

Note of telephone conversation re ME petition

With: **[REDACTED- s.38(1)(b)]** and **[REDACTED- s.38(1)(b)]** (MEAssociation)

Date: 17 June 2019

- Important that Scotland gathers evidence about its practices
- Differences between biopsychosocial model and biopsychosocial medical model
- Looked at SHA Care Framework – considering how relevant for ME
- Neurology, Immunology and Virology
- Fibromyalgia services – ME Association doing some work on
- Patients present with a range of symptoms therefore there will be divisiveness amongst ME community about definitions – to be expected
- AHP services are crucial to care
- SHC – considers focus is useful
- NES – **[REDACTED- s.38(1)(b)]** not involved in this work but hears there are issues – tardiness in progress
- CSO – **[REDACTED- s.38(1)(b)]** – takes case studies from biobank. Peer review is important. Study in Oxford recently knocked back
- Pushing for update to SGPS
- ME Association has funded studies in Poland and Spain
- ME Research UK based in Perth
- Lack of research candidates and case studies hindering researchers

Action – **[REDACTED- s.38(1)(b)]** to facilitate intro with **[REDACTED- s.38(1)(b)]** from CSO

Note of telephone conversation re ME petition

With: **[REDACTED- s.38(1)(b)]** and **[REDACTED- s.38(1)(b)]** (MEAction)

Date: 23 May 2019

- **[REDACTED- s.38(1)(b)]**
- Want SGPS updated – don't want to wait for NICE
- Tymes Trust – **[REDACTED- s.38(1)(b)]** re CYP. Important to include parent voice
- ME Association – **[REDACTED- s.38(1)(b)]** (**[REDACTED- s.38(1)(b)]**), **[REDACTED- s.38(1)(b)]** is spokesperson
- International Consensus document
- ME Highlands and Islands (**[REDACTED- s.38(1)(b)]**)
- ME Glasgow support group

Actions – **[REDACTED- s.38(1)(b)]** to send **[REDACTED- s.38(1)(b)]** list of contacts to speak with about SHC work

Note of telephone conversation re ME petition

With: **[REDACTED- s.38(1)(b)]** and **[REDACTED- s.38(1)(b)]** (Action for ME)

Date: 22 May 2019

- Supportive of SHC exercise if focuses on 'what good care looks like'
- Actively engaging with SHA framework to consider if could be utilised for ME
- Working with **[REDACTED- s.38(1)(b)]** (CNS NHS Fife) to consider good practice and **[REDACTED- s.38(1)(b)]** (NHS D&G) re clinical expertise

With **[REDACTED- s.38(1)(b)]** and **[REDACTED- s.38(1)(b)]** / **[REDACTED- s.38(1)(b)]** (Action for ME)

Date: 23 May 2019

- NICE review of its guideline involving FORWARD ME (Countess of Mar in House of Lords – cross bench peer)
- Chair – **[REDACTED- s.38(1)(b)]**
- Holding workshops with advocates
- Triples number of experts by experience on guideline committee
- Acknowledged lack of high quality clinical evidence and research
- Therefore more focus on patient views
- UK wide survey supported through MEAction, ME Association and Action for ME – to find out affects of treatments on people
- 75% reported adverse affects of GET and 37% of CBT
- Action for ME completed a further survey that was more relevant to Scotland
- NICE has commissioned focus groups particularly for 1) severely affected and 2) children and young people
- Tenders on this work due in June and completed over summer 2019
- NHS Fife currently exploring expansion of its ME service
- **[REDACTED- s.38(1)(b)]** has been involved in work in England
- **[REDACTED- s.38(1)(b)]** chairs the CFS Research Collaborative
- Difficulties around research – researchers work in isolation. Medical Research Council – low number of applications and qualityMR
- **[REDACTED- s.38(1)(b)]**
- Key populations – rural, CYP, severely affected

Note of telephone conversation re ME petition

With: **[REDACTED- s.38(1)(b)]** and **[REDACTED- s.38(1)(b)]** (ME Coalition)

Date: 17 June 2019

- ME is a diverse illness hence diverse views
- SHA – yes keen to do this but important to make progress quickly
- NICE review – viewed as limited – focused inward – should be taking international work into account
- Warns – lots of pent up emotion among ME community – likely to get heated in future
- **[REDACTED- s.38(1)(b)]** objective is to work constructively with SG
- Need to particularly focus on 2 groups – severely affected and CYP.
- **[REDACTED- s.38(1)(b)]** has links re parents and CYP
- CSO – need to involve ME Research UK based in Scotland
- Care is important – research is vital
- Answered questions about NAP and ME
- Support ME Action petition – 3 areas are aims of ME Coalition
- Want National Strategy for ME – **[REDACTED- s.38(1)(b)]** advised NAP is framework that work will be progressed around
- Keen for NACNC to recognise and make a statement about ME

Action – **[REDACTED- s.38(1)(b)]** to consider how to approach NACNC

Note of telephone conversation re ME petition

With: **[REDACTED- s.38(1)(b)]** and **[REDACTED- s.38(1)(b)]** (ME Highlands and Islands group)

Date: 17 June 2019

- Has provided contribution to NICE review but not directly involved otherwise
- **[REDACTED- s.38(1)(b)]** has ME – had adverse outcome from trying GET/CBT
- Concerns about NES – MSP wrote and received a vague reply about process and timescales
- **[REDACTED- s.38(1)(b)]** considers lots could be achieved through NES
- **[REDACTED- s.38(1)(b)]** proposing patient experience section at end of GP module but ME community would like this to be more integral, especially as lack of clinical evidence
- Difficulty with research is that there is not a register of patients like there is for other conditions.
- **[REDACTED- s.38(1)(b)]** is psychiatrist specialising in additions including chronic pain and therefore ME. **[REDACTED- s.38(1)(b)]**.
- Some GPs aware of his work but hardly any patients are. **[REDACTED- s.38(1)(b)]** has many years experience – **[REDACTED- s.38(1)(b)]**. **[REDACTED- s.38(1)(b)]** said other clinicians need to be aware of markers such as this that should have been explored earlier.
- **[REDACTED- s.38(1)(b)]** believes there should be team of specialists involved in ME pathway, including mental health aspect (CBT may have a place for some people but only if delivered by professional specialising in CBT for people with ME)
- In June 2019, highlands group and Action 4 ME held an event to find out the interest for a support group. Inundated with people.
- View shared that relieved someone will be there to support locally
- Difficulty in rural areas – no home or remote service for people who cannot leave their home – impacts on diagnostic tests etc
- Benefits system – adds anxiety and distress
- Clinicians not aware of guidelines or if they are – many admit they would not take notice as do not believe real condition
- Huge cultural challenges

Action – **[REDACTED- s.38(1)(b)]** to share ideas about NES

Meeting with [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] from Epilepsy Scotland (ES)

16/04/2019

- Epilepsy Scotland provided update on its Social Security Support project that SG contributed to via s10 funding in 2018-19.
- Cabinet Secretary for Social Security attended CPG for Epilepsy earlier this year (Convener is Kenneth Gibson MSP).
- Paediatric SIGN guideline for epilepsy due out later this year.
- In mid May, ES has a stand in parliament to promote upcoming campaign about Safety – raising awareness of what the public can do if they see someone having a seizure. ES is partnering with Scotrail to promote via subway in Glasgow. ES expect to see an increase in calls to its helpline as a result. There is a link to potentially reducing demand on unscheduled care through this campaign, as there are 25,000 call outs for ambulances linked to seizures each year and many will be unnecessary.
- ES is trialing a Epilepsy Friendly Award in pubs and clubs – selected venues first before larger roll out.
- ES involved in Epilepsy Register that has been trialled in Tayside and is now being tested in GGC.
- **Epilepsy and Pregnancy – [REDACTED- s.38(1)(b)]** need to follow up. ES considers there is ample guidance out there – just needs practical application.**
- Specialist nursing – concern about lack of numbers affecting timely access
- **Neurophysiology – ES aware that [REDACTED- s.38(1)(b)] will shortly have a meeting with CMO **** follow up**
- Mental Health – ensuring NAP adequately covers this is vital
- **PAVES – Clinician leading will be seeking meeting with Ms Haughey re advocating national rollout *** follow up**
- There is a MCN for paediatric services (SPEN) but not adults. ES is looking to facilitate an Epilepsy Improvement Group similar to Parkinson Excellence Network. Possibility that [REDACTED- s.38(1)(b)] (Lothian Neurologist) might co-chair with [REDACTED- s.38(1)(b)]. Remit would be service based but also consider research too.
- Glad NAP highlights rapid access clinics – N.B, Lothian is trialling these.
- There will be anxiety about condition specific resources in context of NAP looking at generic models. Concern about how this might influence planning re CNSs and getting meds on time etc. Re condition specific standards – calls for them to be co-located alongside general neuro standards on HIS website.
- Richard Lyle MSP likely to ask supplemental about Epilepsy Register (already happened).

- **[REDACTED- s.38(1)(b)]**– ES currently funded for Youth work but this ends in 2020.
- Issue currently in NHS D&G about access to epilepsy nurse for children. Joan McCalpine MSP involved in discussions with Board.

Task and Finish Group - Meeting notes 25th August 2022 14:00-15:00

Attendees and apologies – see end of notes

Item 1 - Welcome & introductions	DISCUSSION
	New attendees introduced themselves: ([REDACTED- s.38(1)(b)]). [REDACTED- s.38(1)(b)] reported on discussions within the Northern Ireland government; once the draft ME/CFS Delivery Plan has been published, they will make a decision on the way forward and feedback to the group.
	ACTIONS N/A
Item 2 –Notes from Last Meeting - Approval	DISCUSSION
	Key points: Correction is needed to state “MERC PAG” instead of “PAG” in notes and public documents.
	ACTIONS To correct notes from last meeting so MERC PAG name is used.
Item 3 – Update on actions from July	DISCUSSION
	A. The public information about the governance structure was cleared and sent out on 17.8.22, for group members to distribute. B. A summary briefing paper will be sent out after each Task and Finish Group detailing progress, for public distribution. It was agreed that it would be fine for people involved in the groups to give general comments on social media, without sharing further content. Eg to confirm support and involvement. C. The Comms Principles and Protocol document will also be shared with group members, explaining what can be shared and when, in order to balance information with need for a ‘safe space’ for discussions.
	ACTIONS
	DHSC to produce first summary briefing paper for publication and share the Comms Principles and Protocol document with members of working groups.
Item 4 – update from 3 rd August Meeting regarding Royal Colleges Involvement	DISCUSSION
	Key points: A. [REDACTED- s.38(1)(b)] has made initial contact with [REDACTED- s.38(1)(b)] ([REDACTED- s.38(1)(b)]) who has agreed to a discussion. B. The Royal College of Physicians has agreed that [REDACTED- s.38(1)(b)] can represent the College at the Attitudes and Education working group. This is a welcome development.

	<p>C. The need for a survey on current attitudes of professionals was put forward as this group is still under-represented within the working groups. Ideas were suggested on who would draft the questions and provide input on the wording. Also, to future proof the survey so that it can be repeated year on year to measure changes/progress. It was suggested that the survey might have better uptake if circulated by the Academy of Royal Colleges.</p> <p>D. Including Neurologists in the survey was suggested. Having the Royal College of Psychiatrists involved would help discussions with neurologists.</p> <p>ACTIONS</p> <p>1. [REDACTED- s.38(1)(b)] to ask [REDACTED- s.38(1)(b)] if the Academy could host the survey, as well as offer advice on reaching out to the RC of Psychiatrists.</p> <p>2. Group members will be talking to [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)].</p> <p>3. A separate sub-group to be formed to discuss the survey further and put it together.</p>
<p>Item 5 Risks and Issues Log</p>	<p>DISCUSSION</p> <p>A. The risk and Issues Log was shared and explained. The for highest risk items were discussed further.</p> <p>C. The need for balance between understanding the problems fully and moving the process forward was discussed.</p> <p>D. The current uncertainty over the political situation and potential new ministers was highlighted.</p> <p>E. An issues regarding ME/CFS not being in the NHS England programme of work was highlighted, need to find levers to influence and persuade people.</p> <p>F. In relation to finances, it was confirmed that £224 million has been invested so far in services to respond to long Covid. There are no specifics on what has been spent on education. An education module has been developed by HEE and RCGP and a training program is rolling out.</p> <p>ACTIONS</p> <p>1. [REDACTED- s.38(1)(b)] to provide further detail to [REDACTED- s.38(1)(b)] re the level of funding and content of the long Covid education and training programs, particularly in relation to fatigue and Post-Exertional Malaise.</p> <p>2. All members to provide comments on the risks and issues back to [REDACTED- s.38(1)(b)].</p>
<p>Item 6 – Working</p>	<p>DISCUSSION</p>

Group Activity	<p>Research – MERC PAG reported that the next meeting is 1 September. Four new members will be joining. Slight changes made to ToFR document. They will discuss establishing 3 sub-groups on a) research strategy, b) building capacity, c) raising awareness.</p> <p>Living with ME/CFS – [REDACTED- s.38(1)(b)] reported that the workshops are enabling the group to involve more people to provide specific knowledge and</p>
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	<p>expertise on particular topics. Housing is an area that the group don't have a lot of information will follow up in wider engagement. The group will use case studies in the workshops to help people understand the context. All workshops are online and last 90 minutes, except the health services one which will be two hours. The workshops will be offered to A&E and T&F group members as well and let us know through emailing [REDACTED- s.38(1)(b)]. Places cannot be guaranteed as we may have to limit numbers due to demand.</p> <p>Attitudes and Education – The group didn't meet in August but have progressed the work using feedback from members on problem statements, causes and impacts as well as asking members for impact statements and suggested actions.</p> <p>ACTIONS</p> <p>1. DHSC to email details of the Living with ME workshops to all working group members.</p>
<p>Item 7 – Any other information updates</p>	<p>DISCUSSION</p> <p>There were no information updates shared by members.</p> <p>DHSC asked if there were any significant dates coming up this year which could be used as a date for publishing the draft Delivery Plan. International Day of Disabled Persons was suggested - 8th December.</p> <p>ACTIONS</p> <p>DHSC to plan with the 8th December in mind.</p>
<p>Date and time of the next meeting</p>	<p>Thursday 22nd September 2pm</p> <p>DHSC to send out new invites for dates in October to December 22.</p>

