



# Access to Therapies for People Living with Neurological Conditions

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Executive Summary

Cheshire and Mersey Service

Improvement Forum

January 2022

Experts in MS

# An introduction to Service Improvement Forums

In 2020 the MS Society launched a new service improvement programme to support professionals working in MS and neurology services to adopt new and innovative ways of working, and to embed improvements across service pathways and clinical commissioning groups (CCGs) / integrated care systems (ICS) structures.

Focussed on delivering one of our organisational goals - “**Ensuring everyone can access high quality treatment, care and support**”- our Stakeholder Engagement Team has worked at a local level with a range of professionals and people using MS services.

Given increasing demands on health and social care services, and competing priorities for staff time, the service improvement programme focuses on embedding change across systems to ensure it is sustainable. Through our [Experts in MS](#) we provide professionals with the resources they need to implement this change and a space to develop understanding and innovation.

The programme approach is twofold:

Proactive - identifying new and innovative ways of working; providing opportunities to evaluate and quantify the impact of new service models and pathways; showcasing these success stories via webinars, reports and forums to enable other professionals to adopt them

Reactive - engaging with local services and people to understand current unmet need and opportunities to improve; convening and facilitating action planning forums to affect change; providing evidence, templates and best practice example to enable change to happen

Our service improvement forums are therefore both national showcases of best practice and new effective ways of working, and local system improvement implementation mechanisms.

Both driven by evidence and the voice of our MS community

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# Summary

## Background:

The 'Access To Therapies' forum was developed as part of an action plan following the Cheshire and Mersey MS pathway workshop in November 2020. Organised and facilitated by the MS Society, the Walton Neurological Centre and Wilmington Healthcare - the MS pathway workshop brought together people living with MS, health care staff and commissioners to discuss the optimum MS pathway and current gaps in delivery of the pathway in the region.

This workshop resulted in a number of conversations, facilitated by the MS Society Stakeholder Engagement Officer, between therapists and local people living with MS. A working group agreed that in order to take the work forward in any meaningful way, and to ensure access to effective local services for people with MS, a wider approach was needed.

As MS services do not operate in isolation, all elements of the pathway needed to be included - community, primary, secondary and acute services. It was also recognised that to be relevant to the Cheshire and Mersey Neuro Rehab review, and therefore able to be picked up by the Integrated Care System (ICS) in the strategic planning, commissioning and prioritising of services, that the focus of the discussion needed to be on all neurological conditions.

And therefore the forum was organised to identify and prioritise activity to improve access to a range of therapies for local people with a range of neurological conditions.

The breadth of the discussion that took place during the workshop is illustrated by the point below made in one of the groups:

'Need to develop a service that incorporates all the services people need to access'.

'Need to break down the barriers between services so there is a pathway that incorporates primary care, local charity condition specific groups, community services, public health wellbeing teams, acute services'

Importantly the discussion on the day and the report below identifies specific pieces of work that can move delivery towards the development of a service pathway that encompasses all the elements of health care detailed above.

The importance that health care staff place on developing this work is evidenced by the fact that in the middle of November 39 people gathered on line for a morning to discuss this, and as one person noted most people stayed until the end of the workshop at 1p.m

## Need:

The identified unmet need focused on access to a range of services and therapies – mainly physiotherapy, occupational therapy, and psychological support alongside respiratory and speech and language. This need was identified and recognised locally by health care staff, commissioners and people living with neurological conditions, echoing the UK wide report from the Neurological Alliance which identified a gap around access to these therapies exacerbated by covid:

'A funded, national strategy is required to improve rehabilitation in the four nations. We recommend a new national leadership role for rehabilitation in the NHS to drive forward this agenda.'<sup>1</sup>

The aim of the forum was to:

- Include a wider range of health care staff and people living with neurological conditions in the discussion to identify and explore the unmet need. There was a specific focus on increasing engagement

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<sup>1</sup> Effects of COVID-19 pandemic on people with neurological conditions and their access to health and care services; and the steps being taken to restart specialist neurology services – Short Debate tabled by Baroness Gale – Briefing for members of the House of Lords 27/5/21

from community services and primary care in order to ensure the whole pathway was considered.

- Identify both areas of good practice that could be spread and priority areas for development.
- Produce an action plan to address need and embed improvements in the pathway.
- The action plan would then influence:

Cheshire and Mersey Neuro Rehab review

Neuro Science programme board which is the body that is supporting the ICS in delivering



## Recommendations

The recommendations below are inter-dependent but can be developed separately:

**1/ Communication/ Single Point of Access for services including therapeutic services** There was wide ranging discussion in each of the break out groups on communication. The recommendation is to develop a single point of access for people living with conditions, and for health care staff that enables people to easily access therapeutic support from point of diagnosis and at points of change in the development of their condition. Or as one group discussion stated:

‘The ambition needs to be the right service at the right time, a single point of access, a single point of information.’

