspective and there is no absolute around what the pathway looks like. The pathway could have consistency under rehab medicine but could include pain services and psychiatry. HxC advised that the one agreed perspective is that it cannot be 1 individual and likely needs to be sessional. HxC advised as next steps it would be useful to put discussions and thoughts onto paper and formalise what the medical pathway could look like particularly as Freedom of Information (FOR) requests will likely come in around this. Heather advised it would be useful to formalise the medical part and the discussions will help the subgroup discussion at the next meeting including consideration of how we ensure we have local pathways, for example, if we give funding to community physio then it would be reasonable to be able to access that pathway to avoid a single point of failure. CC advised that there had been discussion at the medics meeting around some Boards looking at routes of a non-medical prescriber noting that there could be additional risks of harm. HW added that locally they had held discussions around this and acknowledged that this route could be easier for some services, particularly as GPs aren't at the same levels of confidence or consistency or knowledge. There are however risks around this within the LC service as this does not sit within a medical team for supervision or future reviews. Having regional experts to link in with would be very useful. HxC advised that the outgoing medic feedback (AH) was useful and that hardly any prescribing had been carried out but there is awareness of off license and private prescribing for Long Covid. There are some risks around this, particularly if patients are expecting this within the service and there will need to be some medical management of this.

No.	Item
	PW advised it would be useful for the clinical subgroup to discuss this and work through options and come up with a proposal around how to deliver this safely. HxC advised there are currently very little approved drugs but there will be emerging drugs and we will need to be mindful of how we manage this. CC provided an example of research in studies and conversations in the national group and lived experience group around fexofenadine and mass cell activation. CC advised that it was clear that having more than 1 medic would be valuable along with visually diagramming current services. HxC advised there are other emerging therapies being trialled such as hypobaric therapy, as seen recently in Shetland. CC advised he was aware of this therapy being offered locally and the outcomes of Israeli research where they had seen improvements but this has not yet moved into guidelines.
4.	**Recruitment** HxC advised that CC's post was out for advert and interviewing would commence next week. Both the medical secretary post and psychology post were also progressing at local job evaluation and we would have a further update at the next meeting. HW asked if all the jobs would be based in Lothian. HxC highlighted that it was agreed at the start that the psychology post would be based within Lothian as the only ME/CFS service offering an already established psychology service. HxC advised that other posts do not need to be in Lothian. The medical post will depend on what is developed and pragmatically, if an employee from another Board applied for the medical post and wanted to do this full time contractually within their own Board rather than have 2 part time contracts then this would be considered. HxC advised that it makes sense for the regional offering or service however to be employed within one Board for access, governance and processing reasons. PW agreed adding that from a logistical and practical view having a specialist hub hosted in 1 Board made sense with posts advertised externally. HxC advised that CC's post was advertised externally although it made sense for this to be a secondment backfill as the post was for only 12 months. HxC confirmed regional posts would be advertised externally and we will consider the challenge around part time or full-time contracts and what is pragmatic for the person and the hosting arrangement as the pathway is developed and routes are clearer.
5.	**Memorandum of Understanding (MOU)** HxC advised that following the bid to SG and agreed level of funding, meetings around the regional service have been held, minuted but nothing formally on paper yet. A memorandum of understanding, as we start to employ people, outlining governance routes and what we do if we disagree would be useful to cover the interim period until soft launch. We have started work on an MOU draft with the hope this will be shared at the next meeting. As the service becomes operational, likely with a soft launch, a more formal SLA can be agreed. HxC advised she will seek advice around the formality and next steps avoiding the assumption that Lothian will be hosting and that this is a regional collaborative partnership. Typically for regional services one Board will host however this is not explicitly a service as it could be more outreach and potentially, we could be hosting people rather than services. HxC will check with CB who has experience of regional planning for steer and advice. PW agreed this was not a straightforward regional offering and it made sense, in the development phase to have an MOU, with flexibility built in to change things as we go. PW added it would be useful to check with finance and legal on planning around the MOU but there is currently enough assurance that Boards will not be disadvantaged and there is confidence that the new model will be figured out.

No.	Item

HW added we are making good progress as a collaborative approach but useful to have shared understanding in writing around what the options are and what we agree. HxC acknowledged that there are challenges that we don't yet know what we are creating but an MOU will provide a useful framework.

HxC advised that most regional services will have standardised agreements in place and perhaps 90% is applicable but the MOU will have some flex in it, agreeing to come together, the principles, governance and handling of any conflict along with the percentage of funding from each Board. The MOU can be discussed in more detail at the next meeting, where we will hopefully have a draft to share.

Action: HxC will seek advice/clarity from CB around the MOU and next steps.

6. **Service User Engagement – Regional LE group**

BW confirmed flyers for the regional lived experience group had been shared across services and released to contacts within ME action and that we had been inundated with emails of interest over the weekend with around 40 people contacting. Initially it was expected to be a smaller group therefore BW and CC will meet this week to plan facilitation of this larger group, perhaps splitting into 2 groups. The first date of the meeting is planned in a couple of weeks. BW will be contacting people this week to acknowledge receipt of interest and providing more information around the meetings, which will be online initially.

CC asked if we know how many people can make online or would prefer face to face meeting. BW advised that the flyer had promoted the online meeting however BW would gather in any requests for face to face while going through the contacts.

7. **National network for Long Covid/Advisory Groups Update**

CC advised 5 people had registered for the 1st masterclass which would be on PoTS. A new email had been received from the national advisory group today. The last paper of recommendations has been shared with the clinical sub-group with JR sharing the most up to date paper with the recommendations of involved professions and medical input. CC will attend the next advisory group meeting on Friday this week. HxC confirmed we have good representation on the MSK/chronic pain advisory group. CC advised that there was a deadline of 7th May for the final paper.

8. **Engagement with 3rd Sector**

HxC advised an email had been received from CHSS with a desire to meet to discuss collective resources. HW advised they had received contact and there was a meeting planned in with CHSS on 18th May.

CC advised he has met with CHSS frequently and asked about support for people with chest, heart or stroke conditions and if CHSS would be open to providing support for Long Covid/ME CFS which they were open to. CC highlighted that within the advisory group paper there was narrative around commissioning of 3rd sector to support services.

HxC advised it would be useful to hear the update following HW's meeting with CHSS and HxC will check with others where they are at with the CHSS request.

Action: HxC will check with AHP directors around the CHSS meeting request.

9. **Communication Planning**

HxC suggested we bring communication to the next meeting for a full discussion and to have a communication plan in place fully before we launch to have consistency of messaging, which in

No.	Item
	turn would help any FOI requests. CC added it would also be useful to write out to reps to have the visual service view of what services we have just now.
10.	**Action: BW will ask subgroup reps for any visual diagrams of their current services.**
	AOB
	No further AOB.

Actions:

- **C/F - All to share Board finance representatives (All)**
  3 finance reps collated so far, 1 remaining rep – BW will follow up with Fife around this. (In progress).
- **HxC will seek advice/clarity from CB around the MOU and next steps.**
- **HxC will check with AHP directors around the CHSS meeting request.**
- **BW will add Communication and engagement to to next meeting.**
- **BW will ask subgroup reps for any visual diagrams of their current services.**

Regional Long COVID/ME/CFS Steering Group

Summary notes and Actions

Monday 11th May 2026 14.00-14.45

Attendees: Heather Cameron (HxC) (NHSL), Charlie Chung, (CC) (NHSL), Belinda Wilson (BW)(NHSL), Paul Williams (PW) (NHSB), Hazel Webb (HW) (NHS Forth Valley)

Apologies: Colin Briggs, (CB) (NHSL), Paul Cameron (PC)(NHSFV), Paul McMenamin (PM)(NHSB), Amanda Wong (AW) (NHSF).

No.	Item
1.	**Introductions & Apologies**
2.	**Previous meetings notes/actions** HxC noted that there were no changes at this point to the minutes of the last meeting. Any changes identified, post meeting, can be sent to BW. **Previous Actions** • **All to share Board finance representatives (All)** All 4 finance reps confirmed. (Completed). • **HxC will seek advice/clarity from CB around the MOU and next steps.** CB is currently on annual leave – HxC will tie in when he returns. (Ongoing) • **HxC will check with AHP directors around the CHSS meeting request.** FV have a meeting set in diary – any other meetings will be considered following the FV meeting. (Ongoing) • **BW will add Communication and engagement to next meeting.** As today is a short meeting, comms and engagement will be added for full discussion at the June meeting. (Ongoing) • **BW will ask subgroup reps for any visual diagrams of their current services.** CC has gathered visual diagrams of current service provision, gaps and opportunities for discussion on the agenda. (Completed)
3.	**Clinical Sub-group Update & visual service representation** CC referred to advisory group 5 (LTC) recommendations around what services should be included in a regional service. These recommendations also cover Lyme and fibromyalgia and other conditions classed as post infectious. CC highlighted from the recommendations that services include a named doctor, OT, Vocational Rehab, PT and clinical psychology. CC presented slides with excerpts of the recommendations and visual display of current services. Group 5 Strategic Priorities.docx SES PACCS steering group slides 11.5.26 CC raised two questions for consideration: What is the medical model; and how does each region access the services? CC advised that to support discussions, he had met with psychiatry and the previous and current, interim medical rehab consultants.

No.	Item
	CC took the group through some of the gaps in services highlighting that while other services aren't prescriptive within the recommendations, no Board has dietetics and that other pathways could be explored. PW acknowledged the complexity and that Boards are at different starting points and that dietetics and other areas could support. PW advised that it was important to consider the difference between what is needed and wanted within a medical model as this could be quite broad. PW advised they have cardiology in Borders but not specifically specialised in this area which also raises questions around how far does the service grow and that we need to be careful with the scope. PW advised we need to balance what patients need, mindful of being too accommodating and that it is important to nail down the scope. CC advised that is a key central point, pre-empted by the previous medic AH, with their approach to medicines and that they weren't a diagnostic service where the support was defined and nothing was considered off the NICE guidelines. CC stated that AH was clear about symptom management and provided the example for cardiology and POTS where there were no pathology and AH's approach was that BP can be evened out. CC also raised that other specialists would accept contact from other physicians to support. HW raised the question that if we have all that we need then is there an argument to offer specialist advice to other areas and will patients be seen virtually if they cannot travel. HW also asked if services could be augmented for example if a physio is part time but wants to increase hours, alongside a specialist within the regional service. CC advised that this would be a big move to access all the different services and that this question is resource dependent. CC referred to the pyramid model as an example with ME CFS service in Lothian and SLT who have a wait time of almost 1 year but after recent discussions are now exploring whether some patients could be seen in different areas and the label is the function and not the condition. HxC advised that there could be a phased approach to the service, recognising that we all have community OT, PT, nursing, GP and what we lack is a medic or experienced AHP consultant and the role of psychology as a pool of experts. HxC highlighted that we are starting from scratch and can do things differently with a bit of flex focusing on patient's wants and needs, widening in some specialist services. PW agreed there could be a phased approach, phase 1 and 2 with core services maintaining ownership of specialist services. PW highlighted it is symptom management in Borders, with 1 OT specialist type role, managing people and there is a risk with a big core regional team and that initially people should meet with core services in the first instance. HxC advised that GPs are core and case managers providing support so that the pathway is visible, SLT for example focuses on who needs seen by a specialist. CC added that core competencies are important and valuable and while we have SLT, we may not need this in every Board as a specialised rehab service could provide the skills to manage people with conditions. HxC suggested that the next steps include an SBAR, with the strong input from medics that the services should not be a single medic and that the medical input could be taken forward on a sessional basis, for example across 3 specialist consultants which could include a GP with specialised interest, psychology and a rehab specialist carrying out 5 sessions, 3 clinical and 2 sessions supporting clinical leadership and developing pathways working with the 4 Boards around what is needed. HxC advised it would be useful to bring back an SBAR at the next meeting to help progress things and this would also help any updates on FOI requests. HxC indicated there is probably enough information to make a proposal for sessions with 1 consultant or specialist taking the lead. PW agreed this sounded reasonable with the ability to review as we go, planning around demand and capacity as we want to avoid consultants sitting with empty sessions.