List of Attendees:

[REDACTED- s.38(1)(b)]

Apologies:

[REDACTED- s.38(1)(b)]

Task and Finish Group - Meeting notes

22nd September 2022 14:00-15:00

Attendees and apologies – see end of notes

Item 1 - Welcome & introductions	DISCUSSION
	New attendees introduced themselves: [REDACTED- s.38(1)(b)] from the Science, Research and Evidence section of DHSC. [REDACTED- s.38(1)(b)] is taking over from [REDACTED- s.38(1)(b)] as research lead on ME/CFS. [REDACTED- s.38(1)(b)] was welcomed to observe as she will be representing [REDACTED- s.38(1)(b)] at the October meeting.
	ACTIONS
	N/A
Item 2 –Notes from Last Meeting - Approval and updates on actions	DISCUSSION
	Key points: a) Wording corrections for CMRC PAG to be MERC PAG have been completed and are reflected in all documents. Notes approved. b) Updates on reaching out to the Royal College of Psychiatry: two discussions have taken place so far with [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)]. The final discussion is for [REDACTED- s.38(1)(b)] to talk to [REDACTED- s.38(1)(b)] from the Academy of Royal Colleges which is scheduled for 30 th Sept. It was noted that the RC of Paediatrics and Child Health have also not been represented at the last meeting of the Attitudes and Education WG or the Living with ME/CFS WG. c) [REDACTED- s.38(1)(b)], DHSC [REDACTED- s.38(1)(b)], has also shared the information with [REDACTED- s.38(1)(b)] in relation to the education material developed on long COVID.
	ACTIONS
	DHSC Secretariat to organise a debrief session in early October re Royal College involvement.
Item 3 – Update on Working Group activity	DISCUSSION
	Research – See the paper 3B for information on progress and next steps. Issues: A) It was proposed that there is cross-over between the Research WG and Attitudes and Education WG re Attitudes and Education i.e. researchers, members of funding panels. An action was agreed to minimise unnecessary duplication.

- B) Some members of the WG support publishing full notes, to enable fuller understanding of the community. This would apply to the other WGs as well. The WG has been unable to resolve this so has escalated to the T & F Group for advice. Different views were expressed:
- the monthly summary paper is sufficient / could include more detail
 - we could give a timetable to show when we will publish the full notes in future (once the work is completed)
 - publishing full notes would damage the agreement about establishing a safe environment. We have made a previous commitment to that.
 - A different suggestion could be proposed

Living with ME/CFS – See Paper 3C for information on progress and next steps.

Issues :

There was discussion around adults with ME/CFS in Further Education, as this was not discussed in the recent Welfare and Employment workshop. A representative from DHSC reported that this will be covered in the Children and Young Peoples workshop. The representative from the Department for Education (DfE) thanked the member for their comments on this topic and confirmed that DfE are keen to support the conversations on this topic.

DHSC confirmed that any crossover will be shared with the relevant co-chairs.

Attitudes and Education – See Paper 3A for information on progress and next steps.

There were no issues raised for discussion.

ACTIONS

1. Co-chairs of Attitudes and Education and the Research Working Groups were asked to meet to discuss the specific objectives that they wanted to achieve in relation to Attitudes and Education of their target groups of staff, to avoid duplication. Then to agree next steps to ensure coordinated action.
2. Members to provide a proposal for consideration about publication of more detail without compromising the safe environment for discussion – to [REDACTED- s.38(1)(b)] by 13.10.22.
3. Members to let MERC PAG know of any people they would like to nominate for the 3 Research sub-groups at [REDACTED- s.38(1)(b)].

Item 4 – Introduction to the Engagement Advisory Group	FOR INFORMATION
	This is a new group that met for the first time on 22 September. It aims to design an accessible engagement process that will launch at the same time as the draft plan so that the wider community can give feedback.
	ACTIONS N/A
Item 5 – Proposed draft timetable	DISCUSSION
	A draft timetable was shared by DHSC to explain what the important milestones are for the Delivery Plan, for us to achieve our aim of publishing a draft document on the 8th of December. Note – the International Day of Disabled Persons is the 3rd of December, but we do not think we can meet that deadline. Key points: <ul style="list-style-type: none"> • We will need to have a draft document to consider at our next meeting in October as well as an outline of what the Engagement Advisory Group suggest for the engagement process. • We may need an extra meeting in early November to consider advice received from Ministers during early clearance. Alternatively, this information could be shared by email. • Members with lived experience requested more time to review the draft plan than 3 working days. •
	ACTIONS DHSC Secretariat to explore ways to increase the time that Working Group members have to review the draft delivery plan. All members to provide comments or other relevant information for the timetable to [REDACTED- s.38(1)(b)].
Item 6 – Any other information updates	DISCUSSION
	None.
Date and time of the next meeting	ACTIONS
	20 th October then revised to 2 nd November 2022 14:00-15:00

List of Attendees:

[REDACTED- s.38(1)(b)]

Apologies:

[REDACTED- s.38(1)(b)]

Ministerial Meeting with #MEAction Scotland – 03 March 2022

Maree Todd MSP and representatives from #MEAction Scotland held an introductory meeting on 3/3/22. The charity submitted an agenda with clear asks ahead of the meeting and Ms Todd was content for policy officials to chair. Discussions were closely aligned to the agenda and stakeholder interaction with the Minister, while robust, was friendly and constructive. Both the Minister and stakeholders valued the opportunity to meet and the atmosphere was generally positive.

The main concerns of the charity were:

- implementation of the NICE guidance in Scotland
- withdrawal of the use of Graded Exercise Therapy in the NHS
- clinician education, including the development of a Practice Based Small Group Learning Module by NES
- development of pathways/services for children and young people with ME/CFS
- development of tiered model of care for adults, as outlined by Public Health Scotland's Healthcare Needs Assessment for ME/CFS
- setting a 'diagnosis target' for ME/CFS

The most pressing of these was that of communication from the Scottish Government to appropriate clinical leads to highlight the change in practice concerning Grade Exercise Therapy, as indicated by the NICE guidelines. The guideline advises against the use of GET (described as making fixed incremental increases in activity) for people living with ME/CFS, however the charity advised at the meeting that they are receiving correspondence from people with ME/CFS who are still being offered GET. There was significant concern that clinicians are not aware of the guidelines, and the potential for causing harm by inappropriate use of incremental exercise.

Stakeholders are aware of the previous communications on this which were disseminated by Scottish Government to health boards, GPs and medical schools in 2020 regarding the draft NICE guideline however are unaware that a draft CMO letter is currently under consideration. The Minister expressed her support for communicating the change in practice around GET to boards and clinicians, and advised that we are currently identifying the best mechanism by which to effectively communicate the changes.

Regarding clinician education, the Minister was able to update and assure stakeholders that NES have begun production of the Practice Based Small Group Learning Module – this information is not included within the briefing as was received just ahead of the meeting.

Attendees	Date	Location
[REDACTED- s.38(1)(b)]	5/3/20	Bobath
Purpose	<p>Commitment 10 We will work with the Neurological Alliance of Scotland and other stakeholders to explore the potential of national care frameworks and how these can inform neurological care and support.</p> <p>Early Action e) Exploring the potential of national care frameworks to provide signposts to neurological care and support.</p> <p>First Steps Link in with NAOs and NHS Leads to consider the impact of existing frameworks such as Huntington’s to identify how this used to transfer positive outcomes across neurological conditions</p>	
Key Points to Discuss	<ul style="list-style-type: none"> • What can we do to build on and learn from SHA framework? • How would we identify approach/ conditions? • Who do we need to involve? • How does it link with HIS Standards, QAD and condition specific developments? • SAC Pathways including motor, sensory, seizures and headache? 	
Issues Raised	<ul style="list-style-type: none"> • SHA were funded by SG but also charity supplemented funding, resourcing and senior leadership to resource activity. Also preparatory work had been evidenced in advance. • Need to consider existing leadership network eg. NHS A&A Health and Social Care neuro networks, MCNs, NHS GGC MFT and SHA Frameworks. • Consideration that discussion to develop national frameworks has immediate relationship with ongoing priority to develop local, regional and national leadership networks. • Also to link with NHS Inform activity. • Environment has changed since NAOs meeting and proposal for 2-3 conditions to be identified. Also informed by approach to support neurological conditions as collective if and where possible. • Meeting with HIS to support systematic approach to improvement next week to consider how this activity aligns – including condition specific reference. • This discussion further reinforces need to prioritise leadership and network model and how this is critical to support improvement. • Focus on standards, implementation and improvement • Helpful to know what are Critical Success Factors from experience of SHA • Focus with explicit deadlines. 	
Actions	<ul style="list-style-type: none"> • [REDACTED- s.38(1)(b)] to follow up with HSCS, CSWO, and CNO re leadership representative. • [REDACTED- s.38(1)(b)] will share SHA Network • [REDACTED- s.38(1)(b)] will outline key indicators required for successful framework development. - Key principles - Toolkit, eg, engagement, leadership, network, connectivity • [REDACTED- s.38(1)(b)] to progress with Grampian and Leadership network • [REDACTED- s.38(1)(b)] to map additional networks know to group e.g. local neuro networks (see [REDACTED- s.38(1)(b)]), MCNs and Neuro Improvement Networks (also CPGs and other interest groups.) • To support implementation and development of HIS Standards QAD • Continue engagement with SAC and MPPP re Clinical Pathways • Align with NHS Inform commitment 	
Follow Up	No date set – as required	

They will introduce us to someone who is in QUADs

For QUAD who dedicates time to part of the NACNC

- set expertise into the process

What's the existing sets. Standards

This would need to be piloted

HIS website – example self-assessment tools

Time limited set expertise to support the development of the self-assessment

Expected timelines, commitment

Anticipate six In the six months

- Pilot

- Evaluation

- Option 1 – look at risks

- Option 2

Preferred Option

- Should come from the National Advisory Group – implementation of the Plan, Policy and Standards

- What is the perceived outcomes – how that fits in

National consistency, building capacity within the system and closer links with HIS

Alignment of mechanisms, exposure is recognised

Links with the QMS model

- mapping, piloting, implementation/ scoping ,

HIS will update doc –

Who is involved, what is the government structure, what have we done around sub groups

[REDACTED- s.38(1)(b)]

- Look to delay project team until new work with HIS

NAG – Programme, director, sub groups supported by SG staff member, Project team

Structure, deadline, pilot board, sets

Primary motivator – capacity building , think about your outcomes, how we link HIS work with government priorities

Doc missing structural elements

Build on the very successful relationship of the NAG and HIS

[REDACTED- s.38(1)(b)] and **[REDACTED- s.38(1)(b)]** would provide specific help

[REDACTED- s.38(1)(b)] will speak to NAG to ensure they are on board with this.

[REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] will check with [REDACTED- s.38(1)(b)] (how this took before)

Interim part – [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] will speak to QUAD

Pilot and evaluation – what are the barriers, what is the surplus, what is the learning from NHS Lanarkshire

QUAD rep – Get that information

How would you roll that out to other Boards – quality of data

Reporting structure – They are reporting to the SG and project team

[REDACTED- s.38(1)(b)] - SAC - ... and slide

[REDACTED- s.38(1)(b)] comes from a Pathways background

One Wednesday they have an educational day

[REDACTED- s.38(1)(b)] to speak to [REDACTED- s.38(1)(b)]

Think about the structure – mindmap

[REDACTED- s.38(1)(b)] – Get in touch about how the implementation phrases are right

West Dunbartonshire – [REDACTED- s.38(1)(b)] – Implementation Planning Director

[REDACTED- s.38(1)(b)] - was Head of Brain Injuries – I think?

Going out to groups then ... one GP

Go through the colleagues and clusters (GPs)

Develop networks through the Plan

SG Attendees	External Attendees	Date / Location
<p>[REDACTED- s.38(1)(b)] - Minutes [REDACTED- s.38(1)(b)] - Chair [REDACTED- s.38(1)(b)] [REDACTED- s.38(1)(b)]</p>	<p>[REDACTED- s.38(1)(b)] - #MEACTION Scot [REDACTED- s.38(1)(b)] -The 25%ME Group [REDACTED- s.38(1)(b)] - The ME Association [REDACTED- s.38(1)(b)] -Action for ME [REDACTED- s.38(1)(b)] - #MEACTION Scot</p>	<p>23 March 2021 Online MS Teams</p>
<p>Purpose</p> <p>Meeting with M.E./CFS stakeholder group to provide an update on policy work and agree next steps.</p>		
<p>Key Points to Discuss</p> <ol style="list-style-type: none"> 1. Gathering views and next steps 2. ME-CFS Public Health Care Needs Assessment 3. NICE guideline 4. Long Covid 5. Funding decisions 6. 'How long is long term?' rapid review 7. ME Awareness Month Activities 8. Healthcare needs assessment 		
<p>Issues Raised</p> <p>1. Gathering views and next steps</p> <p>This is now due to be published by NHS Healthcare Improvement Scotland – Community Engagement after the elections. It had been due to be completed in April 2020. Progress was delayed with the redeployment of NHS HIS staff due to the pandemic and more recently staff absence. Scottish Government has had sight and made a request to share with the group in advance of publication, however it is embargoed. Officials met with NHS HIS, however this was solely to provide them with a bigger picture context.</p> <p>#MEAction Scotland are disappointed that Jeanne Freeman announced the draft was to be published in September 2020.</p> <p>2. ScotPHN ME-CFS Healthcare Needs Assessment</p> <p>The report was published in January 2021. There are no further updates from representatives who attended the last meeting of the short life working group in December. It is still intended that the scope of work being undertaken will be built upon to include children and young people.</p>		

3. NICE Guideline

There is speculation that the publication of the final guidance will be delayed.