**2/ Develop access and use of emerging primary care services to meet the needs of people living with neurological conditions.**

Importantly some of the developments here would support the single point of access above - in particular the development of wellbeing coaches / links to social prescribing for people living with neurological conditions. It was recognised that these developments needed to be supported by training and links to the neuro specialists in health care including neuro OT's, physios, psychological support, respiratory and speech and language. Or as one group stated there is an opportunity to:

‘Develop access to community therapeutic services - GP’s; support to primary care; health and wellbeing coaches; mental health; leisure services.’

**3/ Ensure that new and emerging funding streams are being utilised where possible and appropriate to meet the needs of people living with neurological conditions.** Specifically the discussions on the day identified the additional role reimbursement schemes in primary care, social prescribing resources and also the National Recovery Fund linked to covid.

**4/ Workforce / Specialist Provision** The above recommendation links to the discussion detailed below on workforce and the need to develop and increase the numbers of neuro OT’s, physios, psychological support practitioners who can in turn support the more generic services in the community. This would need to be picked up by the neuro rehab review in the recommendation below.

**5/ The neuro rehab review will involve all stakeholders in information gathering and service development discussions that need to start with mapping existing services** - or as one group stated:

‘A road map of services on a geographical basis needs to be plotted so differences in access can be resolved and this can be communicated to patients.’

**6/ Develop a process whereby primary care staff including GP’s can be engaged in and influence the neuro rehab review and service development more broadly**

**7/ Develop work to address some of the specific gaps /barriers currently that prevent people living with neurological conditions accessing the support they need.** Specifically although not exclusively this needs to address key health determinants such as accessible transport, targeted employment services, adult changing spaces, and support and accessible housing / lifetime homes.

There were some examples of good practice to plug these gaps although more in relation to employment.



**8/ Support and develop an understanding of how people can access and make use of leisure services supported by the staff trained in the level 4 neurological conditions fitness professionals course.** This piece of work is specifically identified as a number of participants asked for more information on this provision

**9/ Ensure all the relevant stakeholders are involved in this service development with a specific focus on ensuring people living with the conditions are included and are supported and resourced to influence the development of accessible therapeutic services.**



## Next Steps

### **To deliver on the recommendations:**

- Discussion and agreement on recommendations / actions to develop from Neuro-Science Programme Board and people involved in the Cheshire and Mersey Neuro-Rehab review.
- Identify people / organisations that can support the development of work on the recommendations
- Enable people living with conditions and people working in the range of services identified above to feed into and influence this work moving forward. This will take place through the Therapy Working Group that supported the planning of the event. They will seek to expand their membership to include other service areas and people living with other neurological conditions (two people currently involved who live with MS).
- The report and recommendations will be discussed by the Neuro Science programme board at their meeting in March 22 and will be taken to the working group for the Neuro-Rehab review.



## Development and Forum Programme:

This online forum was developed with the OT and physio working group (including health care therapists, people living with and affected by MS, NHS commissioners and third sector organisations) who discussed and agreed:

- Programme and presenters
- Questions

(Copies in appendix 1)

The forum included presentations from (full presentations in appendix 2):

- Julie Riley - Strategic Lead for Walton Centre who presented on the Neuro Science Program Board for Cheshire and Mersey and their action plan
- Amanda Brooks - Cheshire and Mersey lead for the area Neuro Rehab review (Liverpool CCG Commissioner) who spoke about the Cheshire and Mersey Integrated Care System and their role in this review.
- Shelly Morris King - Consultant lead for Neuro Physio who spoke on developing access to Emotional Wellbeing and psychological Therapies.
- Rob Wright – St Helens MS Society Group who spoke on what the need is based on two recent surveys conducted with group members
- Jane Johnston Cree – Slaney / Chester Neuro Therapy Centre manager who spoke on the 'Access to exercise project' in West Cheshire and opportunities in primary care

There then followed facilitated small group discussions, a mix of professionals and people living with and affected by neurological conditions.

Each group had a scribe and the comments and discussion were written up. This information was then taken to the therapies working group that supported the planning of this event. This group includes commissioners, people living with conditions and therapists from both the acute and

community / third sector settings. The group write ups are included in the appendix 2.

The working group then considered the break out group comments and suggestions. This group identified the themes in the detailed findings section below and identified actions and recommendations to move this work forward.



## Detailed findings

The information and points below are drawn from the discussions and priorities identified in the break out groups

### **1/ Raise the profile of Neurological Conditions and clearly identify it as a priority**

Several of the break out groups welcomed the fact that the Cheshire and Mersey ICS had identified neuro-rehab as a priority for service development and that the work had been allocated to a lead commissioner to take forward.

It was discussed that the breadth and understanding of the needs of people living with neurological conditions was not understood sufficiently to support service development at ICS level, at 'place' level, and between services that operate across the ICS and at 'place' level both.

The raising of the profile of neurological conditions is already supported by the Neurological Alliance nationally who in their neuro numbers report state that 1 in 6 people live with a neurological condition and -

'Despite the efforts of Right Care, a recent freedom of information request

found that only 37 out of 195 Clinical Commissioning Groups have submitted delivery plans that reference neurological conditions.<sup>2</sup>

There is an opportunity this year and into 2023 to use the data published from the neurological alliance survey of people living with neurological conditions and link this to local information and surveys.