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HxC advised we need to recognise the risks at the start and be clear on the medical input while acknowledging that demand is still unknown.

CC advised the meeting with medics was helpful and it was agreed that a junior role would not be appropriate.

HxC added that local discussions had looked at coming together with REAS and it was clear that the pathway would need an experienced consultant level role.

HxC recapped that the previous rehab consultant had left and that AF had agreed to step into this space temporarily but as a test of change, AF could take on the 1 case from Borders that has come in but in a managed way, referring into the MDT space, if agreeable.

CC advised he hoped to hear from AF around this today.

PW advised that there was some merit to testing the pathway as an evolving pathway and as a gentle support at this early stage.

HxC advised that we need to be mindful of floodgates as it is early days and perhaps not GP referral initially but referrals could be received from local services who can escalate.

CC advised that AH and ME CFS principle is that they don't diagnose and there are blood tests and criteria for referral.

HxC summarised an SBAR will be drafted considering a sessional approach with clear proposals and it would be useful at this early stage to have awareness of any specialists who may be interested in delivering sessions, or a GP with specialised interest in other Boards.

PW indicated he was aware of a GP with specialised interest and would drop him a note. HW advised she would speak to the team to discuss any GP interest but not sure there are any with specialist skills in this area.

Action: All to have any relevant conversations in own Boards around specialists interested in sessional approach (All).

Action: SBAR with proposals for medical pathway to be brought to next meeting (CC).

4. **Memorandum of Understanding/Collaboration Agreement (MOU)**

HxC advised that while we had already had a number of meetings and commitment to a regional service it would be useful to have something in writing around clarity of what we have agreed. A MOU had been drafted to cover the period before we launch a fully functioning service when it would then turn into an SLA. HXC ran through the MOU with the group.

PW advised that he was okay with the MOU and HxC advised she would run it past CB as a sense check then we can circulate for signatures with the 4 AHP Directors or get local advice of who needs to sign off.

5. **AOCB**

The next meeting is not until end of June and HxC asked BW to look for space in the first two weeks of June for another meeting to keep things progressing at pace.

Action: BW to plan in another meeting for early June.

Actions:

Carried Forward

- **HxC will seek advice/clarity from CB around the MOU and next steps.** CB is currently on annual leave – HxC will tie in when he returns. (Ongoing)
- **HxC will check with AHP directors around the CHSS meeting request.** FV have a meeting set in diary – any other meetings will be considered following the FV meeting. (Ongoing)
- **BW will add Communication and engagement to next meeting.** As today is a short meeting, comms and engagement will be added for full discussion at the June meeting. (Ongoing)

New

- **Action: All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach (All).**
- **Action: SBAR with proposals for medical pathway to be brought to next meeting (CC).**
- **Action: BW to plan in another meeting for early June (BW).**

Regional Long COVID/ME/CFS Steering Group
Summary notes and Actions
Monday 8th June 2026 11.00 – 12.30

Attendees: Heather Cameron (HxC) (NHSL), Charlie Chung, (CC) (NHSL), Belinda Wilson (BW)(NHSL), Paul Williams (PW) (NHSB), Hazel Webb (HW) (NHS Forth Valley), Amanda Wong (AW) (NHSF), Paul McMenamin (PM)(NHSB.
Apologies: Colin Briggs, (CB) (NHSL), Paul Cameron (PC)(NHSFV.

No.	Item
1.	**Introductions & Apologies**
2.	**Previous meetings notes/actions**

HxC noted that there were no changes at this point to the minutes of the last meeting. Any changes identified, post meeting, can be sent to BW.

HxC summarised progress on previous Actions

- *HxC will seek advice/clarity from CB around the MOU and next steps. CB is currently on annual leave – HxC will tie in when he returns – on agenda. (Ongoing)*
- *HxC will check with AHP directors around the CHSS meeting request. HW has a meeting set in diary – any other meetings will be considered following the FV/CHSS meeting. HW has met with CHSS and they were looking for support for a 6-week management group, there was no next steps or decision making. CC advised he has worked with CHSS for the last few years and has open engagement with them and their therapists support people on the waiting lists but they cannot see people at home. CC advised there are still a lot of long-term conditions that CHSS do not support but they might be willing to take and wondered if something similar to the 4 Boards SLA could be set up with CHSS. HxC asked if they supported Stroke and CC advised it was for Stroke. HxC advised there may be no resources for 3rd sector, whereas previously there was support for Long COVID but it may be valuable to explore what their current offering is. PW agreed that it would be useful to have a conversation so they are also sighted locally around what is happening with the regional service and see what we can co-deliver. HxC acknowledged that it is difficult to develop something regionally with non-recurring funding. CC advised that in the advisory group 5 paper there are considerations around 3rd sector and this would set us up for a conversation. HxC added that if CHSS identify a need then they could go back to Scottish Government with a bid but with our support. CC highlighted that there may be risk of inequity if this isn't across all the UK and was something to be aware of. CC made the group aware of his own position previously on the CHSS Board. HXC also raised for clarity that CB may also be the current Chair on the trustees Board.*
  ACTION: HxC to reach out to CHSS for a conversation and will include HW and CC in the conversation. *(Ongoing)*
- *Communication and engagement to be added to next meeting. (BW) – On agenda (Completed)*
- *All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach (All). PW has reached out to a contact within Borders and is awaiting a response. PW will follow up. HW advised JR has had an early conversation with the GP group. (Ongoing)*
- *SBAR with proposals for medical pathway to be brought to next meeting (CC) – On Agenda (Completed)*
- *Plan in another meeting for early June (BW). (Completed)*

3. **Memorandum of Understanding/Collaboration Agreement (v0.3)**

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HxC updated that this was tabled at the last meeting and this is designed to cover the development and transition period and that when the service goes live, likely through a soft launch then there will be a formal SLA. HxC has shared the draft MOU with CB but he has been on leave so no comments back yet. PW advised it seems a standard MOU and HW advised there were no concerns. HxC would check that AW also happy to sign. HxC advised that once it was sense checked with CB then we would circulate for signatures.

Action: HxC to sense check with CB and BW will send on MOU for signatures.

4. **Recruitment Update**

HxC advised that the psychology post has been signed off at the local governance meeting and would be heading to job evaluation. PW raised that given where we are in the timeline, there may be an underspend. HxC agreed and raised the question around who is already in this space that could provide additional sessions in the short term and there may be value in someone working with CC to help take forward the model. PW advised that if there was a clinical need for this, it would be easy to circulate and could advise interested people to get in touch. CC advised that this is a developing clinical area and going forward the job may change, with POTS for example, which is within Forth Valley's service and would be useful to get someone if valuable. CC highlighted that 3 out of 4 Boards have existing access to psychology with the 4th Board still having useful engagement and liaison with psychology but would be useful to consider the psychology leadership in this space. HxC suggested that someone (psychology) could contribute 1 day per week looking at the pathway and how that would work.

BW advised the psychology post that Chris has submitted to the local governance meeting now has to go to local partnership for sign off and then to job evaluation. The medical secretary post was now at job evaluation awaiting review.

Action: CC/BW to pull together a couple of paragraphs that can be circulated to AHP Directors for psychology interest (for clarity - not clinical work but to support development of regional services).

5. **Clinical Sub-group Update & SBAR**

CC advised the clinical subgroup had met to discuss profiling of each service and levels of complexity, for example, there are no known bed bound patient levels in Borders, Forth Valley has POTS pathway and a nurse, Fife do not have anything yet apart from 1 person from pain service as the previous nurse, held in high esteem had not been replaced and they were currently developing services. Lothian had AHPs embedded within the ME/CFS service, SLT and LWSS. The group looked at what was needed, the medical input, psychology input, value of an MDT cross region team and the recent trial case of the referral from Borders that JR from FV and FW were able to input into which demonstrated the value of cross Board working and what an MDT approach could look like. PW advised that it sounded very positive the pulling together of expertise regionally as an MDT approach and that for complex cases, not handing over but having broader professional input as a virtual MDT would be valuable. HW agreed that an MDT approach with a different make up and lots of knowledge would support the team with peer signposting and being able to speak to other clinicians. AW advised that there was a little uncertainty in Fife with the pain service going forward as services are being developed but that they are meeting locally to formalise planning, look at recruitment and it was beginning to take shape with scoping work and some admin support now in place. AW advised that as they move forward then JF and LC might come into this space as AW's deputies. CC advised that if existing psychology steps into the leadership space with extra hours that LC used to work within Lothian ME/CFS for a number of years before Fife.

HC recapped for AW, who joined the meeting at item 4 that so far, we had discussed the MOU would be circulated by BW for signatures once oversight sought with CB.

CC summarised the content of the SBAR that had been drafted with input from discussions with neuropsychiatry, psychology and rehab consultant input, clinical subgroup feedback and incorporated the lived experience group feedback and advisory 5 paper (document embedded

below). PW advised we would need to make a decision around the scope, what is included and what we are delivering and if there are 2 arms, the first being the MDT and symptom management acknowledging there is a second arm with diagnostics and POTS and whether this should be managed within the medical service. CC clarified that there might not be diagnostics and that main conditions would be managed still within primary care. PW advised that for patients and those who self-diagnose, seeking treatment this would support and benefit Borders. HxC advised the paper is helpful and sets the additional work we need to do but there is a small concern around the medical model as described in addition to the MDT as with Pots, for example, which needs some medical management but others might lead on this depending on how they present and rather than calling it a medical model and MDT the role of the medic is within the MDT but holding the diagnosis would be uncomfortable as it's not a diagnostic service and the initial diagnosis is with the GP or pathway as per guidelines and where they are uncertain our MDT can be a way or route to referral to progress. CC agreed that ideally, we need more than a medical model. PW advised that historically the nice guidelines can't deliver all aspects but moving forward we could deliver this and we have a recent case study that could be explored. HxC advised that the case study was a lovely example of a test case showing collective working and not handing over and raises the question of how the regional team can support with patients who are still owned by their own Boards. CC agreed and highlighted that JR had helped with the case study to provide information around saliva and compression management. AW advised it would be useful to capture the trials and pilots as a compendium for others can learn about the approach and useful to document and share.

CC agreed this was a great suggestion and added that the POTS masterclass was recorded for sharing and advised that the advisory paper 5 will help and would be useful to be available nationally.

HxC advised there is a wider education piece and we need to pull these resources together. HW added that the MDT approach with the medical as part of it would be preferred than purely medical model. HW added the FV team were keen to learn and not just hand over but noted it might take a long to get to from where we are to make it work.

CC advised that he was happy to work on this if we recruit a medical colleague for the 12 months basis to look at best progressing this. HxC advised we could look at 1 or 2 medics offering 5 sessions per week for the next 12 months in this interim period as the service develops or 1 medic, if they wanted to do this alone was not a deal breaker but we are aware of the previous medic's feedback around isolation and we would prefer a 2nd medic for sustainability.

PW agreed a 2nd medic would provide a safety net, resilience and offer different clinical perspectives.

HxC advised we would probably look at the rehabilitation medicine job description but would get some advice from medical recruitment around the sessional approach in the interim. CC advised we could also look at other options with expressions of interest and that one medic had reached out to find out more about the service.

ACTION: HxC will pursue the exploration of interim sessions with medic with medical recruitment.