The previous meeting in December discussed potential next steps after publication of the final guideline. It was again agreed that the stakeholder group should come together to assess the merit of different options. This is to include engagement with clinical groups and Scottish Intercollegiate Guideline Network.

It was agreed that no decisions on next steps could be taken until publication. NICE will provide key stakeholders with sight of the guideline 2 weeks in advance of publication.

There was some discussion about SIGN and how they consult and include patient experience when developing guidelines. Concerns were expressed about the screening of evidence and patient experience.

It was agreed that progress will also require clinical involvement and expertise.

4. Long-COVID

It was explained that recent correspondence submitted by #MEAction Scotland will be responded to in line with pre-election guidance.

Scottish Government long-COVID policy work focus is on research, developing clinical guidance, and its operational delivery. It is not solely focussed on long-COVID, but this is being considered, like other long-term conditions. The rapid guideline for long COVID is an evolving document and will be built upon.

There is not a comparative document to build upon for ME-CFS, as the Scottish Good Practice Statement is out of date. The intention is therefore to pick this up when the ME-CFS NICE guideline is published.

It was raised that in post-infection illness, indicators of spontaneous improvements need monitoring, and a concern was raised that the ME-CFS cohort are at risk of being lost within the fatigue cohort.

The CSO and National Institute for Health Research are closely linked and are currently funding long-COVID related research. There is also practical support for individuals with long-COVID from Long-COVID Scotland Action and Chest, Heart and Stroke Scotland. Attendees were interested to understand what is being funded, including practical support for long-COVID.

4. Funding

The funding bid to continue the promotion and dissemination of the CPD module partnership project was successful.

The care framework bid was unsuccessful. However the concept of a care framework is a priority in 2021/22 and will be progressed via the Neurological Alliance. It is not condition specific.

There have also been a number of projects across neurology where, although ME was not specifically mentioned, it will be a condition of the grant that they look at other conditions and take the interests of other conditions into account.

Work is also being undertaken to explore how the Neurological Care & Support Standards can be used to build on a quality of care approach and to raise standards of care for people with ME-CFS.

5. How long is long term?

There was no update available re. publication of the ScotPHN rapid review of the evidence of links between COVID-19 and the development of ME-CFS, and on the comments submitted from stakeholders.

6. ME Awareness Month

SG will light up government buildings on ME Awareness Day. Other ideas included the Scottish Government intranet promoting a case study. The publication of the Gathering Views report could be used to celebrate what has worked. There is also an opportunity to write a piece on ME and health literacy and self-management. SG have a staff ME network.

#MEAction Scot focus continues to be on Millions Missing. They will host a series of interviews, drop in/drop out sessions. AfME will publish their Mentor ME guide. The 25% ME Group traditionally campaign, and are keen to highlight the CPD module.

Stakeholders agreed any support for the promotion of the CPD would be welcomed.

Other updates: The James Lind Alliance is progressing without any delays. Chris Ponting is now the principal investigator for DECODE ME.

7. A.O.C.B.

There was further discussion about the ScotPHN ME-CFS Healthcare Needs Assessment. This work is still at a very high level. How this is built upon and has practical application taking account of work already being done at primary care level needs consideration.

The Scottish Government has the scope to look at research, and the role of technology, including clinical trials. For example the Scottish Health Technologies Group were commissioned to look at the efficacy and safety of disease modifying therapies that led to new clinical pathways for MS.

The CSO can also provide support via their seed corn funding for neurology, to engage clinicians and academics.

There was some discussion about identifying and engaging clinicians in the work and gathering their views on next steps. It was noted that **[REDACTED- s.38(1)(b)]** who was involved in the writing of the SGPS is now retired. Consideration needs to be given to how to create an environment that attracts people to the field and supports clinical research.

It was agreed that it was the right time for SG to begin engaging with clinicians and to convene a group that would support the building of relationships prior to bringing together with the wider stakeholder group.

Actions

1. ***[REDACTED- s.38(1)(b)] offered to prepare a briefing to support future discussion re. SIGN.***
2. ***SG to coordinate date of next meeting in line with advance sharing of final guideline with a view to deciding next steps for Scotland.***
3. ***SG will send link to projects and what is being funded re. long-COVID, including practical support for individuals.***
4. ***SG will liaise with AfME to build relationship with RCGP and make connections to support extension of CPD project***
5. ***SG to confirm date of next meeting re. ScotPHN steering group.***
6. ***SG to share a link to the healthcare needs assessment for chronic pain, to demonstrate how other policy work is being developed***
7. ***SG to convene meetings with clinicians and engage in conversations about recent policy work and potential next steps when NICE guideline is published.***

Attendees: [REDACTED- s.38(1)(b)]

Agenda

1. Feedback from NICE Stakeholder Round Table Meeting, 18 October 2021

It was noted that [REDACTED- s.38(1)(b)] had provided a useful online written summary of the NICE meeting on the 18 October. Those who had attended the meeting on 18 October were asked to feedback any general thoughts or comments. The feeling was that the meeting was well chaired, stakeholders made to feel welcomed by NICE and discussions went well. Advised amendments made to the guidelines were minor and didn't give any concern to patient representatives.

NICE had agreed to update on next steps to stakeholders after today (26/10/21).

2. SIGN guidelines/ Scottish Good Practice Statement (SGPS)

There have been some previous discussions, both from SG and third sector organisations, with SIGN. The feedback has been that SIGN will not produce guidelines without clear evidence.

The feeling is that if SIGN do not produce new guidelines, it would be useful for them to endorse the SGPS when produced, which would better communicate any recommendations to clinicians and patients. Previous experience has demonstrated that the timeline for producing guidelines could take up to two years so this approach could be more beneficial.

It was highlighted that it would be good to get confirmation from SIGN on what they can offer as well as confirmation from them that lack of evidence is a factor in not producing SIGN guidelines.

ACTION: Scottish Government (SG) to contact SIGN to explore initial thoughts on what they could offer and confirm any barriers in producing guidelines.

3. Multi-disciplinary teams

The group were asked to give their thoughts on multi-disciplinary teams and how this might look for ME/CFS care. Rather than new teams being created, these would be existing teams with changes to their coordination. It was suggested that the 'specialists' in ME/CFS would need specific training and expertise and there is a lack of trainers who are able to carry out appropriate training. It was suggested that teams should be medically/ consultant led and coordination of care from different specialties, although a generic problem across healthcare, would be the best option.

ACTION: [REDACTED- s.38(1)(b)] agreed to approach Neurological Allowance of Scotland (NAoS) to ask for thoughts on coordinated care models/potential role of care coordinator and to feedback to the group at the next meeting.

4. Healthcare education/ engagement with medical schools

[REDACTED- s.38(1)(b)] updated that the CPD module was presented to the Scottish Deans Medical Education Group (SDMEG) who have agreed to review the module with the view of introducing into the curriculum. This was circulated to the educational leads within the medical schools.

Clinical Priorities colleagues have introduced [REDACTED- s.38(1)(b)] with [REDACTED- s.38(1)(b)] who has asked medical schools for details of how ME/CFS is taught. He is coordinating a joint statement on the feedback and SB would circulate this once received.

NHS Education for Scotland (NES) have committed to a practice based learning module. They were completing an assessment of needs which was paused when the NICE guidelines publication was paused. [REDACTED- s.38(1)(b)] has requested an update on how this is moving forward.

Clinical/ healthcare education seems to be crucial and SIGN guidelines would highlight gaps in training.

[REDACTED- s.38(1)(b)], an Occupational Therapist based in [REDACTED- s.38(1)(b)], carries out training in ME/CFS and could potentially offer this in Scotland. [REDACTED- s.38(1)(b)] agreed to get in contact with her to get her thoughts on this.

ACTION: [REDACTED- s.38(1)(b)] to speak to [REDACTED- s.38(1)(b)] about training and report back to the group

5. Research

[REDACTED- s.38(1)(b)] has met with the Chief Scientist Office (CSO) in relation to wider Neurological Framework research. CSO specifically welcomed proposals from ME/CFS, however, have not received any recently. [REDACTED- s.38(1)(b)] reported that Research UK, which would usually look at bids smaller scale than would go to CSO, have a number of applications at the moment, but there is usually more funding available than is granted each year.

It was felt that low interest in ME/CFS research funding could be because of the lack of researchers in the field with little investment. It was additionally suggested that there were ME/CFS related applications that don't receive funding due to the subject matter and it would be useful to determine if this is the case and why. It was suggested that the group could look in to this further and discuss offline.

[REDACTED- s.38(1)(b)] would be in touch with [REDACTED- s.38(1)(b)] to take this forward and [REDACTED- s.38(1)(b)] suggested Action for ME's Research Manager would be useful to include.

ACTION: [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] would look in to research funding to determine the barriers to ME/CFS applications and report back to the group.

6. AOB

6.a. SPIRE request on prevalence data

The group asked about an update on gathering prevalence data on the condition. [REDACTED- s.38(1)(b)] updated that a request had previously been made to SPIRE for data but, due to a technical issue, they were unable to process this until next year. [REDACTED- s.38(1)(b)] agreed to get an update on the likely timing for this.

ACTION: [REDACTED- s.38(1)(b)] to contact SPIRE get an update on timescales for this.

6.b. Graded Exercise Therapy (GET) in Scotland

The group asked about what measures could be taken to ensure GET was not being prescribed in Scotland. [REDACTED- s.38(1)(b)] agreed to find out what was being done regarding this and to report back.

ACTION: SG to explore this and report back.

6.c. Cumberlege Report/ Liverpool Care Pathway

There had been a number of references to the parallels between the Cumberlege Report and Liverpool Care Pathway and it would be useful to get a response from the Patient safety Commission on this.

ACTION: SG to contact the Patient Safety Commission for a response to parallels between the Cumberlege Report and Liverpool Care Pathway.

6.d. Healthcare Needs Assessment (HNA) for children and young people.

Public Health Scotland (PHS) had started work on a HNA for children and young people. This work had been paused due to clinicians involved being redeployed to other areas due to the pandemic. SG agreed to get a further update on this.

ACTION: SG to contact PHS for an update on the progress on HNA for children and young people.

6.e. Neurological Framework end of project reports

A previous request to receive the Framework end of project reports was still outstanding. The reports would be useful to review to see what learning can be transferred to ME/CFS work. It was updated that five projects have completed to date and work is underway to share the reports online via a SG webpage. The reports could be shared in the interim.

ACTION: SG to share end of project reports and to update on wider sharing.

6.f. Health and Social Care (HSC)/ SIGN

It was highlighted that adult social care need to be addressed and that NICE now includes health and social care. It is unclear if this applies to SIGN too. SG agreed to look in to this and confirm.

ACTION: SG to look in SIGN covering HSC and to report back to the group.

6.g. Stakeholder Mediation

[REDACTED- s.38(1)(b)] updated that there could be some funding available to commission some external mediation to ensure positive and equitable stakeholder engagement going forward, particularly in the future development of Scottish guidance. The group agreed this would be worth exploring.

ACTION: SG to look at mediation options and to report back to the group.

Note of ME/CFS Stakeholder meeting – 24/2/22

Attendees: [REDACTED- s.38(1)(b)]

Agenda

1. Welcome and Introduction

2. Review of Previous Minutes & Actions

The group reviewed the minutes and actions from the last meeting. Points of discussion included:

- **Implementation of NICE guidelines.** Further updates on this can be found under item 4.
- **Multi-disciplinary teams and coordination of care.** [REDACTED- s.38(1)(b)] had discussed this with the Neurological Alliance of Scotland and noted the care coordinator role approach outlined in the Scottish Government Long COVID strategy. A further discussion took place around how this kind of model might look in ME/CFS. It was suggested that the group think about this and feed in any comments. It was noted that MDTs are in place in England.
- **Healthcare education/ engagement with medical schools.**

The group felt there was a lack of progress from NHS Education for Scotland regarding the Practice Based Small Group Learning Module and stressed the importance of education for progress in ME/CFS treatment. An example of GET still being advised by a GP in Scotland was highlighted. [REDACTED- s.38(1)(b)] reported that she was awaiting an update from NES on progress regarding production of the module.

- **SPIRE request on prevalence data.** It was updated that SPIRE data had been delayed. The Scottish Government are expecting a further update on timescales shortly.
- **Graded Exercise Therapy (GET) in Scotland.** There was discussion around the NICE recommendations, and strong feeling among stakeholders present that GET be no longer offered to people with ME/CFS in Scotland. SG are currently looking at the best mechanism by which to most effectively communicate the changes indicated by the NICE guidelines regarding GET and CBT.
- **Healthcare Needs Assessment (HNA) for children and young people.** SG has been in touch with PHS to confirm a point of contact on any progress around children and young people.

3. Stakeholder Consultation Exercise

The group updated on their experiences of the SG-commissioned stakeholder consultation exercise, undertaken by Blake Stevenson Ltd.

It was generally fed back that the exercise had been really positive and those who took part felt the process had worked well. There was feeling that concerns were taken on board and there was a good understanding of the issues.

Questions were raised about the consultation report, how the details and summaries would be broken down, for example, by respondent. There was uncertainty around format but the expectation was that it would be broken down by issue/theme.

In regard to dissemination of the report, the group asked how widely this would be circulated. It was confirmed that this would be published and widely circulated once finalised.

Once the report was published, decisions would be made on further actions in terms reviewing the existing Scottish guidance on ME/CFS. The formation of a task and finish group was suggested, however it was agreed that it would be best to see the findings of the final report prior to confirming any next steps.