In addition to this the MS Society produced a Neurology Now report in 2022 which stated:

‘Despite 1 in 6 people in the UK living with a neurological condition, neurology services are stretched, underfunded and overlooked. These services were neglected long before the pandemic – this can’t continue.’<sup>3</sup>

## **2/ Single and Easy Point of Access to Therapeutic Services and the Development of Communication between all sections of the health care system.**

The development of communication with a specific focus on improving access to the services people need came up in all the break out groups as a priority and included:

- Communicating clearly about what services are available to people who could benefit from using those services
- Develop communication / information for people living with neurological conditions so they know about the benefits of therapeutic services (alongside self-management strategies) such as movement, exercise and activity, fatigue management, mindfulness and stress management.

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<sup>2</sup> <https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-numbers-2019-1.pdf>

<sup>3</sup> <https://www.mssociety.org.uk/sites/default/files/2021-10/Neuro%20Report%20V3.pdf>

- Communication and information needs to be developed / streamlined to support health care staff to refer to appropriate services.
- Bring this together in a single point of access that can be easily updated

These points are supported by the following comments:

‘Effective communication of services essential, not just to the potential users of service but to other service providers so they have the right contacts and access routes for their patients.’

The importance of the exercise programme was stressed as a crucial thing keeping people going

‘Also the benefit of physio is not given enough importance in health system in terms of prevention and rehab – it is very cost effective but no money put into it.’

Positively there were several suggestions about how to improve communication and move towards a single point of access including:

- Linking in with and supporting social prescribing to meet the needs of people living with neurological conditions.
- Support and develop the use of the level 4 neurological conditions fitness instructors in leisure services and beyond.
- The local neurological charities need to develop an easy to use resource of the support and contact points they provide that is available in one place
- Develop some pilot work through neurological wellbeing coaches in a community setting as they could be the single point of contact for people living with a neurological condition.

In addition to this the additional physiotherapist roles in primary care were discussed and the following point was made:

- ‘Can we tap into the extra Government funding for physios in GP surgeries for some neuro physios based in the community?’

- 'Would this need some support from the CCGs/ place based commissioners?'
- 'Could neuro physios be part of a PCN cluster as numbers too small to justify one for each GP practice?'
- 'Maybe they could be based in a Therapy Centre?'

There were some blocks / gaps identified to overcoming some of the barriers around single point of contact / communication including:

- Therapy staff ordinarily can't make referrals to social prescribing services, only GP / primary care staff can.
- There is a lack of information about the Walton Centre's Nurse Advice Line / single point of contact

'Need info about the nurse advice line and the clinics they run to be circulated - not sure how this information currently gets out to the people who need to know.'

- The difficulty of keeping this information up to date was discussed and it was suggested that a person needed to be given the role of supporting updates to the information on services available with sufficient time to develop this across Cheshire and Mersey.

'How do we get all this information in one place? Even when it is in terms of various on-line hubs it is only up to date for a period of time. Need a living, breathing person to keep this up to date and ensure info is disseminated.'

- It is important this information is appropriate to the changes and progression of neurological conditions that people experience

'Need the Cheshire and Mersey model that develops to support access for people at points of change in the development of their condition e.g. when struggling to continue working, stop walking.'

### **3/ Pathway development, communication and information flow between services**

This point follows on from the previous one about communication and specifically focuses on the role of commissioners and service development leads as well as health care staff.

One of the big priorities the presentations covered, and that was then picked up in the break-out groups, was the importance of commissioners and service planners making clear links between different services. This would include mental health services, community long term conditions and public health to support emotional and psychological support and activity and exercise at a community level to ensure they meet the needs of people living with neurological conditions where they live.

It was recognised that this work in the community needed to be supported by specialists in neurological conditions who could facilitate and support learning and understanding as well as receiving referrals where people's needs couldn't be met in the community e.g. access to cognitive assessment when that is needed; access to specialist OT and / or physio support; via the employment support interventions offered at the Walton Centre.

It was recognised that currently this is not how services develop in most cases and the current pressures on health care staff and the way in which people are pulled in many different directions was one of the things that prevents this happening. This was considered by all the break-out groups as important to developing systematic access to therapeutic services.

The following comments were made in the break out groups that support the above points:

- 'Need to break down the barriers between services so there is a pathway that incorporates primary care, local charity condition specific groups, community services, public health wellbeing teams, acute services'
- 'If we could get over some of these barriers then OT and physios could do joint visits with link workers, and know that they were supported on the actions to take to meet the needs of someone with a neuro condition'
- 'Commissioners and service planners making the links between different services e.g. mental health, community long term conditions and public health to support emotional and psychological support and activity and exercise at a community level to ensure they meet the needs of people living with neuro conditions where they live.'
- The importance of the exercise programme was stressed as a crucial thing keeping people going

- 'Also the benefit of physio is not given enough importance in terms of prevention and rehab – it is very cost effective but no money put into it.'
- Key feedback – 'How do we motivate people and keep them activated in a cost effective way?'