6. **Lived Experience Group**

CC advised we had received around 92 people interested in the lived experience group and we had held four meetings ranging from 15 to 20 attendees in total around 60-70 people and they were hugely valuable. We are currently compiling numbers from each Health Board but some people had ME/CFS for 30 years and some were newer and that key themes had been gathered such as service engagement, service access, transition from children to adult services, education and equity. CC added we have also met people individually and have met with ME action and overall the experiences were very positive and we have captured all the discussion points,

No.	Item
	feedback and suggestions. Next steps are to compile a report to send to people and offer membership of a core group and wider group with alternative ways for people to contribute. **ACTION: CC will amend wording within SBAR to incorporate medical model within MDT.**
7.	**Communication and Engagement – Regional/Local Updates** HxC advised that while we will not be doing a huge launch and will likely be a soft launch internally across 4 Boards, now we are getting closer to formalising plans it is useful to think about the messaging to our own staff. BW added that it was evident at the Nottingham LC Conference that staff were interested and already beginning to ask questions and it was probably a good time to deliver some consistent messaging for local staff, particularly as we have started the lived experience groups and they already know what is happening and could ask local services. Potential avenues could include a newsletter or at a later stage, an online meeting. PW advised it would be useful to have refhelp updated and support clinical members of staff, primary care colleagues and key groups of the public who go to their GP have accurate information and be aware of what's being developed especially if the lived experience group are aware and managing expectations. HW agreed that would be useful and asked if we have articulated how we will refer people to the service yet. HxC advised that it was laid out in the SBAR that the starting point is the MDT referral by local services so that they are there to offer support and GPs cannot bypass. HxC added we will need comms for primary care and what are the internal services within the Board. CC advised that with the Lothian medic, we had the referral pathway separate to ME CFS as they only had 1 person to triage. HxC advised we did also receive direct GP referrals and that we will have to have a conversation around what's pragmatic to support and be flexible and accept the odd one that comes through. CC added that for referral to ME/CFS the GPs have to do the pre work around diagnosis and tests before referral. HxC advised there is a need for a clear communication plan and we will re-visit this soon but that in the meantime we could do a brief 1-page update around the intent of a regional MDT service supporting local Boards and we will bring a draft to the next meeting for sharing then with local staff. **ACTION: BW to draft a 1-page briefing document to support staff engagement around the regional service.**
8.	**AOB** HW advised that she and PC would be giving apologies for the next meeting as they were both on leave.

Actions:

- *HxC will seek advice/clarity from CB around the MOU and next steps.*
  CB is currently on annual leave – HxC will tie in when he returns. BW will circulate MOU once CB has oversight for signatures (Ongoing)
- *HxC to reach out to CHSS for a conversation and will include HW and CC in the conversation. (Ongoing)*
- *All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach (All). PW has reached out to a contact within Borders and is awaiting a response. PW will follow up. HW advised JR has had an early conversation with the GP group. (Ongoing)*
- CC/BW to pull together a couple of paragraphs that can be circulated to AHP Directors for psychologists' interest (for clarity - not clinical work but to support development of regional services).
- HxC will pursue the exploration of interim sessions with medic with medical recruitment.
- CC will amend wording within SBAR to incorporate medical model within MDT.
- BW to draft a 1-page briefing document to support staff engagement around the regional service.

Regional Long COVID/ME/CFS Steering Group
Summary notes and Actions
Monday 20th July 2026 1.00 – 2.30 pm

Attendees: Heather Cameron (HxC), Charlie Chung, (CC), Belinda Wilson (BW), Hazel Webb (HW), Jacqueline Fearn (JF).
Apologies: Colin Briggs, (CB), Paul Cameron (PC), Amanda Wong (AW), Paul Williams (PW), Paul McMenamin (PM)

No.	Item

1. **Introductions & Apologies**

HxC welcomed JF to the group.

2. **Previous meetings notes/actions**

CC raised that there was 1 minor amendment to the minutes. BW advised this would be amended. HxC noted that there were no additional changes at this point to the minutes of the last meeting.

HxC summarised progress on previous Actions

- *HxC will seek advice/clarity from CB around the MOU and next steps. CB is currently on annual leave – HxC will tie in when he returns. BW will circulate MOU once CB has oversight for signatures. BW confirmed that we are only waiting on 1 signed paper from AW (Ongoing)*
- *HxC to reach out to CHSS for a conversation and will include HW and CC in the conversation. (Ongoing)*
- *All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach (All). PW has reached out to a contact within Borders and is awaiting a response. PW will follow up. HW advised JR has had an early conversation with the GP group. Update covered as part of agenda. (Ongoing)*
- *CC/BW to pull together a couple of paragraphs that can be circulated to AHP Directors for psychologists' interest (for clarity - not clinical work but to support development of regional services). BW confirmed this had been drafted and circulated as part of the papers. JF advised that they weren't sure around the funding and perhaps this could be clarified. HxC advised that the original bid was for an 8a psychology post within the regional service and this was amended to an 8b and there was the opportunity for someone to work with CC to help develop what the role will look like. HxC confirmed there would be financial backfill and we could amend the paragraph for clarity and recirculate. JF suggested we wait until after the psychology meeting in case any further updates are discussed. CC/JF will take to the psychology meeting and BW will amend as necessary and recirculate to AHP Directors (Ongoing).*
- *HxC will pursue the exploration of sessional recruitment with medic with medical recruitment. HxC has had conversations locally around what is possible and will progress further with medical recruitment formally (Ongoing).*
- *CC will amend wording within SBAR to incorporate medical model within MDT. CC has updated the SBAR (Completed)*
- *BW to draft a 1-page briefing document to support staff engagement around the regional service – on agenda (completed).*

3. **Recruitment Update**

HxC advised in addition to the psychology post, the regional medical secretary post was progressing. BW confirmed this was at job evaluation and the panel had met to discuss, had come back with questions and these had been submitted and we were now waiting for the outcome. HxC advised in terms of medical input we have debated how much is needed, whether it is a rehab specialist, GP with specialist interest in LTC and that it was useful to look at offering

on a sessional basis with 2 or 3 medics. HxC had spoken to the recruitment team in Lothian and it is within the art of the possible, but we now need to look at who can be on panels for external recruitment, adding some complexity but HxC hope to have more information by the next meeting.

HxC advised we have had medical input in the Lothian model for the last year however the more recent consultant will be retiring in next few months which will leave an internal challenge for Lothian as their post may not be replaced within neuro rehab, this potentially also raises a capacity issue. JF asked what the full makeup of the regional service would be, whether it would include medic, psychology and any AHP staff?

HxC advised in addition to the medical and psychology posts, CC is in an AHP consultant post and has been involved locally and nationally and that during his secondment for the next 12 months this will involve looking at work from an AHP perspective and help inform decisions around that post and role. JF asked if the regional team would be a small cohort dealing with more challenging and complex cases, with a multi professional approach, bringing in extra layers of expertise, a tiny team but centralised expertise, providing complex advice for local teams. HxC agreed that was a good summary of the vision.

4. **Clinical Sub-group update & SBAR**

CC summarise the background of the clinical sub-group, meeting monthly to look at the operational aspects of the regional service. CC advised more recently the group had been looking at where the regional pathway and MDT will fit into other pathways. CC acknowledged there is a risk of volume outweighing the need but not everyone needs to see the regional team and the group have been looking at what is available locally, with awareness that if other services are busy, we cannot add more. There are planned upcoming conversations around this in the group, particularly looking at where people fall between the gaps when what they need isn't condition specific and what we can manage. CC anticipates we could see a high proportion of people with orthostatic intolerance and PoTS that may hinder access to each other and it was important to look at how patients access the wider range of services. HxC advised this could be a potential model for the way LTCs access services in a timely way and had received positive comments from colleagues in neuro psychiatry that we are thinking about this, trying to do the right thing and genuinely not just take something off the shelf although this does present challenges that we are now experiencing.

5. **Lived Experience group (Education & Report)**

Education

CC highlighted that education was a key theme in the report and recent conversations, looking at the levels of education, ongoing education for GPs and around who and how to refer, and raising awareness of conditions in other services as people had spoken about their conditions not being recognised when treated in other parts of the system. CC advised the Bath service programme would begin soon with 6 sessions for us delivered by those with higher level expertise and that the PoTS masterclass and Nottingham conference had both been very valuable. CC added that the national advisory paper 5 relates strongly with education and it would be useful to start planning how we educate GPs on the referral mechanism and assessment pathways and that we need to revisit this rather than deliver one off with a plan or programme of engagement. CC added it could be valuable looking at what is mandatory and what exists that we can link to.

HxC advised there would be value in setting up a formal education sub-group, looking at what we have, where the gaps and challenges are and looking at sustainability and not necessarily educating our expert staff groups but the wider and supporting groups and consider how we reach them in a consistent way. HxC added having a group or a presence for staff to ask questions to or to help gain reassurance with would be helpful, having two distinct sub-groups. CC added that would be a great idea and that a group could have a list of resources ready to link in with other

services, modules and perhaps higher education involvement. CC advised the national paper 5 included undergraduate education and core competencies.

JF advised they had set up an education sub-group in pain management and the model works well with different levels such as level 1 awareness, level 2 information for MDT approach, level 3 for specialists working in services. HW agreed this would be helpful with lots of learning. HxC asked CC to set up an education sub-group.

Report

BW advised the circulated report was the combined outputs of the four lived experience group meetings and this report had been sent out to the people who attended the groups for their additional comments up to 24th July. The report will then be finalised and re-circulated. BW advised the comments were very positive and when presented at the sub-group, they had confirmed the themes were in line with what was being seen in daily clinics. BW advised that CC and BW attended cuppa in Falkirk, the peer support group for Long Covid and similar themes were raised at this group. CC added that it was interesting to hear the differing opinions of the group in Falkirk and that was consistent with the lived experience groups feedback and comments. CC advised there had also been another meeting with ME Action and they advised the themes were consistent which gave us some confidence in what was captured.

HxC advised that listening to the population is important in shaping our services and we have considered a patient rep on this group to ensure our approach is meaningful and that having a patient feedback loop is important, as patients can be frustrated with progress.

CC advised the group he had received a question around governance of lived experience groups from a colleague in another Board area whose request for set up had been rejected and wondered if anyone had any knowledge of this. BW advised that the governance question had been brought up by IG as a result of a Datix recently, but there is no formal path or governance arrangements in place but we have fully engaged with and have been supported by the Public Engagement manager and have followed the appropriate guidelines and policy.

Action: CC to set up education sub-group, look for potential volunteers and chair of group.

6. **Communication and Engagement (Newsletter and 3rd sector engagement)**

BW advised the draft newsletter had been circulated to the sub-group and out with the papers. HxC advised circulating to the AHP Directors for wider distribution.

CC advised that in terms of 3rd sector engagement we were already engaged with CHSS, ME Action but could consider contact with Action for Lyme disease and potentially we need a plan for what engagement looks like but still need to ruminate around the best way forward. HxC added we could invite the groups to talk about where we are in our journey but be clear we are not commissioning services and manage expectations, allowing space to discuss what they offer. CC advised that Lyme disease may be a campaign group rather than offering services, but it was useful to know that a medic could be partially funded by ME Action and in the recent Borders test case, the patient could have been funded and came through ME Action. HxC advised it would be useful to scope out and gather information from all Board services and HSCP areas however this could be challenging given the number of different HSCPs but worth seeing what they do. JF agreed it would be useful to scope out what is available in different areas and asked if the idea was to utilise 3rd sector as part of low-level support in the recommendations? HxC advised it was a complex landscape, particularly as in Lothian we have 4 HSCP areas with different models. HxC suggested that we consider a shared conversation in the near future when we are further down the line with our developments. HxC added that 3rd sector were involved in the national sub-group 5 and the SG aim to publish their programme for government, after the first 100 days, in September so we can review at this point. CC advised that in the meantime, he will bring for discussion at clinical sub-group and try to find out what is available.

Action: CC to discuss what is available from 3rd sector at clinical sub-group.