It was hoped that, with the report due at the end of March/early April 2022, we would be in a good position to discuss it at the next meeting.

4. Implementation of NICE guidelines

It was updated that officials had recently met with NICE, who confirmed that they are preparing an Implementation Support Statement to accompany the guidelines on ME/CFS.

Officials also met with SIGN, who were clear that there were no current plans to produce SIGN guidelines so soon after the publication of new NICE guidelines. It was also highlighted that there is a long lead-in and production time for SIGN guidelines. SIGN had suggested that officials could consider a Scottish Implementation Note, similar to that recently produced for Long COVID.

It was explained to the group that the Long COVID implementation note was produced by a Scottish Government-led task and finish group, and is hosted on the SIGN website.

It was highlighted that one of the aims of the Blake Stevenson consultation exercise is to gather views on the best approach/format for updating Scottish guidance – e.g. revising the Scottish Good Practice Statement vs. producing a Scottish Implementation Note.

There was a discussion about impact, with concern expressed by stakeholders that the SGPS had been introduced with little awareness/visibility and 'status' around it. Some attendees felt that badging was important to ensure any guidance was effectively disseminated and implemented. It was also noted that the Long COVID update was a 'living document' and stakeholders felt this an important precedent to follow.

A question was asked about the membership of any task and finish group. It was explained that the Blake Stevenson report would help in informing decisions around this.

5. Neurological Framework Round Three of Funding

There was an update on round three of funding through the Neurological Framework. The deadline for applications was 7 March 2022 and the SG would welcome any applications in relation to the care and support for people with ME/CFS.

6. AOB

It was highlighted that the minutes of the last meeting were not available until very close to the meeting. It was agreed to get the minutes of this meeting out in good time ahead of the next meeting.

Notes of meeting with Neurological Alliance of Scotland (NAoS) and the Minister for Public Health and Women's Health, Jenny Minto MSP

24 May 2023 10.30-11.00

Attendance at the meeting: Jenni Minto MSP, Minister for Public Health and Women's Health; [REDACTED- s.38(1)(b)], NAOs (Chair), Parkinson's UK Scotland; [REDACTED- s.38(1)(b)], NAOs [REDACTED- s.38(1)(b)]; [REDACTED- s.38(1)(b)], NAOs Admin Assistant; [REDACTED- s.38(1)(b)], NAOs Trustee, Brainstrust; [REDACTED- s.38(1)(b)], NAOs Trustee, Revive MS Support; [REDACTED- s.38(1)(b)], NAOs Trustee, Quarriers; [REDACTED- s.38(1)(b)], NAOs Trustee, Cerebral Palsy Scotland; [REDACTED- s.38(1)(b)], Child Brain Injury Trust; [REDACTED- s.38(1)(b)], Child Brain Injury Trust; [REDACTED- s.38(1)(b)], Epilepsy Connections; [REDACTED- s.38(1)(b)], Headway Dundee & Angus; [REDACTED- s.38(1)(b)], MND Scotland; [REDACTED- s.38(1)(b)], MND Scotland; [REDACTED- s.38(1)(b)], Brain and Spine Foundation; [REDACTED- s.38(1)(b)], Quarriers; [REDACTED- s.38(1)(b)], Neuro Hebrides; [REDACTED- s.38(1)(b)], ME Action; [REDACTED- s.38(1)(b)], Edinburgh Headway; [REDACTED- s.38(1)(b)], PSP Association; [REDACTED- s.38(1)(b)], Scottish Tremor Society; [REDACTED- s.38(1)(b)], MyAware; [REDACTED- s.38(1)(b)], MyAware; [REDACTED- s.38(1)(b)], Alzheimer Scotland; [REDACTED- s.38(1)(b)], Thistle Foundation; [REDACTED- s.38(1)(b)], FND Hope UK; [REDACTED- s.38(1)(b)], Compass; [REDACTED- s.38(1)(b)], Compass; [REDACTED- s.38(1)(b)], Scottish Post Polio Network

The Minister expressed her thanks to the group, for the opportunity to hear about progress and the challenges faced by the people NAOs represent. She also was also keen to hear how she can work with members addressing the needs of the neurological community.

[REDACTED- s.38(1)(b)] gave a presentation on the work of NAOs and findings from their recent patient experience survey.

There was an opportunity for members to raise any issues and ask the Minister questions.

Issues raised:

- ME – a survey was undertaken of the 14 NHS boards to find out about awareness levels of the NICE guidelines for these conditions. 10 responded. Only 7 knew about the guidelines. There needs to be training and protected time for learning for staff.
- Post Polio syndrome – there needs to be better awareness of this condition
- Huntington's – a motion was signed by a number of backbenchers (one of the most supported motions) asking for improved allocation of resources for people with Huntington's

- Questions were also raised in relation to essential tremor, Functional Neurological Disorder (minister's awareness of), public health measures in relation to foetal alcohol or valproate syndrome, and progressive supranuclear palsy.

Note: prior the meeting, NAOs members were asked to submit questions for the Minister. These were circulated after the meeting and can be found here: **[Internal SG Link](#)**

Nurse Competencies Mapping 3rd Steering Group Meeting

Monday 8th April 2024 1500-1600 **Note of meeting**

Agenda Item

1. Welcome, Introductions and Apologies
Apologies received from [REDACTED- s.38(1)(b)], [REDACTED- s.38(1)(b)], [REDACTED- s.38(1)(b)],
Welcome to [REDACTED- s.38(1)(b)] (SG For [REDACTED- s.38(1)(b)]) and [REDACTED- s.38(1)(b)]

2. Actions from previous meeting (18.03.2024)
i) [REDACTED- s.38(1)(b)] – survey group for recommendations for comms plan around engagement, in terms of which networks to approach for review
(Carry forward)
ii) All – please share any relevant core documents with [REDACTED- s.38(1)(b)] (Completed)

3. Delivering Nurse Competency Mapping
[REDACTED- s.38(1)(b)] gave an overview of the draft frameworks – 4 specialist and one general framework and outlined plans to include content on methodology, use of existing frameworks as the basis for the work.
[REDACTED- s.38(1)(b)] had questioned in previous comments whether the language was suitable/ accessible, but group felt this was appropriate for nurses working in this clinical area.
[REDACTED- s.38(1)(b)] suggested some rejigging of content in some sections and the addition of some drugs for the Parkinson's framework.
Action1
Group to review draft frameworks and forward any comments/suggested amendments to [REDACTED- s.38(1)(b)] or to contact him directly to discuss by 26th April.
Action 2
Group to confirm, job titles with [REDACTED- s.38(1)(b)] for list of acknowledgements.

4. *Questions and discussion*
Epilepsy nurse specialist Steering group membership will be addressed.
Nurses from [REDACTED- s.38(1)(b)] team in NHS Tayside have agreed to join the group and
[REDACTED- s.38(1)(b)] is asking a Band 7 from her team to join.
Action 3
[REDACTED- s.38(1)(b)] to send [REDACTED- s.38(1)(b)] nurse's contact email ([REDACTED- s.38(1)(b)] sent already)
[REDACTED- s.38(1)(b)] to invite the nurses to the next meeting.

Discussion continued on the importance of circulating the final draft frameworks once amended with any comments from the group, to key stakeholder groups for sense check and as a means of engagement prior to publication.

Action 4

Group to send [REDACTED- s.38(1)(b)], contact details of stakeholder groups

5. AOB

Action 5

[REDACTED- s.38(1)(b)] CNOD meeting update - at next meeting

6. Date of next meeting:

Beginning of May - tbc

Item 3, a: Virtual v Face to Face guidance

The group received an update on the guidance, with an example of the guidance shared with the group. The group also discussed the input from service users and third sector organisations in to the guidance. NAOs has developed a survey to members on the proposed guidance.

Action: [REDACTED- s.38(1)(b)] / [REDACTED- s.38(1)(b)] to circulate a draft copy of the survey to the group for comment and approval prior to sending out.

Update: A draft version was circulated and we are hearing an update on the survey at this meeting.

Action: [REDACTED- s.38(1)(b)] offered to produce a project plan to outline the timescales involved in delivering the survey.

Update: A project plan has been produced and circulated.

Item 3, b: Neuro AHPs and Neuropsychology Near Me Guidance Project

The group heard about the planning of the AHPs and Neuropsychology Near Me Guidance Project. A date has been set for 16 September for an online event to gain feedback on and promote the guidance.

The group discussed the use of AHP group sessions and how this would be in the scope of this work. [REDACTED- s.38(1)(b)] has contacts that will be able to advise

Action: SG team to check with AHP contacts that group sessions can be included in the event.

Update: It was felt that as the session was for such a short period of time, there was little time to break in to groups. Additionally, the process for booking means we are unable to identify attendees prior to the event. Group sessions would be explored prior to any follow up activities/ events.

Item 4, a: Workforce - Update on workforce survey data

[REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] provided a summary of the recent survey results. It was agreed that it would be useful to share the results with neurological contacts and SG workforce colleagues for any input.

[REDACTED- s.38(1)(b)] provided an update on AHP workforce paper and on recent discussions regarding the Neurophysiology non-medical workforce. It was agreed that these areas should be considered along with others once wider feedback had been received on the survey results.

Action: SG to share survey data with neurological contacts for input and feedback. Once complete RPG will undertake a prioritisation exercise.

Update: The results were shared with health board neurological contacts and feedback has been shared with the group for discussion at this meeting.

Action: SG to share survey data with SG colleagues for input and feedback.

Update: The results have been shared with colleagues and we are awaiting feedback.

Item 5: Modernising Patient Pathways Update

The group heard about the planned MPPP event taking place on the 1 September. It was agreed it would be useful for a couple of NAOs members to link into the event.

Action: [REDACTED- s.38(1)(b)] to share event details with AS to identify representatives.

Update: The event details have been shared.

Item 6. Sharing Practice

The group heard an update on the proposed practice sharing events that had been planned for the innovative projects. It has been discussed with NAC executive that the project evaluation reports should be reviewed initially prior to holding events. This will be used to make recommendations for further roll out / scale-up.

Action: SG team would add to the agenda for discussion at the next NAC meeting.

Update: This was discussed at the last NAC meeting.

Item 7: Update on networks

[REDACTED- s.38(1)(b)] updated on the neurology network that was currently being put together. There was some difficulty in reaching some health boards for information and the group made some suggestions on leads to try within the missing boards.

Action: [REDACTED- s.38(1)(b)] to share the network list to date with [REDACTED- s.38(1)(b)] for any additional contacts.

Update: the contact list has been shared for input.

Item 8. AOB

Redesign Project Group, 30 June 2021 – Actions

The group discussed the dates of upcoming meetings. It would be useful to still hold these on a monthly basis and these would be circulated to the group shortly.

Action: [REDACTED- s.38(1)(b)] to circulate future dates for meetings

Update: Meetings have been arranged and circulated up until December 2021.
The remaining meetings are:

Wed 6 October (2-3.30pm)
Wed 3 November (2-3.30pm)
Wed 1 December (2-3.30pm)

Item 2. Virtual v Face to Face Guidance

a. Medical

The group reviewed and discussed the final draft of the guidance to confirm the final version to be published. It was suggested that, although the guidance focusses on video consultations, it would be useful to acknowledge the role of phone calls. [REDACTED- s.38(1)(b)] agreed to add a paragraph in the guidance introduction to acknowledge this.

The group discussed the circulation and promotion of the final guidance. The guidance will be hosted on the Technology Enabled Care Team (TEC) webpage and it was agreed that [REDACTED- s.38(1)(b)] would circulate a link to this through the neurology network.

Action: [REDACTED- s.38(1)(b)] to add clarity of phone calls to the final guidance prior to finalising.

Action: [REDACTED- s.38(1)(b)] to circulate guidance through suggested networks.

Update: The suggested amendments to the document were made, to include the clarity around phone calls. The document has been circulated to through the neurology network, the National Advisory Committee for Neurological Conditions (NACNC) and the Resign Project Group membership for further circulation. Initial feedback received has been very positive.

Item 3. Virtual v Face to Face Guidance

b. Neuropsychology

[REDACTED- s.38(1)(b)] was unable to attend this meeting but had sent an email to update on progress of this work. [REDACTED- s.38(1)(b)] has discussed neuropsychology guidance further with [REDACTED- s.38(1)(b)].

Neuropsychology have their own professional guidance on virtual consultations and [REDACTED- s.38(1)(b)] plans to use this, as well as the guidance created for neurology as a template. [REDACTED- s.38(1)(b)] will raise this with Heads of Neuropsychology (HONS) at a meeting in December and hopes to report back at the next meeting.

Action: [REDACTED- s.38(1)(b)] to raise neuropsychology guidance with HONS and feedback at the next meeting.

Update: [REDACTED- s.38(1)(b)] will be providing an update on this work at the next Redesign Project Group meeting on 9 March.

Item 4. Clinical Nurse Specialist

[REDACTED- s.38(1)(b)] updated the group on the national competency framework, work closely aligned to the Chief Nursing Office Directorate work on transforming roles. A sub-group with representatives from across a wide range of NHS Boards and conditions has been established. The group felt this would be

Redesign Project Group, 1 December 2021 – Actions

valuable work. It was agreed that it would be useful for the neurological team to discuss the next steps further with NACNC Executive at their upcoming meeting.

Action: [REDACTED- s.38(1)(b)] to put on agenda with NACNC Executive to discuss next steps.

Update: An update on this will be discussed at the next Redesign Project Group meeting on 9 March.

Item 5. NHS Inform

In updating and discussing the progress of NHS Inform, [REDACTED- s.38(1)(b)] mentioned that she was finding it difficult to make contact with clinicians across health boards, particularly in NHS Tayside. [REDACTED- s.38(1)(b)] suggested he might be able to help so [REDACTED- s.38(1)(b)] agreed to send over existing contacts to [REDACTED- s.38(1)(b)] for further input.