The developing Neuro-rehab review and the Neuro Science Programme Board work on their action plan were identified as ways to take this work forward



## Neuro rehab review for Cheshire and Mersey

It was clearly stated that the voice of people who use the services alongside all parts of the health care system need to be involved in the neuro-rehab review for Cheshire and Mersey and this needs to include community, primary care, secondary and acute.

This was seen as an opportunity to identify current gaps in provision and develop a consistent approach to provision of therapeutic support across Cheshire and Mersey. One group summed up the range of work that it was hoped this review could address with the support of the people and organisations present:

- Programme Board lead a piece of research to map out current delivery and inequalities in service between areas.
- Draw out NICE guidelines on access to therapies for a range of neuro conditions and map the current services with these standards
- Ensure input from health care staff and people living with conditions on what the delivery of these standards needs to / could include. Link with existing services e.g. IAPT, access to exercise etc.
- Develop a business case from the above information.
- Develop a road map of how and which services can be developed in line with the above work.





## Resources / Funding

The need to resource services and support for people living with neurological conditions was made in several groups and - as identified in the recommendations - there were several current suggestions of funding streams that needed to be explored to identify how they could be used to provide therapeutic services for people living with neurological conditions.

When the issue of funding came up though it was frequently to identify the way in which the provision of these services was preventative of the need for additional primary, secondary care / Continuing Health Care provision. This is illustrated by the point below from one of the groups:

‘Funding issues might become apparent, however there should be enough flex in the system to do some developmental work. There’s evidence about how prevention work is effective both in health outcomes and system savings - need to keep evidencing this to secure agreement to work in a different way.’

To ensure access to therapeutic services there is a clear need for the neuro rehab review to include funding and resources in the development of the business case. That will enable these services to be put in place sustainably.

### The role of the ICS:

Anxiety was expressed about this new structure in several of the groups:

‘Where do we fit in (as staff or people with a condition) and how can we be heard? – Where will the money go and will there be less than before? There is a worry about losing existing good stuff that we do.’

There was also a concern about losing people’s expertise in relation to commissioning and service development of neurological conditions:

‘As the changes proceed (to ICS) people move on, and new roles are being developed, so it’s essential communication is kept up to date’

It was also seen as positive that neuro-rehab had been identified by the ICS as a priority area of work. Potentially one of the roles that the ICS could support as well as the neuro-rehab review is detailed below.



## Workforce

There was an acknowledgement that there was mounting pressure on health care staff working in and around neurological conditions as with all health care staff at present. In addition the lack of specialist therapists in OT, emotional and psychological support, respiratory and speech and language were discussed.

Although it does not replace the need to develop additional specialist support, it was acknowledged by two of the groups that strengthening links with leisure services and the charities that support people with neurological conditions providing significant peer support, could ease the pressure on these specialist services and workers. This is illustrated by the comment below:

‘Some (not all) of this could be addressed by developing stronger links with leisure services and supporting access to local gyms with staff who have some training. Need to link the people already trained to therapists (similar to model operating on stroke prior to covid in St Helens)’

In addition the comment about workforce linked to the importance of not separating out physical and mental health practitioners which often causes problems for people when they receive their diagnosis as they report they don’t get enough support in relation to their mental health:

‘A lot of discussion about the link between mental and physical health that are considered separately to the detriment of patients wellbeing. Is there a way that this could be more joined up? Especially at diagnosis where mood disorders (anxiety and depression) are well recognised issues, early support at this point was vital and helped patients manage until access to other services happens, as was peer to peer support. This is also important for Carers as well as patients. Can the pathway look at where this support currently sits? Does it need to be earlier?’



## Innovation and good practice

During the discussions in the break-out groups there were several examples of good practice given which included:

- Merseycare life rooms and opportunity to develop social prescribing for people living with neurological conditions through this service
- Link between wellbeing team and stroke service prior to covid. Wellbeing staff on wards ensured there was a handover from the physio in hospital to the wellbeing team. Could this model be developed for all neurological conditions?
- Access to Exercise Project is available in West Cheshire only but the trained fitness professionals in Level 4 for Neurological Conditions are in several areas now. How can they be used more effectively to meet the needs of people with neurological condition and expand on the numbers already trained?
- Live well website run by Cheshire West And Chester Council as single point of contact for services, which is staffed to ensure information is updated
- Brain Charity Service on employment support has developed further post covid, and this links with the provision of a Walton Centre Occupational Therapy led clinic supporting people to maintain employment roles.

## Other gaps in service / People not currently involved in the discussion

A number of gaps and or barriers were identified to accessing therapies that are not directly linked to health care but do impact on peoples' wellbeing and ability to access therapeutic services:

- Transport – How will people get to and from activities and services?
- Services need to develop around emotional and psychological support from the point of diagnosis (This was seen as a very important time for this support).
- Changing places for adults - when people are out and about it was stated that there are nowhere near enough.

- Develop a focus on keeping people in / supporting people in employment who are living with neurological conditions– Link in with Brain Charity service
- OT's in social care need to be involved in discussion also
- Housing – need fully accessible housing to develop



## Acknowledgements

A thanks you to members of the MS Society Stakeholder Engagement team who supported this event to take place.