No.	Item

7.

Frequency of Meetings going forward

HxC advised it is a good point to review and refresh and might be useful for 1 further meeting at the end of August and we will review again at this point.

Action: BW to liaise with HV around availability for next meeting.

8. **AOB**

CC advised he had been approached by a GP/Medic from Borders who was involved in rapid cancer care and a local GP and was the person that ME Action go to and send patients for medic advice. CC had discussed the regional service and posts, but the colleague had advised they would not have capacity at this time to consider applying. CC advised he was a great contact to have access to. HxC advised that the colleague could be helpful in negotiating in the GP space or helpful in the education space.

Actions:

- *BW to follow up with AW for the signed MOU.*
- *HxC to reach out to CHSS for a conversation and will include HW and CC in the conversation. (Ongoing)*
- *All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach (All – Ongoing)*
- CC/JF to take the psychology paragraphs to the psychology meeting for discussion and any other updates and BW will recirculate to AHP Directors for any psychologists' interest (for clarity - not clinical work but to support development of regional services).
- HxC will pursue the exploration of interim sessions with medic with medical recruitment (Ongoing).
- CC to set up education sub-group, look for potential volunteers and Chair of group.
- CC to discuss what is available from 3rd sector at clinical sub-group.
- BW to liaise with HV around availability for next meeting.

Regional Long COVID/ME/CFS Steering Group
Summary notes and Actions
Monday 24th August 2026 10.00 – 11.30 am

Attendees: Charlie Chung, (CC), Belinda Wilson (BW), Hazel Webb (HW), Jacqueline Fearn (JF), Paul Williams (PW).
Apologies: Colin Briggs, (CB), Paul Cameron (PC), Amanda Wong (AW), Paul McMenamin (PM), Heather Cameron (HxC

No.	Item

1. **Introductions & Apologies**

CC welcomed JF to the group, PW made introductions to JF.

2. **Previous meetings notes/actions**

CC noted that there were no amendments to the minutes of the last meeting.

CC summarised progress on previous Actions

- *BW to follow up with AW for the signed MOU. BW confirmed a follow up email, copying in JF, has been sent and we were now just awaiting the signed document from AW. (Ongoing)*
- *HxC to reach out to CHSS for a conversation and will include HW and CC in the conversation. CC confirmed a meeting has been set up with CT from CHSS (Ongoing)*
- *All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach. CC confirmed RK from Borders had reached out and while he does not have capacity for the role is happy to link in and provide some clinical feedback on developments if needed. (All – Ongoing)*
- *CC/JF to take the psychology paragraphs to the psychology meeting for discussion and any other updates and BW will recirculate to AHP Directors for any psychologists' interest (for clarity - not clinical work but to support development of regional services). (Completed)*
- *HxC will pursue the exploration of interim sessions with medic with medical recruitment (On agenda - Ongoing).*
- *CC to set up education sub-group, look for potential volunteers and Chair of group. (On agenda).*
- *CC to discuss what is available from 3rd sector at clinical sub-group. CC confirmed it was mainly campaign groups active in this area however CHSS meeting could be an active partner in future services and would be discussed at future meeting. (Complete).*
- *BW to liaise with HV around availability for next meeting. (Complete)*

3. **Recruitment Update**

Medical Post

CC advised that HxC had explored other avenues and to move things on, is considering using the bank as there is a couple of people, external to the regional Boards, who might be interested. CC advised that the current medic in Lothian, AF, was retiring and his position may not be replaced and conversations are ongoing with general management, but for those interested the bank option route might be quicker.

P/T Psychology post

CC advised 4 people had shown interest in the post and CC has met to provide more information. A recent change however is that the post banding cannot be advertised at 8b and will need to be at the person's current job grade. CC will be contacting those interested to advise of this and will then take forward a process for those still interested. JF advised that the expertise required for the role would be more likely to be at band 8b, as anything lower than this band would be newly qualified or a junior psychologist. PW agreed with JF around the function and practical knowledge of an 8b. PW acknowledged that recruitment is extremely challenging and there are concerns on

No.	Item

the medical side but a work around would be great in the interim period to get things moving. HW asked if this related to the 1 day a week post and agreed that we really need an 8b if the 8a would be fairly junior. CC advised that HxC had suggested that for the recruitment process, each person could submit a paragraph of their view of the work and what they would do.

CC advised there was a change to the 0.5 psychology post as originally there was management attachment on the job description. After recent meetings with CH and the other Board psychologists, it was agreed to take away the management element for the regional service and the job description will progress to evaluation without the management element.

Medical Reception post

BW advised this was still at job evaluation and their response had been delayed due to annual leave however they had indicated a decision was imminent.

4. **Clinical Sub-group Update & Service specifications**

CC updated the recent group had discussed the details and delivery of the service specifications outlined in the national advisory paper and what is coming from NICE.

CC shared a set of slides outlining each Board's current services, advising that feedback from the clinical sub-group will inform the final slides. CC clarified that in NHS Fife, the consultant level psychologist post was band 8c and the principal clinical post was band 8b.

The group discussed having an agreed triage model, front loading the model to do initial triage, to avoid people on long waiting lists finding out latterly that they don't need that service and reduce barriers to accessing services.

The group discussed the benefits and challenges highlighted on the slides, considering how to deliver certain services such as PoTS which currently is addressed in NHS FV but not in other Boards services. It was highlighted that feedback from the sub-group focused on education, such as the Bath workshops and making conversations around the condition everyone's business.

PW asked if there was a timeline mapped out for delivery of the service. CC advised that this was essential and a proposal will be developed with recruitment.

Action: Develop proposed timeline trajectory for service delivery and bring back to next meeting.

5. **Lived Experience group**

BW advised that the next dates for the group were being planned in for late September/early October for the core group and in December for the wider group. Engagement for the groups is high and there are around 30 people interested in joining the core groups so there may need to be two groups initially. It is expected that the next meetings focus on the theme of education which was key from the introductory meetings and something that we could get started on quite easily. PW advised he had received interest for the group and would send this in to BW/CC.

6. **Education Update**

CC advised that the first date for the education sub-group was planned in and would be looking at Board areas and the national picture, also linking in with the national peer group that still exists.

7. **Frequency of Meetings going forward**

The group agreed that it was important to still meet frequently at this stage, due to the high level of activity but there was value moving to 6 weeks. CC advised if needed, updates could be shared electronically within the 6-week period.

No.	Item
	Action: Meetings to be set up 6 weekly. (BW)
8.	**AOB** PW asked if there was any update on the recent patient from the Borders that AF had agreed to see. CC advised that FW had last updated him last week to advise she had been in touch with AF and CC had asked for an update if there was no news by Friday last week. PW asked if he could be kept in the loop as he was receiving more FOI's and this case would provide some reassurance in terms of what was happening, and the regional developments.

Actions:

Ongoing

- *BW to follow up with AW for the signed MOU (Ongoing – await signed MOU).*
- *HxC to reach out to CHSS for a conversation and will include HW and CC in the conversation. CC has contacted for meeting. (Ongoing)*
- *All to have any relevant conversations in own Boards around specialists interested in regional medical service with sessional approach (All – Ongoing)*
- HxC will pursue the exploration of interim sessions with medic with medical recruitment – possibility of bank sessions (Ongoing).

New

- ***Develop proposed timeline trajectory for service delivery and bring back to next meeting (CC/BW).***
- ***Develop proposed timeline trajectory for service delivery and bring back to next meeting.***
- ***Meetings to be set up 6 weekly. (BW)***

Clinical Sub-group

No.	Meeting Date	Action	Owner	Due Date	Status	Updates
1	20.4.26	CC to send out group 5 paper	CC	18.5.26	Complete	this has been sent out to all and JR shared the most up to date paper.
2	8.1.26	HC/BW to amend draft TOR & recirculate.	HC/BW	30.3.26	Complete	19.3.26 TOR accepted with amendment of Board on membership table. 4.2.26 HC/BW to update the TOR to clarify membership roles and responsibilities.
3	8.1.26	Plan additional monthly meetings in diaries.	BW	31.1.26	Complete	
2	20.4.26	JR to send details of informal group	JR	18.5.26	Complete	JR has sent on details of lived experience group, next meeting on 26th June. JR added there was a national information group and she would share details of this
3	20.4.26	BW to draft TOR and share with group	BW	18.5.26	Complete	TOR has been drafted and shared.
4	20.4.26	BW to populate proforma and share with group	BW	18.5.26	Complete	Service details collated and captured by CC slides for discussion at meeting.
7	8.1.26	HC will have conversation with medical consultant around supporting clinical model.	HC	19.3.26	Complete	19.3.26 HxC has met with AH for feedback and potential inclusion where possible to help develop and input to the new regional pathway.
5	20.4.26	BW will arrange further meeting dates	BW	18.5.26	Complete	New dates in calendar.
6	18.5.26	JR to look at sending videos at 6-month mark to patients out to group	JR	08.6.26	Open	
7	18.5.26	JR will send details of next national group	JR	08.6.26	Complete	
8	08.6.26	Discuss & further explore the need for regional psychology lead outwith	CC	29.6.26	Complete	CC has held a meeting with psychology reps from regional Boards.
9	08.6.26	Share the regional steering group papers with the clinical group	BW	29.6.26	Complete	
13	19.3.26	HW to be added to all future meetings	BW	30.3.26	Complete	HW added to all remaining diary dates.
14	19.3.26	Change name of contact email box to LTC	BW	28.4.26	Complete	
15	19.3.26	Circulate flyer for LE group to clinical subgroup	BW	28.4.26	Complete	
16	28.4.26	•HxC will seek advice/clarity from CB around the MOU and next steps	HxC	11.5.26	Complete	
10	08.6.26	Final comments on SBAR to be sent to CC by 26th June	All	29.6.26	Complete	
18	28.4.26	•BW will add Communication and engagement to to next meeting	HxC	11.5.26	Complete	
19	28.4.26	CC/BW will ask subgroup reps for any visual diagrams of their current services.	CC	11.5.26	Complete	CC has incorporated current services into visual slides that have been presented within the clinical sub-groups and steering group.
11	08.6.26	Share Lothian adaptive equipment list and costs with RS	BW	29.6.26	Complete	
21	11.5.26	SBAR with proposals for medical pathway to be brought to next meeting (CC).	CC	8.6.26	Complete	CC has brought updated proposals in SBAR to group.
22	11.5.26	BW to plan in another meeting for early June	BW	8.6.26	Complete	
23	8.6.26	•CC/BW to pull together a couple of paragraphs that can be circulated to AHP Directors for psychologists' interest (for clarity - not clinical work but to support development of regional services).	BW	8.6.26	Complete	CC has received a few interested parties.
12	29.6.26	All to think about next steps are with the medical model/PoTS and what the risks are for the service	All	10.8.26	In Progress	Will capture risks as they arise during discussions. Emerging risk log created to capture.
25	8.6.26	•CC will amend wording within SBAR to incorporate medical model within MDT	CC	20.7.26	Complete	
26	8.6.26	BW to draft a 1-page briefing document to support staff engagement around the regional service.	BW	20.7.26	Complete	
13	29.6.26	BW will circulate briefing note again to reps after signing off for local distribution	BW	10.8.26	Complete	
28	20.7.26	•CC/JF to take the psychology paragraphs to the psychology meeting for discussion and any other updates and BW will recirculate to AHP Directors for any psychologists' interest (for clarity - not clinical work but to support development of regional services).	BW	24.8.26	Complete	
14	29.6.26	As part of larger comms plan, consider set up of regional page in public domain for all to access	All	10.8.26	In Progress	Captured for future enagagement and communication plan
15	10.8.26	All to share current referral forms and send to BW for collation	All	21.9.26	Open	
31	20.7.26	•BW to liaise with HV around availability for next meeting	BW	24.8.26	Complete	
16	10.8.26	JR to share GP talk with the group	JR	21.9.26	In Progress	
17	10.8.26	Names for Bath sessions to be sent to BW	All	21.9.26	Open	
18	10.8.26	CC/BW to invite LWSS to one of the next meetings	BW/CC	21.9.26	In Progress	BW has extended invite and CC has invited SM to future meetings as Lothian service rep
19	10.8.26	CC to consider delivery of workshop around cognitive rehabilitation	CC	21.9.26	Open	
20	10.8.26	JR to send psychology referral numbers to BW who will circulate to the group	JR	21.9.26	Open	
21	10.8.26	BW to share agenda/papers with this group	BW	21.9.26	Complete	
22	21.9.26					
23	21.9.26					

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31	20.7.26	•BW to liaise with HV around availability for next meeting	BW	24.8.26	Complete	
21	10.8.26	BW to share agenda/papers with this group	BW	21.9.26	Complete	

Regional Long Covid/ME CFS Clinical Sub-group

Draft Minutes – 20.4.26

Regional Long COVID/ME/CFS Clinical Sub-group Meeting

Tuesday 20th April 2026 15.00-16.00

Attendees: Charlie Chung (CC) NHS Lothian; Fiona Wardell (FW) NHS Borders; Jennifer Ritchie (JR) NHS Forth Valley; Rosalyn Standish (RS) NHS Fife; Belinda Wilson (BW).