Action: [REDACTED- s.38(1)(b)] to send on NHS Inform clinical contacts to [REDACTED- s.38(1)(b)] to input further

Update: Contacts have been shared and a further update on this work will be discussed at the next Redesign Project Group meeting on 9 March.

Item 3. Virtual / face to face guidance

a. Medical guidance - feedback/update on published guidance

The group discussed the guidance that was published in December which included an additional wording around telephone calls, as suggested at the last meeting. In addition to this, [REDACTED- s.38(1)(b)], Near Me National Lead, has asked [REDACTED- s.38(1)(b)] do a video blog on the guidance.

In regard to feedback on the use of the guidance, it was suggested it would be useful to conduct a formal survey after six months since publication. It would be useful to know any challenges and to possibly gain an idea of the impact and process across conditions. To capture an initial understanding, it was agreed to do a survey across the neurological network to gain feedback on the use and any challenges faced, volume of use and, for example, what happens when it doesn't work correctly.

ACTON: [REDACTED- s.38(1)(b)] to develop and email neurological network with a survey on the use of the guidance.

Update: A survey has been drafted as a paper for discussion at the meeting in May.

Item 3, Virtual / face to face guidance

b. Neuropsychology guidance

[REDACTED- s.38(1)(b)] updated on the development of neuropsychology guidance. This has been discussed with the neuropsychology heads of department for feedback. Although face to face consultations are preferable, virtual appointments can be useful in certain cases, for example screening new patients. It would be useful to do an audit on services in remote and rural areas. [REDACTED- s.38(1)(b)] agreed to draft an outline ahead of the next meeting.

ACTION: [REDACTED- s.38(1)(b)] to share at next meeting

Update: [REDACTED- s.38(1)(b)] will update on progress at the next meeting.

4. Rehabilitation Framework Update

As [REDACTED- s.38(1)(b)] was unable to attend the meeting, an update paper had been circulated to the group which [REDACTED- s.38(1)(b)] talked to.

There had been a previous update around the Rehabilitation Action Plan which has now been delayed.

A recent focus has been on a 'Once for Scotland' rehabilitation approach, setting out a national programme of improvement work that will aim to deliver 'good rehabilitation' for all, at the point of need across Scotland. The ambition is for good conversations to occur as early as possible, perhaps in a primary care setting by an AHP or link worker who will discuss the range of rehabilitation options available across all sectors. The group discussed this further and were supportive of the

proposal to have [REDACTED- s.38(1)(b)], or colleagues from Rehabilitation, joining the meetings on a regular basis to update on the progress of work.

Action: [REDACTED- s.38(1)(b)] to invite Rehabilitation colleagues along to the future meetings

Update: [REDACTED- s.38(1)(b)], Senior Policy Manager is attending the next meeting to update on Rehabilitation progress.

5. Workforce

a. AHP working group Terms of Reference

The group heard an update on AHP working group and a Terms of Reference for was circulated for reference. The proposed group's aims would be to better understand the current workforce; develop tools to enable more accurate prediction of the impact of the changing workforce on the availability of care and support; understand changes in demand in Neurology and Neurorehabilitation services in acute/community settings and their potential impact on AHP workforce; and recognise the benefits of AHP roles in providing care and support.

An initial meeting would be set up with [REDACTED- s.38(1)(b)] to discuss the next steps and focus of the group.

Action: [REDACTED- s.38(1)(b)] to arrange an initial meeting, to include [REDACTED- s.38(1)(b)].

Update: A meeting was held on 10 May and an update on this will be provided at the next meeting.

5. Workforce

c. Neuropsychology Care pathways

[REDACTED- s.38(1)(b)] discussed the *Survey of Neuropsychology Services to people with Neurological Conditions* paper that was circulated prior to the meeting. The scoping exercise was set up following concerns that the pandemic had impacted on service waiting lists. It was hoped that the survey, which would be circulated to department heads of neurological services with input from staff, would test and seek views on solutions that have been implemented.

The group were asked for feedback on the proposed survey. The survey includes dementia which would be taken out as not covered by neurology. It was also agreed that it would be useful to add a question about pathways and dedicated services.

Action : [REDACTED- s.38(1)(b)] agreed to amend ahead of sending out.

Update: - the questionnaire was amended after last meeting and has been circulated to all neuropsychology departments in Scotland. [REDACTED- s.38(1)(b)] is awaiting responses.

3. Virtual / face to face guidance

a. Medical guidance evaluation

An online questionnaire on the use of the guidance is being produced with the plan to send this to neurology service managers and clinical contacts for distribution to relevant colleagues. It is hoped that the results of this survey will be available by the next meeting.

ACTION: [REDACTED- s.38(1)(b)] to undertake survey and feedback results at next meeting.

Update: The survey was distributed with a deadline of 19 August for completion. The results of this will be discussed at the next meeting in September.

b. Neuropsychology guidance

[REDACTED- s.38(1)(b)] was unable to attend but sent an update, via email, prior the meeting. She has drafted neuropsychology remote guidance for people with neurological conditions and passed to heads of neurology for comment and hopes to share a draft at the next Redesign Project Group meeting.

ACTION: [REDACTED- s.38(1)(b)] to share a draft of the neuropsychology remote guidance ahead of the next meeting.

Update: [REDACTED- s.38(1)(b)] will share a verbal update on progress at the next meeting in September.

6. Workforce

a. AHP working group – update and discussion on workforce planning tools

[REDACTED- s.38(1)(b)] updated that she and [REDACTED- s.38(1)(b)] had met with [REDACTED- s.38(1)(b)], National Allied Health Professions Workforce Lead, Healthcare Improvement Scotland (HIS), and [REDACTED- s.38(1)(b)], Allied Health Professions Education Advisor, Scottish Government. It was decided to look at the model that HIS had developed in measuring workforce capacity and demand. HIS are keen to pilot the use of the tool in neurology.

The West of Scotland would be keen to be a pilot site for this tool and it was hoped that this would run over a two week period and the Redesign Project Group AHP Sub Group would review the results.

The next steps would be to hold further discussions with NHS Ayrshire and Arran practical in terms of identifying AHP areas in using the tool.

The group discussed other areas where this could be piloted. Tayside was considered, as they had done a lot of work in this area, although not necessarily within neurology.

ACTION: [REDACTED- s.38(1)(b)] to set up further meetings to discuss and update at the next meeting.

Update: A meeting between [REDACTED- s.38(1)(b)], [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)], to discuss next steps, was held on 16 August. An update will be provided at the next meeting in September.

b. Neurophysiology update

[REDACTED- s.38(1)(b)], who had joined RPG for the first time, outlined background to the review of healthcare sciences that is currently progressing, scoping education and career structures. [REDACTED- s.38(1)(b)] is professional adviser for physiology. Surveys were undertaken in early 2022 looking at where current professionals have been educated and staff complement variation across boards. Glasgow Caledonian course is coming to an end and negotiations are progressing around a science graduate education approach. Sustainability of this small workforce is a challenge. A first draft of the healthcare sciences strategy will be ready in July and complete by the end of 2022. Sarah will update the group on progress.

ACTION: [REDACTED- s.38(1)(b)] to update progress.

Update: [REDACTED- s.38(1)(b)] will provide an update on progress at the next meeting in September.

d. Clinical Nursing Specialist (CNS) competency framework update

[REDACTED- s.38(1)(b)] provided an update on the CNS competency framework. Prior to the pandemic, it was highlighted that competencies and education were important in retaining nurses in Scotland.

The Neurology Clinical Nurse Specialist Project Group met in May 2022 (a paper, with notes from this, were circulated prior to the meeting) and agreed to look further at aligning nurse competencies and produce a transforming roles competency matrix, along with recommendations and next steps, for sharing at the next meeting.

ACTION: [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] to draft a paper, outlining outputs and recommendations for the next stage.

Update: A paper has been drafted and circulated and will be discussed at the next meeting in September.

2. Nursing

a. Transforming Nurse Roles

[REDACTED- s.38(1)(b)] provided an update on the Neurology Nursing Competencies paper which was circulated to the group prior to the meeting.

A review of Clinical Nurses Specialist competencies for four major neurological conditions in Scotland, MS, Parkinson's disease, MND and epilepsy has taken place.

It was found that there are specific competencies that exceed the core competencies outlined in the Transforming Roles paper.

Following discussions with three of the four neurological institutes nurse managers found that there is an opportunity to improve appraisal and mentoring processes new and existing posts.

Clinical Nurse Specialists are keen to establish a network for appraisal and mentorship.

The paper is currently being review by the Chief Nursing Officer Directorate (CNOD).

b. Neurology Clinical Nurse Specialists joint proposals between Neuro, workforce, Chief Nursing Officer

A internal paper is being developed as part of work with CNOD. This work will help understand variations and areas of good practice.

Clinical Priorities and CNOD, with input from Workforce colleagues, are looking to identify gaps and succession planning. This work will also consider the findings from the Transforming Nursing Roles work.

An Action Plan is being drawn up in coordination with CNOD and will look to the Redesign Project Group to input in to this.

ACTION: [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] to have a separate meeting to discuss both of these papers.

Update:

3. Neuropsychology

a. Workforce capacity / training survey

[REDACTED- s.38(1)(b)] updated that the information on the workforce capacity/training survey is currently being gathered and is hoped to be available at the next meeting.

b. Development of Virtual / Face to Face Guidance

[REDACTED- s.38(1)(b)] updated that the guidance is currently in draft and would like to get thoughts on next steps from [REDACTED- s.38(1)(b)] before bringing to the group.

[REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] offered to look at this, as done previously with the medical guidance, to provide feedback.

ACTION: [REDACTED- s.38(1)(b)] to forward draft guidance to [REDACTED- s.38(1)(b)] for input.

Update:

c. Enhanced Psychological Practice training

MW updated on the Enhanced Psychological Practice (EPP) training. As the #My NeuroSurvey identified gaps in psychological support, [REDACTED- s.38(1)(b)] at NHS Education for Scotland (NES) had previously been approached to ask if this could be included in neurology training. [REDACTED- s.38(1)(b)] responded to say that when EPP participants are supervised, then they would be willing to add this. She also mentioned that participant could be enrolled in a MSc qualification but this may be of a too high a level for them.

[REDACTED- s.38(1)(b)] has wondered if there could be a module developed and will discuss with Heads of Neuropsychology Scotland (HONS).

It was also suggested that this could be discussed with [REDACTED- s.38(1)(b)], a Clinical Psychologist with a specialist in Cerebral Palsy, to find out what is currently available to help feed in to this.

It was agreed that [REDACTED- s.38(1)(b)] would liaise with [REDACTED- s.38(1)(b)] on a response to [REDACTED- s.38(1)(b)]

ACTION: [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] to draft a response to [REDACTED- s.38(1)(b)]

Update:

4. Neurophysiology – Healthcare Sciences Strategy Update

SS gave an update on the Healthcare Sciences Strategy. A baseline review has been undertaken by [REDACTED- s.38(1)(b)], Chief Healthcare Science Officer at Scottish Government. A scoping review is being drafted and is expected to be completed by mid-December for Cabinet Secretary to review and hopes to be able to attend future Redesign Project Group to update on this.

[REDACTED- s.38(1)(b)] outlined the background to the review of healthcare sciences that is currently progressing, scoping education and career structures. Surveys were undertaken in early 2022 looking at where current professionals have been educated and staff complement variation across boards. The Glasgow Caledonian University course is coming to an end and negotiations are progressing around a science graduate education approach. Sustainability of this small workforce is a challenge.

Redesign Project Group, 7 September 2022 – Actions

A first draft of the healthcare sciences strategy will be completed by the end of 2022. **[REDACTED- s.38(1)(b)]** will update the group on progress at future meetings.

ACTION: [REDACTED- s.38(1)(b)] to update progress as work develops.