A huge thanks to the people living with MS who gave their time and were prepared to share difficult memories and experiences in relation to their journey with MS. And to the staff and volunteers of the neurological charities who participated

And thanks to the health care staff who have supported the delivery of services and information to date and who will work with the information here to develop this further.

# Appendix 1

## **How can variation in access to Therapeutic Services be reduced for People Living with a Neurological Condition?**

(Cheshire and Mersey Neuro Rehab Review and beyond)\

9.30 – 9.45 – If you join early – Put into small groups and intro yourself.

9.45 – 9.55 – Intro – Chair – Julie Riley – Strategic Lead Walton Centre

9.55 – 10.25 – Setting the Scene

(15 mins) - Amanda Brooks – Lead Commissioner Cheshire and Mersey (Liverpool CCG)  
– The Neuro rehab Review and Neurological Conditions and the Cheshire and Mersey Integrated Care System

15 mins – Julie Riley - Walton Centre – The Neuro Science Program Board its role and work plan.

10.25 – 11.00 Examples of identified need and some possible solutions

- Developing access to Emotional Wellbeing and psychological Therapies – Shelly Morris-King – Consultant Lead for neuro Physiology (10 minutes)

- St Helens Multiple Sclerosis Group – What is the need and other questions answered – Rob Wright – Group Member (10 minutes)

- Access to exercise project in West Cheshire and opportunities in primary care – Jane Johnston-Cree – Manager Neuro Therapy Centre (10 minutes)

11.00 – 11.10 10 minutes Questions

(Spit up into break out rooms)

11.10 – 11.40 Break

11.40 – 12.45 Workshop and possible Questions

- What are your thoughts about info presented? In particular what are the priorities to focus on?
- What potentially could people present be involved in developing to meet the need?
- What might you need from Cheshire and Mersey ICS / Walton Centre / Primary Care Networks etc.?
- Who else needs to be involved and how do we ensure they are included? (Including people living with a neuro condition).
- What are the next steps that should be taken?

12.45 – Bring back from break out rooms


12.45 – 13.00 – Feedback and Next steps to move this forward – Chair with support from Amanda / ICS lead Walton Centre / and workshop facilitators.

Program and break out questions

## Appendix 2

### Amanda Brooks – Lead Commissioner Cheshire and Mersey (Liverpool CCG) – The Neuro-rehab Review and Neurological Conditions and the Cheshire and Mersey Integrated Care System

**Amanda Brooks**  
Senior Planning Programme Manager  
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## Integrated Care Systems (ICS)

The new Health and Care Bill sets out legislative changes required to enable health and care to work more closely together.

An Integrated Care System (ICS) brings together the NHS organisations, councils, and wider partners in a defined geographical area to deliver more joined up approaches to improving health and care outcomes.

There are 42 ICSs in England. Cheshire and Merseyside is one of the largest in the country.

From April 2022, the Cheshire and Merseyside ICS will have legal status and will include a statutory Integrated Care Partnership (ICP), and a new NHS body called the Integrated Care Board (ICB).

There is a lot of new terminology related to the reforms set out by the Health and Care Bill.

## Terminology Explained

**Integrated Care Board (ICB)**  
Integrated Care Boards (ICBs) will be established as new statutory organisations to lead integration within the NHS. The Cheshire and Merseyside ICB will be responsible for ensuring the requirements for board membership will be set in legislation. The Board will be responsible for the day-to-day running of the NHS which includes planning and buying healthcare services. The 8 clinical commissioning groups (CCGs) across Cheshire and Merseyside will transfer to the Integrated Care Board by April 2022, following their closure.

**Integrated Care Partnership (ICP)**  
The Integrated Care Partnership will provide a forum for NHS leaders and local authorities to work together, alongside stakeholders from across the region. They will develop and ICP integrated care strategy to improve health and care outcomes and experiences. The ICP will be a dedicated forum to support joint working relationships across the health and care system, and will support Place-Based Partnerships.

**Place-Based Partnerships**  
The Cheshire and Merseyside ICB will arrange for some of its functions to be delivered, and decisions about NHS funding to be made in the region's nine borough places – through Place-Based Partnerships. The ICB will remain accountable for NHS resources at place-level. They will govern the place-based programmes. Health and wellbeing boards (HWWBs) will continue to develop the joint strategic needs assessment and joint health and wellbeing strategy, which both the ICP and ICB will give due regard.

**Provider Collaboratives**  
There are two separate Provider Collaboratives for Cheshire and Merseyside: The Cheshire and Merseyside Acute and Specialist Trust (CMASST) Mental Health, Community Learning Disability collaborative (M4LDSC). Both will agree specific objectives with the ICB to contribute to the delivery of Cheshire and Merseyside's strategic priorities and are committed to working together to support the delivery of benefits of scale and mutual aid across multiple places or systems.

## What does this mean for Rehabilitation?

Put the voices of people and communities at the centre of decision-making and governance.

Engage and seek feedback from communities early when they are in a position to influence decisions.