No.	Item	Owner	Papers
1.	**Welcome, Introductions & Apologies**	CC/All	
2.	**Board Service Overview & Proforma**	CC/All	
3.	**Draft Terms of Reference**	All	
4.	**PPI**	CC/All	
5.	**Next steps/Work priorities**	All	
6.	**AOB**	All	

1. **Welcome, Introductions and Apologies**

   Charlie welcomed all to the meeting and provided some background context: AHP directors have regional service planning as part of portfolio and there have already been a series of monthly steering group meetings and open conversations around what the regional model will look like. The Long-term conditions advisory group were set to publish recommendations however this has been extended and split into 6 advisory groups with their own recommendations. CC was on advisory group 5 focusing on ME CFS and a detailed paper has been produced with outcomes. CC will send this on to people.
   In terms of recruitment, which may involve a medical consultant, rehab consultant or something else, Lothian's current rehab consultant has left and there is an interim post holder in place. It is anticipated that there could be medic and psychology input as part of the regional service. BW will be providing programme and administrative support and CC will support delivery of the regional model and his role backfilled for 12 months.

2. **Board Service Overview**

   NHS Borders (FW)

   There is an OT providing clinical leadership within the service. Since widening of scope to primary care referrals have increased. Role involves travel to smaller hospitals and will meet patients at home with an example given of a short walk and talk review with a patient that morning.
   There is a good relationship with the pain service. FW started in post March '23, with limited pathway funding. They have links to physio, pain team and triage is carried out for some patients to go to the wellbeing service for tier 2 patients where FW has trained up a nurse, given workbooks for those with less acute symptoms. 90% of referrals come from GPs with some from hospital outpatient service. There are 4 localities and different referral contacts within the 4 locations. There is an offer to train clinicians with a specialist interest in LC, there is 1 OT in East (Duns, Eyemouth) supporting less

complex patients. Patients are responded to within 7 days by phone and a face-to-face session is offered for the 1st session. All appointments have been face-to-face bar 2, with the 1st near me patient the other day. 4-6 weeks for follow up. There are thoughts GPs are not recognising symptoms until quite late but they have been round GPs and reminding them the service exists. There was an upturn when opened to ME CFS and numbers doubled. Dietetics and physio are services they struggle to access and referrals are bounced back to wellbeing service recommended. Physio waiting list is long. They haven't needed clinical psychology staff group. Potentially have a medic would be beneficial, especially is part POTS, would be good to have more clinical expertise.
CC added it would be useful to get thoughts from directors around AHP and nurse input.

NHS Forth Valley (JR)

JR and a physio triage all patients. All first visits are in person and they use each other's knowledge. Referrals are made as required to psychology, support here is 2 days per week. There is a steady stream of patients seen including ME/CFS, LC, POTS and other conditions such as chronic Lyme. They see all patients under 12 weeks with some exceptions with prison patients due to the lengthy process. FV have 5% of the Scottish population but over 25% of the prison population. They provide an education programme for prisons involving a visit with nursing staff, LC workbooks and after the first visit will do an education session then they can manage patients. It is unlikely that patients would be referred to a regional psychology service. Currently there is a paper around transfer of patients from primary care to cardiology to help move patients between services. JR is currently doing a non-medical prescriber course to help move things forward for patients.
They have a lived experience group and make connections with other conditions.
If opening to ME CFS, POTS then this may double the remit. Currently cardiology picks up patients, diagnose and then send back to GP for management however post diagnosis referral they will not normally see POTS patients if asked. It is a struggle with POTS to find a GP. GP assessment guide is used however despite having 1 hour with patients around 45 minutes is spent with referrals administration. Referrals received can be patchy with drug list and history missing and triaging is difficult. As the NSS group has finished, there is an informal operational group, meeting monthly for discussion, chat, pooling knowledge. JR will send on information about this to people.
They work closely with pain service. For group sessions, they have videos from services, such as dietetics. They do not include paediatrics.
CC advised that within the regional service this will be adults and initially within Lothian CYP did not think they would have the numbers but there are arising complexities for CYP especially with the impact of Covid itself and with neurodiversity.

NHS Fife (RS)

LC funding was shared amongst services including psychology, IPAS, Inter care team and pain service (PT and OT). Referrals are made if there is any pain and patients seen within 12 weeks. Other parts of the service are opened up if the patient has elements of pain. RS is part of the advisory group 6 overseeing developments. Post Covid there is an MDT approach including nurses. Historically there was a service but they have struggled to recruit to this post over the last 2 years. MDT approach is the plan going forward. There is a separate service if there is an element of pain and reviews carried out to determine what service is most appropriate for these patients.

NHS Lothian (CC)

ME/CFS service was already in place over the past 12/13 years, supported by psychology with PT and links with pain PT. In the first year of funding, there was a partnership with CHSS for a digital LC pathway where GPs referred patients into a digital portal, answered a series of questions and tailored talks or slides were delivered as part of a self-management approach. CHSS pulled out last year and the pathway stopped.

Core services involve ME CFS with 2 OTs, PT, Psychology, SLT (1/2 post) and links with respiratory teams and work support who offer support returning to work and for companies with employees under 250. Recently brought in was a rehab medical consultant and services are delivered via an MDT approach.

There was concern opening the medical pathway that floodgates would open with some anxiety initially from ME CFS who were triaging, that patients would be referred to just get to the GP however not all GPs know fully yet about the medical referral option. For POTS, cardiology is not keen as it is out of their remit but with the medical consultant they are open to joint working. The medic or services do not diagnose; the GP does this and there are strict referral criteria with blood tests. The guidance and pathways are on REFHELP, who were met with recently to discuss creation of a video and they are waiting on us coming back to them with information. We are missing dieticians but this could be a conversation for further ahead particularly as budgets aren't yet finalised. Services are delivered remotely, using near me, group sessions and there is support from OT with adaptives.

3. **Draft Terms of Reference**

   BW advised a draft paper will be developed with remit and asked the group how often to meet. It was suggested monthly or sooner as appropriate. CC advised would be useful to include membership and the possibility of others to join with advanced notice if needed.

4. **PPI**

   CC thanks JR for the information around the lived experience group and advised that he and BW will likely attend the meeting on 22nd June.

5. **Next steps**

   CC summarised that the group 5 paper will be shared, we will populate and share the proforma, TOR and we will get further meeting dates in the diary.

6. **AOCB**

   CC advised that it would be useful to have a visual diagram of services similar to the PAICS document to highlight gaps/opportunities and where Boards could support each other. As there is no blueprint, this group will be able to shape what the model looks like. BW added that education could be built in with the opportunity for people to share learning and resources. CC advised that there will shortly be Bath workshops offering specialised topics and these sessions would be offered to the group. CC will share more details once dates are confirmed.

Actions:

1. **CC to send out group 5 paper**
2. **JR to send details of informal group**
3. **BW to draft TOR and share with group**
4. **BW to populate proforma and share with group**
5. **BW will arrange further meeting dates**

Regional Long Covid/ME CFS Clinical Sub-group

Draft Minutes – 18.5.26

Regional Long COVID/ME/CFS Clinical Sub-group Meeting

Monday 18th May 2026 15.00-16.00

Attendees: Charlie Chung (CC) NHS Lothian; Fiona Wardell (FW) NHS Borders; Jennifer Ritchie (JR) NHS Forth Valley; Nicola Gray (NG) NHS Forth Valley; Rosalyn Standish (RS) NHS Fife; Belinda Wilson (BW).

No.	Item	Owner	Papers
1.	**Welcome, Introductions & Apologies**	CC/All	
2.	**Previous Minutes/actions**	CC/All	
3.	**Update from recent meetings**	CC	
4.	**Regional Lived Experience Group**	BW	
5.	**Visual service mapping and discussion points**	CC	
6.	**AOB**	All	

1. **Welcome, Introductions and Apologies**
   Charlie welcomed all to the meeting and to Nicola who was joining us for the first time.

2. **Previous Minutes/Actions**

   The previous minutes were accepted with no amendments but if there are any amendments after the meeting, these can be sent to BW.

   Previous actions:
   - **CC to send out group 5 paper –** this has been sent out to all and JR shared the most up to date paper. (Completed)
   - **JR to send details of informal group** – JR has sent on details of lived experience group, next meeting on 26th June. JR added there was a national information group and she would share details of this (In progress).
   - **BW to draft TOR and share with group –** TOR has been drafted – BW will share final version and we will review as necessary. (In progress)
   - **BW to populate proforma and share with group –** BW has developed proforma and will continue to capture information as we go along on each service area and share the final version. (In progress)
   - **BW will arrange further meeting dates –** dates in diary for next few months. (Completed).

3. **Update from recent meetings**

   CC advised that he had recently met with the past and present medics, along with neuro psychiatry colleagues to help understand challenges and what might work in a regional service.

CC provide a recap from the recent steering group meeting with the AHP Directors. At that meeting it was discussed how we would drive things forward with the development of the regional service and the recruitment of the roles to support the service, the administrative medical secretary role and the psychology post. JR added that if the leads are meeting and coming back with questions, then that will also provide NG with an understanding and asked if there are plans around communication for staff. CC confirmed a robust communication plan will be needed as part of the regional work activities.

4. **Regional Lived Experience Group**

BW advised that we had received a huge response to the flyer for the lived experience group across four Board areas and thanked people for sharing. Due to the large numbers, it had been agreed that we would offer 4 online meetings which would be introductory meetings, aiming to tell people what the plans were for the regional service development and to obtain thoughts and feedback from people around how they would like the groups to work and move forward. BW advised she would let people know the dates of the meetings and they were very welcome to join.
CC added that we will allow people during the meetings time and space to talk about their experiences and consider other request such as should we allow carers to be part of the group as their experience is also very valuable.

Action: BW to share dates of meetings with people.

5. **Visual service mapping and discussion points**

CC took the group through a presentation and summary of current Board service provision and service gaps, including a summary of what was recommended as part of the advisory group 5 paper around what professions should be included as a minimum and what other professions could be included such as nursing, dietetics and while some professions aren't named this has been left open.
To support current learning, CC has set up and paid for specialist workshops – 6 sessions and all four Board areas staff will be invited to the online sessions. CC invited the group for comments on the visual service mapping and regional service development.