Update:

**Action points from National Advisory Committee for Neurological Conditions -
Redesign Project Group – 25 January 2023**

Item no.	Item
1.	<p>Present: [REDACTED- s.38(1)(b)]</p> <p>Apologies: [REDACTED- s.38(1)(b)]</p> <p>Joining today was [REDACTED- s.38(1)(b)], Chief Nursing Officer Directorate, to present on the AHP Education and Workforce Review</p>
2.	<p>Notes of the last meeting and matters arising All matters arising included in the agenda</p>
3.	<p>AHP Education and Workforce Review</p> <p><u>AHP Education and Workforce Review</u> AM provided an overview of the work to date. Recommendations from the review were approved by Cabinet Secretary at the end November 2022 and will be published early 2023. An implementation plan will be produced to help ensure policy direction.</p> <p>The RPG would review and discuss when published.</p>
4.	<p>AHP Professional Judgement Tool</p> <p><u>AHP Professional Judgement Tool - Update</u> The current work on the tool, involving NHS Ayrshire and Arran, NHS Greater Glasgow and Clyde and Healthcare Improvement Scotland, is ongoing. Preparation work has been done and awareness sessions will take place on 2 and 9 February. The final report is expected to be completed by 14 March.</p> <p>It was agreed to bring this back to group for discussion at the next RPG meeting in March.</p> <p>ACTION [REDACTED- s.38(1)(b)]: to update on the outcomes of the pilot at next meeting.</p>
5.	<p>Centre for Sustainable Delivery – Neurology Update</p> <p><u>GP Factsheets</u> CfSD are making final checks of the GP factsheets prior to publication. If available, it was hoped that these could be added to the Neurological Framework newsletter going out at the end of January.</p> <p>ACTION [REDACTED- s.38(1)(b)]: If received in time, [REDACTED- s.38(1)(b)] to forward on links to factsheets to [REDACTED- s.38(1)(b)] for inclusion in Neurological Framework newsletter.</p>

	<p><u>Discharge Patient Initiated Reviews (PIR)</u> Following establishment of PIR in of this in NHS GG&C and NHS Fife currently implementing, additional health boards have shown an interest in PIR and CfSD are looking to support.</p> <p><u>Speciality Delivery Group</u> The group is currently working with clinical leads to develop topics for future meetings. It was noted that there is a similarity to the group being developed through NACNC, so keen to be coordinated with this.</p> <p><u>Headache pathway</u> [REDACTED- s.38(1)(b)] is scheduling in time with [REDACTED- s.38(1)(b)] to discuss the headache pathway.</p>
6.	<p>Workforce Delivery Group</p> <p>The initial meeting of the group was held in mid-January and a paper circulated to RPG to outline discussions and next steps. The Minister has approved an initial outline of this work and keen for this to have an impact. At the meeting, the group were keen to focus on nursing, particularly with CNOD and SEND participation.</p> <p>There was, as yet, no NAOs involvement and [REDACTED- s.38(1)(b)] agreed to send on an invitation.</p> <p>Action [REDACTED- s.38(1)(b)]: to send on invitation for NAOs membership of the group.</p> <p>The group were asked to feedback any further thoughts on the paper to [REDACTED- s.38(1)(b)] as soon as possible.</p> <p>Action All: To feedback further thoughts on the paper to [REDACTED- s.38(1)(b)].</p>
7.	<p>Healthcare Sciences Review (Neurophysiology)</p> <p>The review looked at the wider healthcare landscape with the baseline review highlighting a lack of healthcare science visibility. A further questionnaire was sent on to seek key priorities with recruitment, retention and education as emerging themes.</p> <p>Work is ongoing on the next stages in collaboration with education and CSO colleagues.</p>
8.	<p>Neuropsychology</p> <p>[REDACTED- s.38(1)(b)] was offered apologies so [REDACTED- s.38(1)(b)] provided an update on Neuropsychology in her absence.</p> <p><u>Workforce Survey</u></p>

There were no further updates available regarding the survey. It was hoped that [REDACTED- s.38(1)(b)] will be able to present the results at the next meeting.

Virtual / Face-to-face consultation guidance

Following the last meeting in November, [REDACTED- s.38(1)(b)] had received further comments and made additional changes to the guidance. The next steps would be to contact Near Me team involved in the publication of the clinical neurology guidance to get advice on publication.

Action [REDACTED- s.38(1)(b)]: To get in touch with Near Me to arrange a meeting to discuss publication of the guidance.

Education and training

[REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] have written to [REDACTED- s.38(1)(b)] at NES to request for inclusion of neuro as part of programme. She has advised that NES are holding an internal review of the course, so this is progressing. There were no timescales for this so [REDACTED- s.38(1)(b)] agreed to contact NES to find out more.

Action [REDACTED- s.38(1)(b)]: To get further updates on timescales form NES on the timing of the programme.

9.

Progress Updates:

NHS Inform

[REDACTED- s.38(1)(b)] had offered apologies so no update was given. An update would be provided at the next meeting.

Rehabilitation Framework

The recruitment in to [REDACTED- s.38(1)(b)] post is ongoing and there is an intention to pick up this work once the post is filled.

**Action points from National Advisory Committee for Neurological Conditions -
Redesign Project Group – 12 July 2023**

Item no.	Item
1.	<p>Present: [REDACTED- s.38(1)(b)]</p> <p>Apologies: [REDACTED- s.38(1)(b)]</p>
2.	<p>Nurse Census Workforce Planning Tools</p> <p>[REDACTED- s.38(1)(b)] gave a background to the national census of Clinical Nurse Specialists that NES is leading (attached slides provide more detail). It will include all clinical nurse specialities (not just neurology). A letter to Nurse Directors and workforce leads will go out at the end of July outlining data collection methodology. Run of workforce tools will take place in October and January and will require the census data to be in place before this. HIS are also developing a calculator that will enable rostering to be more directed to need.</p> <p>The following discussion included points around neurology specific competencies, education, training and governance. [REDACTED- s.38(1)(b)] agreed to pick up issues around comparability of data points and coding with [REDACTED- s.38(1)(b)] offline.</p> <p>Action 1 - [REDACTED- s.38(1)(b)] advised that their census spreadsheet will be sent to Boards at the end of July.</p>
3.	<p>Discussion on merging Workforce Delivery and Redesign Project Groups - Outline terms of reference</p> <p>The draft Terms of Reference are an amalgam of two different groups and could be rationalised to reflect a higher level objectives. Comments were invited from group members, .</p> <p>Action 2 – all members asked to review draft Terms of Reference and provide comment by 26 July.</p> <p>[REDACTED- s.38(1)(b)] agreed with [REDACTED- s.38(1)(b)] that discussions on various topics could be broken into smaller groups, noting the length of time taken to discuss previous items. Extending the length of the meeting should also be considered.</p>
4.	<p>Nurse competency mapping</p> <p>[REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] had met with [REDACTED- s.38(1)(b)] who had outlined some of the challenges with nurse competency mapping led by the CfSD. Process, effective governance,</p>

	<p>quality assurance, and mechanisms for local adoption are priorities to address.</p> <p>Action 3 - [REDACTED- s.38(1)(b)] to arrange an initial meeting to plan out how to address these aspects of the work, to include [REDACTED- s.38(1)(b)]. Bring proposals to the next RPG.</p>
5.	<p>AHP Professional Judgement Tool</p> <p>[REDACTED- s.38(1)(b)] provided the group with an update on her work on the AHP Professional Judgement Tool, piloted in NHS GGC and NHS A&A, with support from Healthcare Improvement Scotland.</p> <p>[REDACTED- s.38(1)(b)] noted initial overall positives with this pilot, specifically the ability to capture data from more acute areas.</p> <p>This update was positively received by the group, with interest and questions raised about this pilot working in outpatient settings. MW is in conversation with HIS about a neuropsychology professional judgement tool.</p> <p>Action 4 – [REDACTED- s.38(1)(b)] to share final report with the Re-Design Project Group in September.</p>
6.	<p>Matters arising</p> <ul style="list-style-type: none"> - Neuropsychology (EPPP) <p>[REDACTED- s.38(1)(b)] gave an overview of EPPP, suggesting consideration into renaming this. [REDACTED- s.38(1)(b)] met with NES about development of module for psychological therapies practitioners who do not specialise in neurology. Further discussions need to take place through Heads of Neuropsychology Scotland (HONS) about the best approach (full module or video), who would be available to lead it and the resources required.</p> <p>[REDACTED- s.38(1)(b)] advised [REDACTED- s.38(1)(b)] that there would likely lots of third sector organisations who could help in that space, citing that many would have interest in this. This was welcomed by [REDACTED- s.38(1)(b)].</p> <p>Action 5 – [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] to meet to discuss resources needed after HONS meeting on 3 August. Include [REDACTED- s.38(1)(b)] in this discussion to identify approach to third sector input.</p> <ul style="list-style-type: none"> - Neuropsychology (Virtual Guidance)

[REDACTED- s.38(1)(b)] advised of a bit of stagnation in this space, and will forward final version to [REDACTED- s.38(1)(b)], approved through HONS. – fully reviewed by this group as well.

Action 6 - [REDACTED- s.38(1)(b)] to proof read and link with TEC around publication and dissemination.

- **Neuropsychology (workforce survey)**

[REDACTED- s.38(1)(b)] provided an update on Workforce Survey, and wants to get momentum behind this. This is another NES system that looks at the data. [REDACTED- s.38(1)(b)] shared her concern that a recent pull of data showed that neurophysiology has only increased by 4.9% with a 52% increase in caseload since 2016. - the lowest compared to others

It is hoped that the draft survey will be ready by the time of the next meeting

7.

Strategy updates

- **Centre for Sustainable Delivery ([REDACTED- s.38(1)(b))**

Headache pathway

- Headache pathway submitted to Speciality Delivery Group for comment and approval on 20 June.
- Additional 'modules' to be developed for cluster headache and indomethacin to support Headache pathway

GP factsheets to support ACRT

- GP factsheets finalised and published on the [Neuro SDG webpage](#)

FND

- SLWG established to develop FND pathway. First meeting held on 30 June (further dates scheduled over summer and into autumn)
- FND Initiation document submitted and approved (subject to caveat around measurement)

Facial Pain

- SLWG to be established for Facial Pain pathway development
- nominations have been requested

- **Rehabilitation Framework** (no update)

- **AHP Education and Workforce Review** (no update)

- **Healthcare Sciences Review** (no update)

- **NHS Inform** – Pages have been newly published or revised on 13 neurological conditions with a further 5 in progress.

8.	For noting: <ul style="list-style-type: none">- Note of RPG Meeting of March 2023 - G-AP training https://g-apframework.scot/
9.	AOB The next meeting is Wednesday 6 September

**Action points from National Advisory Committee for Neurological Conditions -
Redesign Project Group – 29 March 2023**

Item no.	Item
1.	<p>Present: [REDACTED- s.38(1)(b)]</p> <p>Apologies: [REDACTED- s.38(1)(b)]</p> <p>Joining today was [REDACTED- s.38(1)(b)], Education Team Leader, Chief Nursing Officer Directorate, and [REDACTED- s.38(1)(b)], Head of Innovation, Centre for Sustainable Delivery.</p>
2.	<p>Notes of the last meeting and matters arising All matters arising included in the agenda</p>
3.	<p>AHP Professional Judgement Tool - pilot in NHS Ayrshire & Arran and NHS Greater Glasgow & Clyde</p> <p>The pilot has now concluded and work is underway on the report and will be finalised in April.</p> <p>Overall the team found it quite demanding but managed to collect valuable data.</p> <p>A report will be available at the next meeting where [REDACTED- s.38(1)(b)] will update on the outcomes.</p> <p>ACTION [REDACTED- s.38(1)(b)]: to update on the outcomes of the pilot at next meeting.</p>
4.	<p>Allied Health Professions Education and Workforce Policy Review – update</p> <p>The report has been published since the last meeting. Work is ongoing on mapping activities to ensure all activities are captured and to identify any gaps.</p> <p>An action plan is being developed and will hopefully be completed over the next couple of months.</p> <p>The report and its findings are being promoted widely and formal presentation will be made to relevant local and national groups, including SEND.</p> <p>ACTION [REDACTED- s.38(1)(b)]: to send over information on the report to [REDACTED- s.38(1)(b)] for inclusion in the newsletter.(COMPLETE)</p>
5.	<p>Workforce Delivery Group</p>

The group met on 16 March 2023 and an agreement was made for NHS Education for Scotland (NES) to undertake a census on Clinical Nurse Specialist (CNS) roles.

NES have sent on a list of CNS classifications for the group to review and comment on roles relating to neurology, including any omissions.

Further work is needed to develop guidance and in gathering data across health boards.

This work will be brought together for the next Workforce Delivery Group meeting to discuss the next steps.

6.

Updates in Brief

- Neuropsychology

Virtual guidance

Guidance on conducting virtual appointments has been completed and shared with the Near Me for any additional comments.

Enhanced Psychological Practice programme

[REDACTED- s.38(1)(b)] also met with NES around the Enhanced Psychological Practice (EPP) programme. The options of introducing a webinar or an in-depth TURAS module. It is felt that the TURAS module may be more achievable and MW will discuss this with the Heads of Neuropsychology to get further thoughts.

It was noted that **[REDACTED- s.38(1)(b)]** had been finding it difficult to get workforce data and RB agreed to contact **[REDACTED- s.38(1)(b)]** to ask if any support could be provided by the group.

ACTION RB: [REDACTED- s.38(1)(b)] to contact **[REDACTED- s.38(1)(b)]** to ask if any support required.

- NHS Inform

Updates have been published on ataxia, epilepsy, functional neurological disorder, Huntington's disease, migraine, motor neurone disease, multiple sclerosis and muscular dystrophy, transverse myelitis and cerebral palsy.

It is hoped that further conditions, including dystonia, progressive supranuclear palsy and Parkinson's disease will be published shortly.

It was suggested that these updates are highlighted in the next Neurological Framework Newsletter, to also include a call for suggestions on any conditions currently missing.

ACTION [REDACTED- s.38(1)(b)]: to include updates NHS Inform in the next newsletter to call for any suggestions on conditions (COMPLETE)

- Neurophysiology / healthcare sciences

As [REDACTED- s.38(1)(b)] was offering apologies, the group were asked to refer to the paper and updates providing in the paper circulated prior to the meeting.

- Rehabilitation Framework

It is hoped that the new AHP Professional Advisor (Rehabilitation) post will be recruited to shortly.

- Centre for Sustainable Delivery

The Speciality Delivery Group are working on the annual work plan for forthcoming year. Priorities are ACRT and PIR and the improvement in measurements of these.

GP Fact Sheets

It is hoped that the GP Fact Sheets will be published on the CfSD website shortly.

Suggestions have been made to include a user note within the factsheets – these will not to replace, but rather supplement, patient letters.

Pathways

Work is ongoing to look at presenting the headache pathway in an accessible way. It is hoped that this will be approved at next Speciality Delivery Group meeting

Discussions are ongoing around work on the FND pathway.

7.

The Accelerated National Innovation Adoption (ANIA) Pathway

[REDACTED- s.38(1)(b)] provided an update on ANIA and a wider discussion took place on its uses within neurology.

The neuro team will look at any technologies that could be used through ANIA.

8.