Understand the community's needs, experience when using health and care services.

Build relationships with excluded groups, especially those affected by inequalities.

Healthwatch and the voluntary, community and social enterprise (VCSE) sector will be key partners.

Coproduce and redesign services and tackle system priorities in partnership with people and communities.

Learn from what works and build on the assets of all ICS partners – networks, relationships, activity in local places.

Provide clear and accessible public information about vision, plans and progress, to build understanding and trust.

New ways of working that better meet the needs of local people.

Working collaboratively will create new and flexible roles, with development opportunities for staff and increased job satisfaction.

Health and care professionals will have more time to spend with people who need their help.

Having a greater impact on the health and wellbeing of our communities and a reduced level of bureaucracy will create a happier workforce with greater levels of purpose and job satisfaction.

Shared records and increased data sharing (another change outlined in the White Paper which will make joined-up working easier) will allow more timely access to patient information.

Improved communication between staff across all parts of the CSM system.


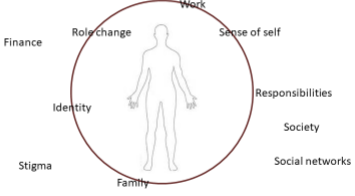
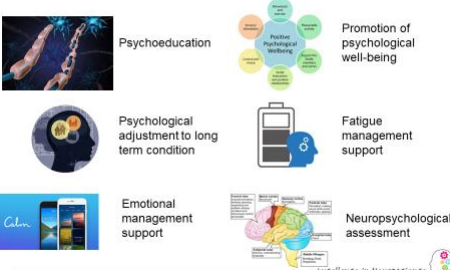

New technology and improved communication between services will make working lives easier and more efficient.




## Julie Riley - Walton Centre – The Neuro Science Program Board its role and work plan.

<div data-bbox="603 275 726 324">   The Walton Centre  NHS Foundation Trust </div>  <h3 data-bbox="339 443 649 504">People Living with Neurological Conditions</h3> <p data-bbox="343 521 646 555">The Neurosciences Network Programme Board 17/11/21</p> <div data-bbox="579 582 726 616"> Excellence in Neuroscience  </div>	<div data-bbox="1204 275 1327 324">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="884 297 1040 324">Introduction</h3> <ul data-bbox="884 365 1080 515" style="list-style-type: none"> <li>• Fit with HCP (ICS)</li> <li>• Role and purpose</li> <li>• Membership</li> <li>• Work plan</li> <li>• Reporting</li> </ul> <div data-bbox="1181 582 1327 616"> Excellence in Neuroscience  </div>
<div data-bbox="603 633 726 683">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="280 656 391 683">HCP/ICS</h3> <ul data-bbox="280 712 608 936" style="list-style-type: none"> <li>• Work programme</li> <li>• Transformation Board – CEO</li> <li>• Links to Neurosciences Network Programme Board <ul style="list-style-type: none"> <li>– Mental health</li> <li>– Prevention pledge</li> <li>– Pain management</li> <li>– Physical activity</li> </ul> </li> </ul>  <div data-bbox="579 947 726 981"> Excellence in Neuroscience  </div>	<div data-bbox="1204 633 1327 683">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="884 656 1110 683">Role and purpose</h3> <ul data-bbox="884 712 1291 943" style="list-style-type: none"> <li>• To enhance care and improve neurology and neurosurgery outcomes for our population</li> <li>• Good patient and carer experience</li> <li>• Improve equity of access</li> <li>• Best practice pathways</li> <li>• Reduce variation</li> <li>• Drive efficiencies</li> </ul> <div data-bbox="1150 824 1321 943">  </div> <div data-bbox="1181 947 1327 981"> Excellence in Neuroscience  </div>
<div data-bbox="603 992 726 1041">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="280 1014 438 1041">Membership</h3> <ul data-bbox="280 1070 517 1285" style="list-style-type: none"> <li>• WCFT</li> <li>• Acute Trusts</li> <li>• Voluntary organisations</li> <li>• Primary care</li> <li>• General Practice</li> <li>• Commissioners</li> <li>• Representative for patients</li> <li>• Public Health</li> <li>• HCP/ICS</li> <li>• Local Authority</li> </ul>  <div data-bbox="579 1299 726 1332"> Excellence in Neuroscience  </div>	<div data-bbox="1204 992 1327 1041">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="884 1014 1139 1041">Work plan/Activities</h3> <ul data-bbox="884 1070 1106 1285" style="list-style-type: none"> <li>• GIRFT recommendations</li> <li>• Emotional support</li> <li>• Physical activities</li> <li>• Pain services</li> <li>• Rehab review</li> <li>• Everton Minds</li> <li>• Thrombectomy</li> <li>• Topics from other members</li> <li>• HCP update</li> <li>• Spinal</li> <li>• Pathways</li> </ul> <div data-bbox="1181 1299 1327 1332"> Excellence in Neuroscience  </div>
<div data-bbox="603 1350 726 1400">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="280 1373 408 1400">Reporting</h3> <ul data-bbox="280 1429 687 1552" style="list-style-type: none"> <li>• Use A3 methodology</li> <li>• Chairs report to BPC and HMC</li> <li>• Bi monthly update to HCP/ICS</li> <li>• Outcome of this meeting will be included</li> </ul> <div data-bbox="459 1599 528 1648"> <h1>A3</h1> </div> <div data-bbox="579 1664 726 1697"> Excellence in Neuroscience  </div>	<div data-bbox="1204 1350 1327 1400">   The Walton Centre  NHS Foundation Trust </div> <h3 data-bbox="884 1373 1085 1400">Any questions?</h3>  <div data-bbox="1181 1664 1327 1697"> Excellence in Neuroscience  </div>