JR advised that keeping the day to day locally would be useful, making referrals only when stuck taking it through MDT.
CC added that it would be most risk free, as the regional service badged as an MDT.
JR advised that diagnosis should be considered and careful to avoid this, as it takes so long to do this.
NG asked who would be able to refer into the regional service and added it would be good to have a network.
CC advised this will shape it and ideally MDT referral where patients will come in from the area team.
FW agreed with referrals from local Board and only a medical focus. With referrals to triage, there can be uncertainty around diagnosis and it is up to GPs to manage as they will be the default, and useful to remind GPs that it is important to triage locally.
RS agreed it would be helpful to triage locally before they are referred on if people want another opinion and that an MDT approach first would add reassurance for people.
CC advised that there are multiple aspects why referrals are valuable with an MDT approach and that diagnosis is done before referral and this was the approach with the recent medical consultant who provided medical oversight and a listening ear which was valuable to those who felt not acknowledged or believed. There is however a risk of anxiety from an MDT approach if there is no engagement with other services.

NG asked if there will be a regular MDT with medical, psychology and what other people might be employed?
CC advised there are 2 professions proposed but with space and capacity considered and different models, the professions might not need to be full time.
FW advised that there is a clinical psychology team in Borders, a well-resourced team and has not felt that people are missing out as GPs are able to refer and patients are satisfied with what they are receiving, adding that psychology is not just for that patient group.
JR added that in FV, they are referring 25-30% of patients to psychology and that NG could not support any more and if numbers double, it would be good to have MDT capacity but it would be useful for NG to speak to someone.
CC advised that having a regular psychology post is still attractive as pain can be only temporary. CC added an MDT approach and not standalone taking referrals would be preferable with medics strongly supportive of an MDT. CC asked what people would do if they don't have these services. JR advised they can refer to community services or related services and have links with teams dependant on patient's needs. NG added they can refer to on of the other rehab services. JR advised that they can talk to other services about patients with no issues but there are challenges with writing to GPs especially for prescriptions as GPs make decisions and we won't know what those are until we next see the patient. It would be useful to be able to speak to someone sooner. CC asked FW what they do for physio. FW advised they have a lot of goodwill with physio colleagues and one colleague has a special interest, there is also another PT that sees patients but it is not a quick route. FW added it would be helpful to have a central point/website with good LC physio links. FW asked how long patients wait to be seen in FV. JR advised that all patients are contacted within 12 weeks by either JR or the PT then referred to NG if needed but added that dieticians won't see patients in FV but have special videos to core topics for them. CC advised that it's clear waiting times are dependant on individual circumstances, and that SLT for example can take up to a year. CC added that SLT are in conversation around how they can address this, thinking about the pyramid model but there also challenges with access to dietetics. CC noted it was useful however that the steering group was made up of AHP Directors and we could take this to them and open up discussion around other services. CC advised that there was a wait for referral to community OT in Lothian and a challenge. JR advised that they have an 8-week group session with no more than 10 people and when questions were submitted they were able to play a video back from dietetics which was helpful. It would be useful to set up regionally so patients can go through these videos, even better would be setting up as a once for Scotland approach. JR advised she can look at sending the videos that they provide 6 months after discharge, as part of offer to refresh as they noticed that people were dropping off at the 6-month mark. CC asked who did the videos and JR advised it was SLT, the pain team and that they send these to everyone.

CC outlined that for the medical part of the pathway this could be sessional with two doctors, as part of an MDT approach.
NG shared that the experience of 1 session for MDT, monthly with medic from neurology would be useful to discuss and that people would benefit from all discussions of cases as part of an educational side.
FW advised that she was not yet sure, if this should be GP or consultant and that we need to define what we want our medic to do. It could be someone with a specialist interest able to do naso lean testing, prescribing and have weight with other specialists such as cardiology and that maybe there should be a checklist.
CC advised that JS, in Ireland from an infection specialist background for example, would be an interesting choice.
RS advised that it could be more than 1 person, such as a GP with specialist interest.

JR advised we would need a list of what they would do such as seeing patients physically, virtual MDT.
RS advised that diversifying the pool would also be helpful and could approach an education lead for GP trainees or it could be a rotational GP which might help keep costs down.
JR advised she would discuss further with contacts locally.
CC added there could be the inclusion of a nurse led service, as people could learn from JR for example. JR added that what was clear is that she would not just want to hand off patients and would want to learn from the regional service.
CC advised we will revisit this at the next meeting.

Action: JR to look at sending videos at 6-month mark to patients out to group.

6. **AOCB**

Actions from meeting:

- **BW to share dates of meetings with people.**
- **JR added there was a national information group and she would share details of this.**
- **JR to look at sending videos at 6-month mark to patients out to group.**

Regional Long Covid/ME CFS Clinical Sub-group

Draft Minutes – 29.6.26

Regional Long COVID/ME/CFS Clinical Sub-group Meeting

Monday 29th June 2026 15.00-16.30

Attendees: Charlie Chung (CC) NHS Lothian; Fiona Wardlaw (FW) NHS Borders; Jennifer Ritchie (JR) NHS Forth Valley; Belinda Wilson (BW) NHS Lothian;

Apologies: Rosalyn Standish; Max McKenzie

Item

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1. **Welcome, Introductions and Apologies**
   Charlie welcomed all to the meeting and noted apologies.

   Previous Minutes/Actions

   The previous minutes were accepted. Previous actions:

   - **JR added there was a national information group and would share details of this. (Completed)**
   - **JR to look at sending videos at 6-month mark to patients out to group. (Ongoing)**
   - **Discuss & further explore the need for regional psychology lead outwith meeting (CC) (Ongoing)**
   - **Share the regional steering group papers with the clinical group (BW) (Completed)**
   - **Final comments on SBAR to be sent to CC by 26th June (ALL) (Completed)**
   - **Share Lothian adaptive equipment list and costs with RS (CC/BW) (Completed)**

2. **Updated SBAR**

   SBAR
   CC thanks everyone for their comments on the SBAR and explained that main thing to come back from the steering group was to make an adjustment to it highlighting the
   MDT to be the medical model. CC has also amended based on this group's comments that have come in.
   FW asked if CC had received her comments last week or if these were too late. CC confirmed he had received the comments and they are not late as the SBAR will continue to be updated as we move along as the psychology meeting is being held in July and comments from this meeting will also help inform the SBAR. FW emphasised that she liked the suggestion made by JR around the GP trainee rotational role and this would be a fantastic addition.

3. **PoTS (agenda item 5)**

FW highlighted the other issue is PoTS as Borders does not currently have any interventions or clinicians that would actively do assessments. JR advised that no Boards have someone doing this. CC advised that no Board has everything that is needed and we will be able to call on the AHP directors in supporting development that might involve or connect other services. As an example in Lothian, the PoTS agenda hasn't been addressed as services are focused on managing the fatigue with limited medical management but there is no real pathway for PoTS. CC asked about the assessment of PoTS and any other elements and highlighting that the two physios in Lothian work remotely or do groups so there are no facilities, gym space, tilt table. CC advised that other services at Astley Ainsley may have gym space and it opens up a question around what can be done. FW advised that one of the challenges were already stretched services and that if other colleagues in other services were asked to do assessments that would probably not be welcomed.

JR offered RS a visit at FV to view their services. JR advised they built their model off from Glasgow and Lanarkshire but tweaked it slightly and that their clinic space is only 8 by 6ft and they have a plinth that patients can lie on and they do a NASA lean test and send the results to the GP. JR stated they advise the GP of the results, that are indicative of PoTS to support the GP in any diagnosis. They do not say the patient has PoTS but advises they have a positive assessment for it. JR advised the test itself takes only 15 minutes. JR advised that potentially the regional service would have a virtual MDT where complex tests could be discussed and consensus around PoTS sought. FW agreed this sounded sensible. CC advised that in Lothian there would be similar challenges with services and while there is a bigger core team in Lothian potentially this might mean a change in practice because of the volume. CC highlighted comments brought up around OT where there is nobody that can take up work as they are diagnosis specific but there could be leeway to have conversations around working with patients in their ADLs and not excluding people and these are upcoming conversations.

JR advised that they always see patients face to face for the first appointment and potentially once their situation has been assessed a band 3 could do the NASA lean test and the paperwork. JR highlighted that a lot of clinics send the patients home to do the testing. JR added the test is straightforward but it's the interpretation of it that can be challenging. FW agreed that it was not our role to diagnose but she would like to see how to implement the test and feel confident around carrying these out. JR highlighted the PoTS is a clear diagnosis with heart rate over 120-130 over a baseline but it's the orthostatic intolerance that sits under this that can be challenging to interpret. JR advised the hope would be that these could be discussed as a regional team that helps with support to write to GPS.

CC advised that it would be good to start putting this procedure on paper. CC asked FW if they had a lot of numbers coming through with this presentation. FW advised that they have not but wondered if there might be untapped patients not being identified or referred in the first instance and the general awareness of services is a separate issue.

JR advised everyone that goes to FV gets a NASA lean test as fatigue could be the only symptom but they could have PoTS. JR added 15% have PoTS but probably around70% have orthostatic intolerance. FW advised she is relying on GPS doing tests prior to referral but that what JR is seeing is really good practice and is something to be considered if we are all having a similar approach.

FW will consider and speak to JR and involve RS.

JR asked if the clinicians in Fife are moving with the current service once developed or if it will be brand new set of people. CC advised he wasn't sure but suspected it's the funding moving to other teams and perhaps set up under community team structures. JR advised that was similar to their service as they sit under REACH, which is the community team. JR added they also have the neuro rehab team and they are part of something bigger.

CC highlighted that this is something for us to consider around sustainability if someone leaves post as the nurse in Fife that was spoken about with high regard and his post was unable to be replaced. JR agreed that it was knowledge that was then lost. CC advised it would be useful to have the medic in

place to help have these conversations as this will drive the model. CC summarised that we anticipate some key challenges and that demand we are unsure of, especially in Borders. JR advised that in the national paper, written by JS there are around 11%. CC added as a reminder that the AHP directors can help support in liaising with other services.
CC asked about the recruitment process for the medic. BW advised that HxC was having conversations around this but BW had checked with medical recruitment but wasn't getting anywhere around knowledge of the sessional approach so hopefully HxC would be able to provide an update.
JR asked what financially we have for the medic. CC confirmed that we have funding for around 5 sessions, which is the starting point and we have had interest from 2 people so far and hopefully we will have a medic soon. JR asked how the medic and MDT will work. CC advised that this is still to be determined but we have knowledge from AH and after initial challenges setting up a regular MDT, there was time in diaries to discuss cases so this could work similarly for the regional service. CC highlighted that it wasn't a linear pathway necessarily where patients waited weeks or months to get to services then back to waiting on medical again and that there were early conversations that AH was involved with along with a system where people could go straight to AH as they had already been involved with services. JR reiterated that a big MDT is so helpful. CC advised comments are very helpful and we can begin to put the details on the SBAR around the MDT. JR advised that we need the medic to begin building around this. CC acknowledged that this will involved a shift in thinking for some services but we're able to put PoTS on their agenda for conversations then we should make a list of people in that bracket so they are ready for the model that's coming up.
CC advised that once we have the medic we can determine what the MDT looks like. CC asked BW around the risk register that will be starting this will help us look at any unintended consequences. CC highlighted that one of the consequences could be flood gates opening but that in Lothian this didn't really happen, likely as not everyone is aware and there is still a lot more to do around education. BW added that as we had the process set out from the start, that patients had their diagnosis and there was requirements for referral and it was on REFHELP and it was clear, this helped the numbers. BW advised AH saw over 30 patients in about a year so floodgates weren't opened and it was manageable with AH offering around 6 sessions but AH has recommendations around the sessions which we can dig out.
CC advised it would be useful for us to think about next steps and the risks as based on the lived experience group, patients in Fife could start knocking on doors and floodgates could open. JR added another risk is remote medicine as it is easier when you can see people. CC advised at the peer group meeting on Friday a question was asked around where the service/person will be based and that it would be great to have elements of moving around with some face to face, rather than being completely remote. CC has a conversation coming up with one of the interested people and this will be valuable and he can mention these things. FW added that meeting someone in person can make a difference especially the first time and that patients do prefer face to face. CC advised that Lothian services are restricted and aren't permitted to see patients via home visits but some come into clinic but there could be value in doing a visit in a determined way, to ask lots of questions for valid interaction and this current method could be a false economy.