AOB

**NATIONAL ADVISORY COMMITTEE FOR
NEUROLOGICAL CONDITIONS –
Service Improvement Forum
Paper 1**

Meeting date: 8 November 2023

Agenda item: 2

For: Noting and approval

Title: Service Improvement Forum – Minutes of September 2023

**Source &
Rationale:**

**Actions
required:**

Redesign Project Group is invited to:

- Note and approve

Author: [REDACTED- s.38(1)(b)]

Date: 2 November 2023

**Action points from National Advisory Committee for Neurological Conditions -
Service Improvement Forum – 6 September 2023**

Item no.	Item
1.	<p>Present: [REDACTED- s.38(1)(b)]</p> <p>Apologies: [REDACTED- s.38(1)(b)]</p>
2.	<p>Note of RPG Meeting of July 2023</p> <p>There was an error in the previous notes of the last meeting, on page 6, last paragraph, to be amended from 'neurophysiology' to 'neuropsychology'.</p>
3.	<p>Revised Terms of Reference & 6 month work plan</p> <p>The revised Terms of Reference for the group amalgamate Redesign Project Group and Workforce Group. ToR have been further amended following discussion at NACNC.</p> <p>The group is to be renamed to the Service Improvement Forum. Once approved, the Terms of Reference will be sent to NACNC for final approval.</p> <p>Action: all to review document and feedback to [REDACTED- s.38(1)(b)] within 2 weeks prior seeking sign off from NACNC.</p>
4.	<p>Rehabilitation Framework</p> <p>[REDACTED- s.38(1)(b)] has been in post since July, as professional lead for the Rehabilitation Framework. The Rehabilitation Network has representatives from across NHS boards and HSCPs with its first meeting in the coming days. This is an opportunity to hear about locally refreshed rehabilitation strategies.</p> <p>This group will be important to link in speciality focus. Work is planned to embed the six principles in other specialities.</p>
5.	<p>Nurse competency mapping</p> <p>Proposal for a short term commission with NHS Education for Scotland (NES) to map three neurological conditions, Multiple Sclerosis (MS), Parkinson's Disease (PD) and Motor Neuron Disease (MND).</p> <p>This will use existing UK and Scotland approved nurse competency frameworks, mapping these to the paper, <i>Transforming Nursing, Midwifery and Health Professions' Roles: Review of Clinical Nurse Specialist and Nurse Practitioner Roles within Scotland</i> (TNR8), to ensure alignment with core competencies for Band 6 and Band 7 nurse specialist roles.</p> <p>It was requested that the process takes competency mapping done in the third sector into account.</p>

	<p>ACTION: [REDACTED- s.38(1)(b)] to check with [REDACTED- s.38(1)(b)] regarding third sector work</p> <p>The group were happy with the proposals set out in the paper.</p>
6.	<p>AHP Professional Judgement Tool</p> <p>The report on the testing of <i>Allied Health Professions Professional Judgement Tool</i> is only just finalised and will be circulated after the meeting.</p> <p>Pilot boards: NHS Greater Glasgow & Clyde, NHS Ayrshire & Arran, acute and regional services including neurology, neurosurgery and neurological rehabilitation.</p> <p>The Professional Judgement Tool was able to accurately reflect demand and capacity and the impact on outcomes within some clinical teams. However, some of the more nuanced requirements of neurological care, such as more frequent and shorter interventions, were not accurately captured. Interventions requiring more than one allied health professional were also a challenge.</p> <p>The Professional Judgement Tool, does not reflect the breadth and width of the AHP workforce across out-patient and community services, social care, third sector and voluntary services.</p> <p>Further development is required before rolling this out.</p> <p>ACTION: [REDACTED- s.38(1)(b)] to meet with [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] to discuss next steps</p>
7.	<p>Neuropsychology primary care training proposals</p> <p><i>Outline commission for Development of a Neuropsychology Educational Resource</i>, proposes to develop a short neuropsychology educational resource:</p> <ul style="list-style-type: none"> - To improve the understanding of healthcare professionals of the mental health support needs of people with neurological conditions - To improve the rate of appropriate referrals <p>It was agreed that this is an important piece of work and supported by the group.</p> <p>ACTION: [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)] to refine the proposal prior to taking this forward</p>
8.	<p>Strategy updates</p> <p>Nurse Census - Data not yet available.</p>

AHP Education & Workforce Review - the implementation plan has been shared with stakeholders. Feedback has been taken on-board and work is underway to group themes and make it more accessible. A report will be shared with the group once ready.

Healthcare Sciences Review – A substantive update should be ready for the next SIF meeting.

ANIA – Parkinson’s Watch - Update on progress would be provided at the next meeting.

Centre for Sustainable Delivery (CfSD)

- The National Headache Pathway is being taken through the CfSD sign off process.
- FND pathway - a short life working group is refining a draft.
- CfSD is working with Right Decision Service (RDS) to establish a Neurology ‘app’ on the RDS platform. This will initially include the GP factsheets, with the intention to add the Headache Pathway once approved.

NHS Inform - Nearly all of the 20 conditions planned or to be updated have now been completed. The only outstanding condition is Parkinson’s.

The process to manage for any further updates should be easier now the relationships between NHS Inform and clinicians has been formed.

9.

AOB - The next meeting is 8 November

**Action points from National Advisory Committee for Neurological Conditions -
Service Improvement Forum – 7 February 2023**

Item no.	Item
1.	<p>Present: [REDACTED- s.38(1)(b)]</p> <p>Apologies: [REDACTED- s.38(1)(b)]</p>
2.	<p>Note of SIF Meeting of November 2023</p> <p><u>Matters arising:</u> By way of an update from the question at the last meeting around the announcement by the First Minister of £300m of funding to clear waiting times backlog and how to access this, [REDACTED- s.38(1)(b)] updated that the Scottish Government are awaiting confirmation of this year's budget announcement before confirming allocation of this funding – this will be communicated once confirmed.</p>
3.	<p>Clinical Nurse Specialist Update</p> <p>- Nurse census</p> <p>NHS Education for Scotland have supported Scottish health boards to cleanse data in establishing the number and specific roles of Clinical Nurse Specialists (CNS). Data has been collected, including headcount, banding, age and specialty.</p> <p>The data shows that there are 212 CNS roles identified and 23 sub-specialties in relation to neurology.</p> <p>The data categories will be updated every two years on the NHS Scotland's electronic staffing system, eESS.</p> <p>Information from one NHS board is still outstanding and, once inputted, the final management report is due to be completed by March 2024.</p> <p>- Nurse competency mapping</p> <p>[REDACTED- s.38(1)(b)], currently a Research Nurse at the Anne Rowling Regenerative Neurology Clinic, has been recruited to lead on mapping nurse competencies to the Transforming Nursing Roles: Paper 8 (TNR8). The work will look at core competencies and define unique knowledge and skills to create a clear career development framework. The work will be supported by a Steering Group of which [REDACTED- s.38(1)(b)] will represent the Service Improvement Forum.</p> <p>In terms of timescales, the mapping will take place in early summer 2024 and digitised following that.</p>

4.	<p>Centre for Sustainable Delivery</p> <ul style="list-style-type: none"> - FND Pathway <p>[REDACTED- s.38(1)(b)] presented on the development of national pathway for FND and, for wider context, the role of the Centre for Sustainable Delivery and the Speciality Delivery Group in relation to the development and sign off of pathways.</p> <p>The work around the FND pathway has been aided by previous work in Bristol, where a pathway had been running for 18 months.</p> <p>It was noted that the Pathway suggests a FND practitioner role in each of the NHS boards which would require extra resourcing, which may be an issue given current pressures.</p> <p>There was clear interest in the process of developing the Pathway, particularly in how this could be replicated for other conditions such as, for example, ME/CFS.</p> <p>The Pathway is currently awaiting sign off from the Speciality Delivery Group prior to publication.</p> <ul style="list-style-type: none"> - Developing Plans for 2024-2025 <p>The following work was identified to be taken forward in the coming year.</p> <ul style="list-style-type: none"> • FND pathway final sign off • Facial pain pathway • Identifying new pathways as part of the 2024/25 Deliver Plan • Work on refining and expanding measurement approaches • Work on evidencing impact <p>[REDACTED- s.38(1)(b)] agreed to share the slides after the meeting.</p> <p>ACTION : [REDACTED- s.38(1)(b)] to share slides to the group</p>
5.	<p>Strategy updates</p> <ul style="list-style-type: none"> - Neuropsychology <p><u>Neuropsychology virtual guidance</u> Neuropsychology guidance has been completed and will be hosted on the Technology Enabled Care website. Further communications will be circulated once published.</p> <p><u>Training</u> The training resource to support a 'neuropsychology informed' workforce though NHS Education for Scotland (NES) is on hold whilst NES clarify core</p>

resource for the coming year. [REDACTED- s.38(1)(b)] agreed to keep updated on this.

Survey data

The staff survey data has been collected and awaiting approval. There will be an update on this at the next meeting.

- **AHP Workforce Planning Tool**

A meeting to discuss the AHP Professional Judgement Tool will take place shortly and updates will be provided afterwards.

- **Rehabilitation Framework**

Work is ongoing on the development of the self-assessment tool, which is set against the six principles of good rehabilitation, alongside the Right to Rehab Coalition. This is awaiting sign off and local work will be done alongside NHS Boards once confirmed.

The ongoing self-evaluation against the Neurological Standards work was raised and [REDACTED- s.38(1)(b)] confirmed that this would help complement this.

It was confirmed that the work will cover both community and acute rehabilitation settings.

There were concerns raised about the specialist rehabilitation being out of scope within NHS Boards, but assurances were made that this would be covered in the Framework. [REDACTED- s.38(1)(b)] agreed to look at what was happening out with Scotland regarding what was in and out of scope.

It was agreed that it would be useful to see an 'easy read' document of the Framework.

- **Pharmacy**

Work on pharmacy competencies is drawing on the work of the nursing competency work, and are keen to see the outcomes of that prior to progressing.

- **AHP Education & Workforce Review**

AHP Policy team are currently working on the implementation plan and an Advisory Group has now been set up, chaired by [REDACTED- s.38(1)(b)], Chief Allied Health Professions Officer. A report on the recommendations is due in March 2024.

	<p>In regard to classification of occupations, there is data on the numbers of AHPs employed but not within each speciality. There will be data available on banding and whether roles work either in paediatric or adult settings, although this information will not be as detailed as the CNS work figures.</p> <p>Trials are ongoing in health boards and it is hoped information will be fed back by April 2023, although time will be needed to input the data after that.</p> <ul style="list-style-type: none"> - ANIA – Parkinson’s Watch <p>An application is being completed, to be submitted by the end of March 2024. The application would then be put into the Horizon Scanning Report where it would then be considered.</p>
6.	<p>6 month work plan</p> <p>For noting that this has been updated.</p>
7.	<p>AOB</p> <p>No other business was noted.</p> <p>The next meeting will take place on the 27 March 2024.</p>

Service Improvement Forum – 27 March 2024

Attendees

[REDACTED- s.38(1)(b)]

Apologies: [REDACTED- s.38(1)(b)]

Welcome and Apologies

Apologies were noted, with [REDACTED- s.38(1)(b)] acting as Chair on behalf of [REDACTED- s.38(1)(b)].

Note of SIF Meeting of February 2024

This meeting was seen as progress update to the February meeting.

Workforce Planning

- Nurse census

Data will be ready for the May SIF meeting

Action: include this on the next agenda.

- Nurse Competency Mapping

This is progressing and it is expected to be able to present a final version to the group at the May meeting.

Action: include this on the next agenda.

- AHP Workforce Planning

The AHP Professional Judgement Tool that was piloted had shortcomings in being able to workforce plan. Next steps:

- Engage with AHP workforce census being undertaken by NES – we need to establish who is in the workforce, their skillset and demographic

Action: [REDACTED- s.38(1)(b)] to put [REDACTED- s.38(1)(b)] in touch with colleagues in NES leading the AHP census work. Include [REDACTED- s.38(1)(b)] and [REDACTED- s.38(1)(b)].

Strategy updates

- AHP Education & Workforce Review

The oversight group for implementation has met twice. A plan has been reviewed. It was suggested the team leading this work could come and present at a future meeting.

Action: Schedule for the May or subsequent meeting.

- Rehabilitation Framework

Work is ongoing on a rehabilitation self-assessment around six principles of good practice. The aim is to have this piloted in Boards to allow them to analyse their practices and look to improve outcomes in the long-term.

- Neuropsychology

Neuropsychology staff survey – this was not ready to be presented at this meeting but the group expect this to be ready to present for the next SIF meeting in May.

Guidance on virtual appointments is ready to publish, but still waiting for TEC team to revise their website.

Action: [REDACTED- s.38(1)(b)] to present staff survey at May SIF.

- Pharmacy

NHS Grampian /Migraine Trust programme is expanding into NHS Tayside, Lothian and Lanarkshire for phase 2. TURAS modules for community pharmacists are being developed and headache pathway is being incorporated.

Proposals to Directors of Pharmacy to formalise the neurology Special Interest Group are progressing.

Consultant Pharmacist role descriptions are being developed. It is yet to be finalised if these posts would be created to be geographic or condition specific. The intention is to co-ordinate appointment nationally.

Action [REDACTED- s.38(1)(b)]: Link with [REDACTED- s.38(1)(b)] in SG who is leading the policy for consultant pharmacists (links to advancing practice agenda).

- ANIA – Parkinson's Watch

An overview of the technology has been drawn up for inclusion in the ANIA Horizon scanning process. Following advice from Scottish Health Technologies Group this needs some further work. Preference is for a technology that has been used in Scotland and we are exploring options for this.

- **Healthcare Science Review**

This was published on 14 March, and was flagged with this group for interest, notably neurophysiology.

Action: Explore a fuller update on this at the May meeting

- **CfSD Pathways update**

Work progressing on a National Pathway for FND.

There have been some recent updates to Headache Pathway modules.

There will be a new National Pathway for Facial Pain. **[REDACTED- s.38(1)(b)]** flagged that Facial Pain goes over multiple specialities and asked for the pathway to be in different locations on the 'Right Decisions' App accessible by all relevant specialities (eg ENT and Max Fax).