# Developing access to Emotional Wellbeing and psychological Therapies – Shelly Morris-King – Consultant Lead for neuro Physiology

<p><b>NHS</b> The Walton Centre NHS Foundation Trust</p>  <h2>Developing access to Emotional Wellbeing and Psychological Therapies</h2> <p>Dr Shelly Morris-King Consultant Psychologist in Neuropsychology Lead for Inpatient Neuropsychology Service</p> <p><i>Excellence in Neuroscience</i></p>	<p><b>NHS</b> The Walton Centre NHS Foundation Trust</p> <h2>Emotional/psychological impact of long term conditions</h2>  <p><i>Excellence in Neuroscience</i></p>
<p><b>NHS</b> The Walton Centre NHS Foundation Trust</p> <h2>Psychological support</h2>  <p><i>Excellence in Neuroscience</i></p>	<p><b>NHS</b> The Walton Centre NHS Foundation Trust</p> <h2>Psychological adjustment</h2>  <p>Gracey, F et al (2009)</p> <p><i>Excellence in Neuroscience</i></p>

## St Helens Multiple Sclerosis Group – What is the need and other questions answered – Rob Wright – Group Member

<p><b>What People living with MS say about access to Therapies?</b> Summary of two surveys conducted by the St Helens MS Local Group in July/ August 2020 and July / August 2021</p> 	<p><b>Covid and the Lockdown - People living with MS</b></p> <p>St Helen's MS Group conducted a survey in August 65 questionnaires sent and 35 received back.</p> <ul style="list-style-type: none"> <li>How has the lock down changed your activity and exercise levels? 22.9 % not at all, 42.8% severely or very severely</li> <li>How has the lock down affected your emotional well being over the last few months? 16.7 % not at all, 41.2% severely or very severely</li> </ul> <p><i>'Balance much worse, was able to walk down the road twice a week to church and slimming world- hardly walk at all now'</i> <i>'Mobility deterioration, experience more falls'</i> <i>'Sadly, I cannot move any part of my body, the physiotherapist helps my life every week; without physio my body became stiff, not moving at all. It has taken three weeks of physio to get it back to how it was'</i></p>				
<p><b>2nd Survey August 2021 – Views / Thoughts and Needs in relation to Therapies including Physio Therapy</b></p> <ul style="list-style-type: none"> <li>64 questionnaires issued</li> <li>40 responses received</li> <li>Response Rate 63%</li> </ul> <p>Age of Respondents</p> <table border="0"> <tr> <td>30-49 years: 13%</td> <td>50-64 years: 33%</td> </tr> <tr> <td>Over 65 years: 45%</td> <td>No Reply: 10%</td> </tr> </table> <ul style="list-style-type: none"> <li>46% of respondents are WORKING AGE</li> <li>1 branch member represents 5 more St Helens residents LIVING with MS</li> </ul>	30-49 years: 13%	50-64 years: 33%	Over 65 years: 45%	No Reply: 10%	<p><b>Info on Therapeutic Services</b></p> <ul style="list-style-type: none"> <li>Have you ever been offered a course of Neurophysio by your Health professional? Yes: 23% No: 75% No Reply: 2%</li> <li>Have the benefits of Neurophysio ever been explained to you by your Health professional? Yes: 22% No: 73% No Reply: 5%</li> <li>Finding out about Physio 21/24 Yes respondents said : Local MS Branch: 88% 1 respondent said: NHS Consultant: 4% 1 respondent didn't know: 4% 1 respondent said 'previous experience': 4%</li> </ul>
30-49 years: 13%	50-64 years: 33%				
Over 65 years: 45%	No Reply: 10%				
<p><b>Benefits of Neuro Physio</b></p> <ul style="list-style-type: none"> <li><i>'Hands on approach is vital'</i></li> <li><i>'Improved sleep, less pain'</i></li> <li><i>'Keeps me motivated to continue exercising'</i></li> <li><i>'Improved sleep and better movement, due to reduced pain'</i></li> <li><i>'Helped keep me driving and able to work for longer'</i></li> <li><i>'Regular maintenance to improve balance and prevent falls'</i></li> <li><i>'It's a lifeline; I don't understand how it works but it does. I slowly learned how to stand and walk about to lead a relatively normal life.'</i></li> </ul>	<p><b>Benefits for Emotional Wellbeing</b></p> <ul style="list-style-type: none"> <li><b><i>'Motivation, Better than any drugs; mentally able to cope'</i></b></li> <li><b><i>'Stopped paid for physio when lockdown started, this is one of the reasons I feel a bit introverted and depressed'</i></b></li> <li><b><i>'Boosts confidence and self esteem'</i></b></li> </ul>				
<p><b>What does the service need to include</b></p> <ul style="list-style-type: none"> <li><i>'Should be offered to everyone with MS for mental health and building confidence'</i></li> <li><b><i>'Teach the physios about MS; THEY DON'T UNDERSTAND'</i></b></li> <li><i>'From past experience, short 20 minute spell, hardly any manipulation, then given a photocopy of basic exercises'</i></li> <li><b><i>'Work in partnership with other disciplines, although Occupational Health came to me and couldn't help'</i></b></li> <li><i>'Tai Chi helps; don't know about anything else'</i></li> <li><i>'Simply offered'</i></li> </ul>	<p><b>Thanks for listening</b> <b>We need to see some action!</b></p> <p>We cannot conduct further studies as our members gave a resounding 63% response to this survey.</p>				