Action: All to think about next steps and what the risks are.

4. Lived experience report

JR advised it was very diverse. FW advised that things that have come up in conversation were reflected in the report and it contained lots of rich feedback.
CC summarised the set of the four lived experience meetings and advised this was the starting point.
CC advised the general feeling was that people would the meetings useful and they felt listened to and

there were themes that were expected but there were surprises with themes of misogyny and how women were treated with their health concerns. JR added there was reassurance that people also weren't asking for things that were unattainable.
BW advised the next steps were to gather feedback from people around the report and that people had been asked to contact our email box to express interest in either the core group or the wider group. So far there are 20 people interested in the core group which may be too large so we will have to consider splitting into two groups depending on final numbers which should be in by mid to late July. From there we will book further meetings, circulate a draft TOR that we can help develop with people that already includes a lot of their considerations such as what their preferences are. BW advised that next steps could involve setting up some short life groups to look at some quick wins such as education as we could easily start looking at centralising some information and education. BW highlighted that we had spoken separately to a group member keen to help with the group who also works for Lothian and we can look at taking this forward.
JR added that a question from Friday's meeting brought up potential flooding of ME/CFS in the service and Long Covid patient's wait goes up. CC added that he wondered if we might see clusters of referrals but potentially things will level out as the population with the existing condition will outnumber the people that are developing the condition through time.
FW advised it was interesting that patients stated they weren't getting boosters and Covid vaccinations and coincidentally had seen 3 patients last week asking for letters to GPs to be considered. FW added it makes sense for people with repeated peaks to be immunised but it's not happening. CC added other people spoke about lack of PPE and how vulnerable that makes them as they are open to recurrent infections. JR advised that there is a government page that shows when the peaks are expected and that the current programme isn't considering the impact of people having to take time off work again.
JR advised that her team asked about getting vaccinated but while flu immunisation stopped passing this on, Covid vaccine works differently and while JR might not get it, she could still pass it on.
FW advised that it raises communication between vaccination services and our services as currently it's only with a little pressure the GP will write a letter or some may not be as lucky. FW advised that she has patients who do better after receiving it. JR asked if we could have a letter that we automatically send to GPS. CC advised these questions are useful and will raise with the steering group as it's potential investment if it stops people from getting it again. JR and FW agreed writing the letters is time consuming as a template doesn't work as it's individualised.

5. Draft communication briefing

BW advised a one-page briefing note had been drafted to support staff with what is happening and where we are with the regional service as we are getting asked more questions. This will be sent to AHP steering group for sign off. JR advised it was useful for a recent FOI. BW wondered if the lived experience groups had triggered more FOIs as there was a recent one for Lothian and Borders. FW raised a potential issue with the Borders patient referred to AF as potentially there is a breakdown in communication with the referral. FW will follow up.

BW checked CC's name was okay to go on the briefing note and CC confirmed it was okay. BW advised if local reps want their names in future this can also be done but in meantime we have the email contact box on the briefing note. BW advised the plan was to do seasonal updates and think about a virtual meeting in future to give staff opportunity to receive an update and ask questions. JR asked if it could go on the website and BW advised there shouldn't be any problem with this once the steering group signs off. BW raised that potentially we could look at having a centralised resource on the internet for staff for progress updates for people to access and we can look at this. CC advised this would be helpful especially for lived experience people who can see that they are involved and what they are doing is visible.

Action: BW will circulate briefing note again to reps after signing off for local distribution.

Action: As part of larger comms plan, consider set up of regional page in public domain for all to access.

6. AOCB

CC confirmed we had changed meeting set up and that our conversations would inform the steering group in advance rather than the other way about and that give the opportunity for us to take any questions into the group.
JR advised HW would be stepping away from her current role but would still have the regional service and steering group in her remit but wanted to raise awareness that she may not be at all meetings.

Actions from meeting:

- **All to think about next steps are with the medical model/PoTS and what the risks are for the service (All).**
- **BW will circulate briefing note again to reps after signing off for local distribution (BW).**
- **As part of larger comms plan, consider set up of regional page in public domain for all to access (BW).**

Regional Long Covid/ME CFS Clinical Sub-group

Draft Minutes – 08.6.26

Regional Long COVID/ME/CFS Clinical Sub-group Meeting

Monday 8th June 2026 15.00-16.30

Attendees: Charlie Chung (CC) NHS Lothian; Fiona Wardlaw (FW) NHS Borders; Jennifer Ritchie (JR) NHS Forth Valley; Rosalyn Standish (RS) NHS Fife; Belinda Wilson (BW); Max Mckenzie (MM) NHS Lothian.

No.	Item	Owner	Papers
1.	**Welcome, Introductions & Apologies**	CC/All	
2.	**Previous Minutes/Actions**	CC/All	
3.	**Update from Steering Group Meeting/SBAR**	CC	
4.	**Local service/pathway/access updates**	BW	
5.	**Future areas of focus for group/advisory group 5 paper**	CC	
6.	**Lived Experience Group update**	All	
7.	**AOB**		

1. **Welcome, Introductions and Apologies**
   Charlie welcomed all to the meeting and introduced MM who has recently joined AHP Practice and Education team as AHP Business Officer and would be supporting this group and the lived experience group going forward.

2. **Previous Minutes/Actions**

   The previous minutes were accepted with a minor amendment around FW name spelling.

   Previous actions:

   - **BW to share dates of meetings with people. Meetings have been shared with all group (Completed)**
   - **JR added there was a national information group and would share details of this. (Ongoing)**
   - **JR to look at sending videos at 6-month mark to patients out to group. (Ongoing)**

3. **Update from Steering Group Meeting/SBAR**

   CC summarised discussions from the regional steering group:

   - MOU developed and AHP directors happy with this.

- ❖ Clinical sub-group feedback and service diagram discussion used to help draft SBAR – feedback from steering group was to amend the medical model to sit within a regional MDT rather than being separated.
- ❖ SBAR not yet finalised - this will be shared with other teams but is a good starting point at this stage.
- ❖ Feedback from lived experience group also incorporated into SBAR recommendations.
- ❖ Communication and Engagement discussed and newsletter will be drafted for sharing at next regional steering group meeting.

SBAR

CC advised this was fully informed by different groups, advisory group 5 paper, policy lead statement and lived experience groups. The SBAR hasn't gone as far as POTS management or MCAS management at this point due to further exploration needed around assessment space and location. The SBAR recommends a regional MDT approach.

JR raised point around the recommendations below:

b) looking at consensus of primary care and this could be promoted by preloading an education programme for primary care and support GPs to diagnosis, with national guidelines and training for primary care.

c) There is value in more than one position and GP trainees could utilise a rotational post which would then filter knowledge and education back to primary care.

f) Psychology – do the steering group know more than we think around the need for this addition. CC advised he would raise this point with the psychologists as would be useful to get their steer around the pathways and education. CC acknowledged that not much would change from a job description perspective and the next stage would be around other conditions and a psychology lead could be a part of this.

RS advised that services in Fife are changing, with actual services still to be defined but that psychology would be part of the picture locally.

FW commented that the scope of access is not an issue as she is working alongside psychology and there is no one waiting at present but they may not have specific clinical knowledge. RS agreed the option to add a GP trainee from primary care and rotated quarterly with 1 GP in every health Board would be valuable. CC advised he would feed this back.

JR raised that it feels as if the two separate meetings are disjointed as it feels are things are discussed and agreed after this meeting. BW advised she could share the steering group agenda and papers in advance with the clinical group and that would enable people to discuss locally and feed into the steering group meetings.

JR asked if there was any scope to label staff as highly specialised, as practitioners and how do we take this forward as this seems like a good time to do it. CC agreed that the clinical teams were at the top of the pyramid and would be useful to have consistency across the 4 regions with shared title and service name taking into consideration bandings and gradings.

FW asked about i) complex presentations and the need for an agreed group definition and referral criteria and what we define as a triage model. FW advised we need to be aware of the scope of the model, levels of complexity with a feedback loop while still having oversight locally.

CC asked for final comments for the SBAR to be in for 26th June and CC would share the revised document next week.

ACTION: Discuss & further explore the need for regional psychology lead outwith meeting (CC)
ACTION: Share the regional steering group papers with the clinical group (BW)
ACTION: Final comments on SBAR to be sent to CC by 26th June.

4. Local service/pathway/access updates

RS advised that they were meeting service leads as part of discussions and service development in Fife and the PT role. They are looking at coordinating nursing and AHP roles and looking at job descriptions.

FW advised that there is a Board restructure and currently the service sits under Community services but may sit under primary care. New service lead roles are being advertised but as FW's referrals come from primary care she is comfortable with that as they will still have support and the changes will not impact greatly and she is still receiving referrals.
CC highlighted that in the example case from Borders, it was useful to get the guidance from JR and that he had received confirmation that the medic consultant was happy to see the patient so all the groundwork was complete.

JR advised that they had received 5 recent referrals and that 75% of patients presented with ME/CFS and POTS and were still seeing Long COVID but not in the same numbers. JR advised they sit under community care and can't see primary care notes and it would be good to find some middle ground in this area. JR raised the question around seeing the notes regionally and how this will work. JR advised that PW had been involved in building a regional centre when previously working at Fife and if would be useful to ask him how they handled data sharing. JR added for point f) in the SBAR recommended the psychology service and wondered if we are looking for a bigger input than is needed and wondered where this directive is coming from is it isn't coming from us but could be from national meetings.

5. Future areas of focus for group/advisory group 5 paper

CC advised there was still time to flag future areas of focus and gave an example of looking at Lothian LWSS and what is needed. JR advised that they have some work support but that is only for employees with under 250 employees. CC advised we need to put this down and explore further in a workshop as we also could tap into paediatrics and while the numbers there aren't huge it would be a useful scoping exercise.
CC advised in Lothian they were left with 0.5 OT for CYP but in West Lothian there is nothing but some good resources have been built up and shared by the two original OTs working together. CC advised that with the impact of lockdown, this highlighted a number of people who may be neurodivergent. JR highlighted that children present differently. CC advised that the Covid kids had withdrawn from the national group and isn't sure of their next plans. CC advised it is within our gift to inform the steering group. CC advised he can check with our own LWSS on what is missing to support patients. FW advised that there was feedback to show that while off work it is difficult for people to navigate a route back especially to write letters to employers and would be helpful to have an advocacy type role. CC advised this was highlighted in the lived experience group sessions and remembered that CHSS previously helped people. JR thought they had pulled funding for this but was aware that there were challenges particularly in the conditions dealt with as CF syndrome is not the same as ME and there are

challenges with letters of support as we need to be careful around diagnoses but would be useful to have someone dedicated to that work space. CC added that CHSS were part of advisory group 5 and there was lived experience there and advocacy there and recently got in touch with CC and it could be valuable to have them involved.

6. Lived Experience Group update

CC advised that the four meetings were very valuable and people engaged very positively and provided some candid feedback and differences of opinion. There were a mix of conditions and people across 4 Board areas. CC summarised some of the themes discussed:
Service engagement; service access; management and re-access; living with multiple conditions; passports; PPE; children to adult transition. CC advised next stages involved groups working along with us with the message that people can engage at different levels either as part of a core group or a wider group. CC advised there are plans to build evaluation and also evaluate earlier as we go along.

7. AOCB

RS asked about equipment and resources as she is looking to set up locally. CC advised that Lothian had purchased adaptive equipment locally and we could share that. BW advised she has a spreadsheet of the orders and costs so will share with RS.