CfSD have been gathering suggestions for 2024/2025 workplan.

Use of Near Me

[REDACTED- s.38(1)(b)] commented that 'Near Me' tends to have better uptake when embedded into the structure of a clinic. NHS Grampian operate Near Me at Board and managerial level who triage calls into the correct clinic, reducing responsibilities for clinicians.

Action ([REDACTED- s.38(1)(b)): Discuss the strategic roll out with TEC.

6 month work plan

This paper was for noting.

AOB

No other business.

MEETING MINUTE: Minister for Public Health and Women's Health with ME Action Scotland, 25 October 2023

Attendees

Jenni Minto, Minister for Public Health and Women's Health
[REDACTED- s.38(1)(b)], ME Action Scotland
[REDACTED- s.38(1)(b)], ME Action Scotland
[REDACTED- s.38(1)(b)], ME Action Scotland
[REDACTED- s.38(1)(b)], ME Action Scotland

Official support

[REDACTED- s.38(1)(b)], Clinical Priorities Unit
[REDACTED- s.38(1)(b)], Clinical Priorities Unit

Note of meeting

ME Action Scotland members introduced themselves by sharing individual stories about their experiences of living with ME/CFS or caring for people with the condition.

1. Implementation of ME/CFS NICE guideline in Scotland, training for clinicians

ME Action Scotland asked for an update on the Scottish Government's (SG) plans for implementing the NICE guideline on ME/CFS in Scotland, saying that too many clinicians were unfamiliar with best practice guidance and were still offering graded exercise therapy to ME/CFS patients as a result, with harmful consequences.

The Minister said that SG fully supported the NICE guideline and that the National Clinical Director had written to NHS boards to raise awareness of it. Her officials had been meeting with stakeholders, clinicians and the Royal Colleges about the potential to work on aligning Scottish guidance with NICE recommendations.

ME Action Scotland said that training for clinicians on ME/CFS needed to improve, noting that at their recent conference stall they received a lot of interest from GPs. They asked for an update on when NHS Education for Scotland's (NES) learning module on ME/CFS would be published. They said they would like to see mandatory inclusion of ME/CFS training with the GP contract in Scotland.

[REDACTED- s.38(1)(b)] said that SG understood NES would be piloting the module in November 2023 and publishing it as soon as possible afterwards. SG had also awarded £32,528 to the Learn About ME online training project for a further 18 months.

2. Survey on ME/CFS services

ME Action Scotland asked about four health boards who still had not responded to SG's survey on ME/CFS service provision.

[REDACTED- s.38(1)(b)] said SG would ask these boards again about their provision in this area and keep ME Action Scotland updated on any responses received. SG had already published an analysis of the data from ten boards.

ME Action Scotland highlighted the fact that the ME Specialist Nurse in NHS Fife had recently died and raised their concerns about the impact on the service.

[REDACTED- s.38(1)(b)] advised that SG have contacted the health board to understand their plans for the situation.

ME Action Scotland asked if any service development work was planned as a result of the survey.

[REDACTED- s.38(1)(b)] advised that there had been early discussion with a specific Scottish health board regarding planning for a local pathway for ME/CFS support, alongside Long COVID. A multidisciplinary group of clinicians and practitioners in the area were undertaking some planning work, however it was stressed that this was at a very preliminary stage.

3. Children and young people with ME/CFS

ME Action Scotland highlighted the experiences of children and young people with ME/CFS and the impact upon their education, carers and families. They asked what SG would do to provide services for children and young people with ME/CFS.

The Minister said she recognised the importance of care for children and young people with ME/CFS. SG had sought views from parents and carers in its earlier stakeholder consultation exercise on ME/CFS.

MEETING MINUTE: Minister for Public Health and Women's Health with MS Society UK, 23 November 2023

Attendees

Jenni Minto, Minister for Public Health and Women's Health
[REDACTED- s.38(1)(b)], MS Society
[REDACTED- s.38(1)(b)], MS Society

Official support

[REDACTED- s.38(1)(b)], Clinical Priorities Unit
[REDACTED- s.38(1)(b)], Clinical Priorities Unit
[REDACTED- s.38(1)(b)], Chief Nursing Officer Directorate

Note of meeting

1. Neurological workforce

MS Society UK asked about the Scottish Government's (SG) plans to ensure the sustainability of the neurological workforce in Scotland.

The Minister said that SG was taking the necessary steps to support NHS staffing capacity. SG was increasing the number of training places in general practice and neurology in line with expert recommendations.

[REDACTED- s.38(1)(b)] said that SG was also identifying ways to strengthen the neurological workforce through the work of the National Advisory Committee for Neurological Conditions. NHS Education for Scotland had been commissioned to map clinical nurse specialist competencies for MS and other neurological conditions to align with 'Transforming Nursing Roles' framework.

2. Rehabilitation

MS Society UK spoke about their participation in the campaign for a 'Right to Rehab'.

The Minister said that rehabilitation should be based on an individual's needs and preferences. The Once for Scotland Approach to rehabilitation aimed to address challenges facing rehabilitation services and support the delivery of meaningful person-centred rehabilitation for long-term conditions, including neurological conditions.

3. Stem cell therapy

MS Society UK asked about referrals for hematopoietic stem cell therapy (HSCT) for people with MS, saying that this was not offered in Scotland and that not enough Scottish patients were being referred to have it in England.

[REDACTED- s.38(1)(b)] said officials had recently met the HSCT Network to hear their concerns about this. SG was planning work to formalise the national referral pathway for HSCT for MS, ensuring all boards were aware of how to refer patients.

4. Prescribing of Sativex

MS Society UK asked about Sativex for patients with MS, saying that there were some NHS boards where access to this had been a problem and providing some examples.

The Minister said that Sativex had been accepted for routine use in Scotland and there was a clear expectation that NHS boards would make it or its equivalent available. She said that officials would follow this up with the NHS boards identified by MS Society UK.

Note of meeting between Minister for Public Health & Women's Health and The Migraine Trust

Date: 30/11/23

Attendees:

- Minister for Public Health & Women's Health, Jenni Minto MSP
- [REDACTED- s.38(1)(b)], [REDACTED- s.38(1)(b)], Migraine Trust
- [REDACTED- s.38(1)(b)], [REDACTED- s.38(1)(b)], Migraine Trust
- [REDACTED- s.38(1)(b)], Scottish Government Clinical Priorities Unit
- [REDACTED- s.38(1)(b)], Scottish Government Clinical Priorities Unit

1) Recent Migraine Trust report 'Heading in the wrong direction'

Following introductions, [REDACTED- s.38(1)(b)] outlined the Scotland-specific findings and the key recommendations of the recent Migraine Trust report: '*Heading in the wrong direction*'.

Challenges faced by people with migraine were becoming more challenging, such as:

- Waiting lists
- Specialist services
- Treatments
- Referrals to secondary care
- Workforce

[REDACTED- s.38(1)(b)] highlighted that the Scotland-specific findings included:

- Average waiting time from GP referral to first appointment across 7 responding Scottish Health Boards was 29 weeks, up from 9 weeks in 2021
- Half of Scottish health boards reported having a specialist clinic for headache.
- Half of Scottish health boards reported that they had undertaken work to review their migraine pathways/arrangements.

[REDACTED- s.38(1)(b)] highlighted the report recommendations which included a national drive to improve migraine care, including the implementation of the new Scottish headache pathway, increasing available specialist services/NHS workforce regarding migraine, improving GP training, and ensuring pharmacists are skilled to have a strong role in migraine care. [REDACTED- s.38(1)(b)] also raised the need for better prevalence data regarding migraine.

Other points discussed included:

- The charity has evidence that 1 in 3 people with chronic migraine have reduced their working hours or lost jobs due to the lack of reasonable adjustments made by employers.

- Some progress has been made on lessening the stigma around migraine, but more action is needed on this aspect within workplaces.
- The charity is looking to link in with companies around employing people with migraine – to analyse how they can improve their practices and offer employees better support. It was suggested on this point that the Migraine Trust may find it helpful to review some of the third sector work previously undertaken regarding epilepsy in the workplace.
- Migraine affects 1 in 7, however it is often conceptualised as an uncommon condition, with more specialism available to those with rarer neurological conditions.
- The Migraine Trust stressed the importance of public education so that people do not conflate migraine with ‘just another headache’.
- The charity have prepared a GP training resource and are happy to share this with Scottish Government.

2) Event: Scottish Parliament, December 13th

Migraine Trust representatives discussed with the Minister arrangements for her attendance at the charity’s upcoming parliamentary event on 13th December 2023.

They explained that this would be a patient-focussed event, with most participants being people with lived experience of migraine. The event is being hosted by Jackson Carlaw MSP and several MSPs have agreed to attend. Speakers will include the Minister, Jackson Carlaw MSP, a person with lived experience, and **[REDACTED- s.38(1)(b)]** NHS Grampian.

The Minister stated a preference to speak last, in order to reflect on points raised by the other speakers.

3) Pharmacy pilot work in Grampian

Migraine Trust representatives described the positive work they have been undertaking with pharmacists in NHS Grampian area to help people manage their symptoms and treatments more effectively. The project has been funded for a second year through the Scottish Government’s Neurological Care & Support Framework. **[REDACTED- s.38(1)(b)]** reported that they have identified other health boards within which to further roll out the work, and that the project has been progressing so well that they anticipate it will likely to exceed the initial objectives outlined in their funding application.

Migraine Trust representatives expressed the charity’s support for the new national headache pathway for Scotland and asked if there was the potential to be involved in the Centre for Sustainable Delivery’s implementation of the pathway with health boards, stating that they would be happy to help with patient experience input, for example.

Officials discussed good points of contact for this and undertook to connect the Migraine Trust with the Centre for Sustainable Delivery, where appropriate.

Note of meeting between Minister for Social Care, Mental Wellbeing & Sport and MND Scotland

Date: 20/2/24

Attendees:

Minister for Social Care, Mental Wellbeing and Sport
[REDACTED- s.38(1)(b)], MND Scotland
[REDACTED- s.38(1)(b)], MND Scotland
[REDACTED- s.38(1)(b)], person living with MND
[REDACTED- s.38(1)(b)], Scottish Government
[REDACTED- s.38(1)(b)], Scottish Government

1) Overview of MND Scotland's Parliamentary reception on 16 April 2024

MND Scotland highlighted that their parliamentary reception in April will have the theme 'Making Time Count' and will focus on MND and social care/NCS. The attendees will largely be service users and their carers. The Minister for Housing will also attend.

2) People with MND & MND Scotland's priorities for a National Care Service.

MND Scotland outlined some of the challenges facing people with MND in accessing assessment and care in a timely and coordinated manner and which keeps pace with peoples' rapidly increasing needs. They highlighted the importance of early and comprehensive future care planning, and outlined difficulties relating to local authority budget constraints.

MND Scotland also raised points about a lack of engagement regarding the NCS and content they would like to propose to be included in Stage 2 amendments. The Minister asked officials to put MND Scotland in touch with NCS Bill team to discuss this further.

3) Short-term/immediate social care solutions for people with MND

In response to concerns raised by MND Scotland about delays to the NCS, the Minister asked whether more could be done to commission social care services for people with MND centrally, in advance of the introduction of the NCS.

4) [REDACTED- s.38(1)(b)] experiences of care

[REDACTED- s.38(1)(b)] described some of his experiences of living with MND and in particular about his problems obtaining social care support which led to a delayed discharge from hospital [REDACTED- s.38(1)(b)]. [REDACTED- s.38(1)(b)] raised points on the difficulties [REDACTED- s.38(1)(b)] encountered arranging care with

his local authority, on need for increased social care workforce, better pay and conditions. **[REDACTED- s.38(1)(b)]** also made points about social care sector staffing difficulties arising from current UK immigration legislation and related visa restrictions.

[REDACTED- s.38(1)(b)] – Chief Officer – Stirling HSCP

Note	Action
Prevalence – local needs assessments	Make it relevant for COOs
Health and Social Care Scotland website – IJB strategic plans – mentions of neurology??	Obtain names of COs on Exec Group. Before 10 Jan meeting – check those in depth of COOs at exec group and electronic search all others for references to neurological conditions
Involve [REDACTED- s.38(1)(b)] – re chief social work officer to be involved in NACNC	Tried during policy engagement but no replies. Need to make specific task to achieve this
Holistic needs – operational	Make it clear to COOs the governance and leadership structure proposed – NACNC is advisory – there will be operational local groups
Director of Regional Planning – [REDACTED- s.38(1)(b)] ([REDACTED- s.38(1)(b)] A&A Chairs group - West region – affordability of specialist NHS workforce, core and cluster model)	Speak to [REDACTED- s.38(1)(b)] in first instance Also SG policy lead for regions (was [REDACTED- s.38(1)(b)])
[REDACTED- s.38(1)(b)]??	
Review dates of strategic plan – stakeholder engagement group	Should be easily obtainable from Integration policy team. Use this timetable to prioritise discussions with IJB/HSCPs
Third sector Interface S (TIS)	Add to comms planned engagement
Social Work Scotland – [REDACTED- s.38(1)(b)] ([REDACTED- s.38(1)(b)] chairs this group)	Add to comms planned engagement
Social Care and Mental Health Leads – [REDACTED- s.38(1)(b)] (SG Mental Health Team)	Find out how this could be useful for neuro framework implementation
Carers’ Centre – links acute care (Ayrshire)	Example of how made acute/ community links
Self assessment – improvements – action plan – local group	Each local group needs to take ownership and develop focused approach to commitments in overarching framework??
Speak to 5 essential elements of HSCS when meeting COOs	
Twitter short clips – social media	[REDACTED- s.38(1)(b)] , [REDACTED- s.38(1)(b)] , others
Not assuming route to involve lived experience – ask best mechanism – might be reference group but might not	Discuss with [REDACTED- s.38(1)(b)] re NAOs