JR advised the group that the national group are pulling together PROMS and she can send on what she is currently using and would be good to pull these together regionally. JR was also meeting with POTS UK to discuss building services and equipment so would keep us updated.

ACTION: Share Lothian adaptive equipment list and costs

Actions from meeting:

- **JR added there was a national information group and would share details of this. (Ongoing)**
- **JR to look at sending videos at 6-month mark to patients out to group. (Ongoing)**
- **Discuss & further explore the need for regional psychology lead outwith meeting (CC)**
- **Share the regional steering group papers with the clinical group (BW)**
- **Final comments on SBAR to be sent to CC by 26th June (ALL)**
- **Share Lothian adaptive equipment list and costs with RS (CC/BW)**

Regional Long Covid/ME CFS Clinical Sub-group

Draft Minutes – 10.8.26

Regional Long COVID/ME/CFS Clinical Sub-group Meeting

Monday 10th August 2026 15.00-16.30

Attendees: Charlie Chung (CC) NHS Lothian; Fiona Wardlaw (FW) NHS Borders; Jennifer Ritchie (JR) NHS Forth Valley; Belinda Wilson (BW) NHS Lothian; Jacqueline Fearn (NHS Fife).

Apologies: Rosalyn Standish; Max McKenzie

Item

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1. **Welcome, Introductions and Apologies**
   Charlie welcomed all to the meeting and noted apologies.

2. **Previous Minutes/Actions**

   The previous minutes were accepted, with the amendment of a small typo.

   Previous actions:

- *All to think about next steps are with the medical model/PoTS and what the risks are for the service (All) (Ongoing action – will capture risks as they arise).*
- *BW will circulate briefing note again to reps after signing off for local distribution (BW). Completed*
- *As part of larger comms plan, consider set up of regional page in public domain for all to access (BW). (On Agenda)*

3. **Feedback from Steering Group**
   CC advised that the steering group had put feelers out for those who might be interested and CC had spoken to a medic from Borders, RK, and while he couldn't consider the role due to no capacity as he works for Action for ME, is a locum and is also clinical lead for oncology services, he has offered to be a source of consultation and guidance and we could possibly offer paid sessions that could be a valuable resource. FW advised that RK did podcasts for ME previously and has published articles in journals and was clinical lead during Covid for NHS D and G.

4. **Membership of clinical subgroup (updated – Psychology)**
   CC welcomed JF to the group for the 1st time, acknowledging that JF was in addition to RS, representing Psychology.

5. **Recruitment update (Medical, admin)**
   CC advised that HxC was liaising with medical recruitment around the medical role to gain best advice on taking this forward.
   JR advised that ideally a medic with PoTS experience would be the gold ticket. JR advised that in some ways they are self-taught but at times knowing more around medication and what feeds into and

someone with that experience would be helpful to support the continual learning to support people with longer term conditions.
CC agreed that it would be useful for someone that is not narrowed by the scope of a specific condition.
JR advised it is a two-way street, learning from each other and that the MDT picture, the bigger team to bounce things off is missing in FV.
JF advised when setting up the MACH (mental health after COVID 19 hospitalisation) centre in response to Covid was a similar learn as you go experience and they learned the importance of having an MDT with expertise, putting heads together around what might be important. JF reflected that their medic at the time was from rehab medicine but that his knowledge and experience wasn't confined to one area with a breadth of interests.
JR advised that the medic could be a GP with a wide umbrella of interest and that there was still value in the GP trainees, getting more hours for less money, while building a bond with GPs and building inroads with GPs. CC advised HxC will keep us updated with progress.

JR asked if there was admin support for the role and if this would impact local admin. BW advised there is currently a regional medical secretary post with a job description that also involves supporting meetings. BW advised that while the specifics haven't yet been designed for the actual role, the expectation is that this person will receive the regional referrals, liaise with patients as necessary and with local service admins and that there should not be any additional impact on current local admin services.
JR advised that it would be useful for triage support as at times when triaging people, there can be some doubt and at times referrals come in without a diagnosis and while the MDT might support with discussions, it can be tricky going back to the GP.
CC asked if JR could put those thoughts down in writing and send in to CC/BW so CC can capture that ask.
JR asked if we could have a unified referral form taken into services or discussed.
JR advised they receive a lot of referrals from GPs that are vague and that you can end up doubting yourself. FW advised it would be useful to share criteria across regions and that shared criteria might be useful for the medic. JR advised that it would be useful for referral forms to be streamlined and robust. JF agreed that a unified approach would be helpful but cautioned that some Health Boards don't have access to some specific services.
CC advised we can pull this together for future discussions.

Action: All to share current referral forms and send to BW for collation.

6. **Regional Psychology post Development**

CC advised that he had received a lot of expressions of interest for the part time temporary post and would be looking at some kind of interview process and that there were people with excellent credentials.

7. **Visits to shadow Forth Valley clinic**

JR advised that FW had a date in diary to visit JR's clinic and RS was also welcome to visit. FW advised she saw this as a "Train the Trainer" opportunity. CC advised he may also consider a visit and has highlighted the opportunity to other services that attend Lothian's clinical forum so JR may receive requests from others.

8. **Education**

JR asked if there was a possibility that services could have minimum competencies and certificates for standardisation. CC advised this suggestion was in the national advisory paper 5. CC will speak to HxC about this.

FW asked how we register for the Bath workshops? CC advised that names can be sent to BW who will collate for the sessions.

CC advised that an education sub-group would be set up soon looking at education and training for practitioners, awareness for other services, for referrers and lived experience education.

JR advised they would be happy to help the group and FW likewise as it was noted that GPs don't understand what we are looking for. JR advised that they have a GP talk they can share with the group.

Action: JR to share GP talk with the group.

Action: Names for Bath sessions to be sent to BW.

9. **Wider Service specification from each board**

CC has put together a list of service specification that could be offered:

- Fatigue management
- ADL work
- SLT – low voice and breathing patterns
- Cognitive rehabilitation/co-operative approach
- Psychology intervention
- PoTS and Orthostatic intolerance
- MCAS/MAST
- Work Support

CC acknowledged that delivery of the above might be slightly different in local services but combined we all have those and it is useful to consider what pathways we have to link into these services.

JF advised that the list was helpful and something to think about this locally and regionally and as discussed previously, a need for regional psychology, as NHS Fife is starting from scratch. JF advised the banding level is also likely newly qualified level and that from speaking with other psychologists in other Health Boards the consensus is that there are junior, general experience levels and having access to greater experience for complex cases, discussion, support and supervision would be valuable.

CC advised that psychology had been discusses at the lived experience group and it was recognised that in some cases this was not received positively.

JF advised that they look at psychology in a positive way, around the psychological impact of living with a physical condition and the ability to engage in everyday life.

JF advised that they have a positive uptake of patients around psychology and that they validate this during the first face to face meeting where the patients have an hour of support and this makes for a nicer conversation.

FW advised that there is value in clinical psychology to support people with loss and grief and they don't have that in Borders, so FW is looking forward to first referrals to a regional model, especially for people that recognise the value and want the help.

JR asked if we know what the demand for psychology might be? JF advised that as NHS Fife haven't had a service for years, it is difficult to know as they are moving in the dark but suspects there might be unmet needs.

JR advised that she could pull off FV numbers as a ballpark figure. JF advised that would be helpful as they have a similar population. JR advised that there is a 12 week wait currently. CC advised there is a

6-9 month wait in Lothian. JR advised they are the gatekeepers for referrals and this helps control the volume but they do send a lot.
JF asked if the service offers group meetings? JR advised they do, these are virtual for 9 weeks, focusing on a different topic each week. JR advised they have videos/talks from other services such as dietetics and if there are questions raised they cannot answer they take these away for answering.
JF asked if there might be an opportunity for some cross Board group delivery, acknowledging that locally not every Board provides the same services. FW advised that it would be useful to share resources, such as an OT video and have a group. JF advised this would be co-operative rather than working in isolation and had this is how the MAC had run nationally with cases discussed.
JR advised that their groups are beneficial after the initial 6 months post discharge and are offered as a refresher which is helpful as they don't have OT, so patients don't just get left they get an element of hand holding and follow up.
CC advised there could be efficiencies with this approach, reduces risks around waiting times, freeing up time for treatment for people with core limitations. CC will look at incorporating this into the proposals.
CC will circulate the list to people and that after speaking with JS, look at working up pathways was key so people can visualise the system.
CC asked if people thought anything on the list was not possible.
JR advised that work support would be difficult as PIP can be difficult to grasp and pass on that knowledge and that having an OH remit doesn't always stretch to patients with real need and it is this work element that distresses patients.
CC advised we could invite work support into this meeting for a focused discussion.
FW advised that there was a retired rehab consultant, EM, who heads the HWL group who has created paperwork designed to keep patients at work and he might be willing to share resources. FW noted that at times you feel you are not doing your best for patients and support is dependent on their OH at work.
JR advised that the scope was limited to companies with less than 250 employees and it would be useful to provide the relevant advice to patients but that the service sits with capacity albeit with a small remit.
CC asked if people had heard of NIDMAR (National Institute of Disability Management and Research training? FW advised that she had attended a work support course a while ago at Lothian AA hospital.
CC advised that NIDMAR is Canadian, offering a year long course with exam and provides accreditation that is recognised globally, and staff in Lothian services are trained. CC advised they are holding a conference next month in Edinburgh, that Lothian work support are involved in. CC advised we will contact LWSS to carry out a spotlight session for people to share information around building pathways.
CC asked for thoughts on cognitive rehabilitation.
JR advised that they could use some help in this area.
CC advised he is trained and delivers sessions at St Andrews University and could give everyone a grounding session in this.
JF advised that psychologists will also have some knowledge in this area.
CC advised there is also eLearning available on this from CHSS (Home - CHSS eLearning) as CC helped to re-write this along with core competencies and it is up to date and CC would be happy to deliver this in a workshop.

Action: Invite LWSS to one of the next meetings.
Action: CC to set up spotlight session relating to work support/NIDMAR training.
Action: JR to send psychology referral numbers to BW who will circulate to the group.

10. Communication and Engagement

FW asked if there would be a central point of information that people can access around the regional service? JR advised she assumed there would be a webpage wet up.

BW advised that this would be easy to set up and has previously set a similar page up for Falls, with a main landing page with national information and links and with different links to HSCP areas as their local services differ.

CC advised that the Right decisions platform Right Decisions | Right Decisions could also be used. JR advised that NHS Inform Scottish health information you can trust | NHS inform was another option to look at to see if this needs to be updated. FW advised that all areas use GP REFHELP RefHelp – Instant Access to Referral Guidelines for Lothian as well. BW will capture these suggestions to inform the later communication and engagement planning.

11. Lived experience group update

BW advised that there has been a temporary pause on the planning for the next lived experience group as our admin support is currently unwell and off work. BW is hoping to get some cover next week so work will then be picked up again planning meetings for either the core or wider group meetings in late September/early October. Feedback from the group around the report summary is also being collated and will be recirculated to the lived experience group once updated.

12. AOB

JR asked if there was anything to be aware of or feed into for the next steering group meeting. CC advised that this was in a couple of weeks. BW advised the agenda had not yet been planned for this, but BW will circulate the agenda and any papers once completed for awareness.

Action: BW to share agenda/papers with this group.

Actions from meeting:

- **All to share current referral forms and send to BW for collation (All).**
- **JR to share GP talk with the group (JR).**
- **Names for Bath sessions to be sent to BW (All).**
- **CC/BW to invite LWSS to one of the next meetings.**
- **CC to consider delivery of workshop around cognitive rehabilitation (CC).**
- **JR to send psychology referral numbers to BW who will circulate to the group (JR).**
- **BW to share Steering group agenda/papers with this group (BW).**