## Appendix 3

### Group 1 - write up

Noted from Rob's presentation it was 'astounding' that the St Helens patient cohort are solely reliant on the MS Society for certain service provision. It was suggested that it would be a good opportunity to undertake a survey, to understand the current services available and who provides these. Good opportunity for this group to lay the foundations going forward.

Noted that there are a number of services in certain areas in place, through non statutory routes such as voluntary sector, creating inequalities. Suggestion of an audit/scoping exercise to assess areas where this is happening and where it isn't.

'It will be interesting to see when the ICS takes the lead how things change, however there are a number of good services.'

Commented that it is about setting expectations for patients, not always 'hands on' is needed. Sign posting can be equally as important and valuable and should be part of any surveys.

Highlighted the difficulties in reaccessing therapies when your condition/circumstances change - it's really important for this pathway to be simple. This is a frequently asked question on the Helpline.

Noted that the above requires a more coordinated approach.

Commented on Shelley Morris-King's slides, 'psychological impact on MS patients is huge, 20 years diagnosed and there was nothing there. Understanding what your life is like now and what it will look like in the future, the anxiety and emotional impact is huge.'

'Needs to be on-going as your condition changes, quite a physical focus, more input for psychological support is required.'

Discussed that there is very limited access for housebound patients, particularly in the South Seton area. As patients are older and their condition progresses their mental health is impacted.

Noted that she was unclear in regards to the Neuroscience Board role and how input with community and house bound patient groups can be maximised.

Commented that some patients attending other hospitals such as Leighton and Stoke, had significant variances in terms of input and access. How could we develop opportunities to share the good work at Walton Centre?

Pathways require improvement, referrals in need to be easier, good communication as to who is who in the team, communication of the teams.

Outlined the referral pathways into Walton Centre, re-accessing services difficulties and limitations.

Noted improvement on-going in Leighton and Stoke, referrals out of area should be considered and accepted where possible.

Commented that a greater understanding of pathways was required; this would enable improving confidence about advising patients in the community. Noted South Sefton the only area without Neuro-rehab teams. Sessions to provide education, training and how to access would be good and improve clinical confidence to refer.

Discussed a previous link group which involved colleagues locally, attendance became low and therefore ceased, other models could be looked at for other conditions.

Noted there are a number of groups in place to discuss options for additional services. Evaluation of current services and numbers involved would be required and how many have merged as groups.

Discussed how Speech & Language services are not equitable across the region or conditions, it would be interesting to assess and demonstrate this. Certain service models are working well, particularly around Neuromuscular and Motor Neuron Disease, really responsive to needs.

Discussed the importance of other colleagues input such as dieticians and speech and language.

Commented that there are a few peer groups within the Liverpool area providing support/exercise through Zoom sessions. It was noted that a number of these groups have ceased during COVID and it was unclear if they had restarted, however the impact is huge.

Discussed the need for cross boundary working and understanding which organisations are offering exercise sessions and where they are.

The group stated the requirement for partnership working with CCGs and Mersey Care, who look after a number of services. CCG logistical issues contributing to areas such as South Sefton with no access to Neuro-rehab.

**Key prioritises:**

- Wider understanding of pathways
- Who is who in the teams and communication
- Newly diagnosed need to be able to access services, local groups working collaboratively
- Being clear on available services - who is providing, where, and ensure they complement each other
- Try and address what wasn't working previously, fix and focus on what we need and can do now in new ways of working
- The role of community therapies – psychology, speech & language, dieticians

## Group 2 - write up

### **What people wanted from the session?**

- To share ideas and get new ideas from hearing how other people deliver services
- Taking forward delivery of support for people with MS where gaps exist

### **Question 1**

New structures – where do we fit in (as staff or people with a condition) and how can we be heard? – Where will the money go and will there be less than before? There is a worry about losing existing good stuff that we do.

Is there a role for this group to get involved with the ICS? – agreed that there is an opportunity here.

### **Question 2**

Greater Manchester rehab network has already been set up and there is a useful webinar on YouTube that we could get ideas from. They mapped services to identify gaps and variation.

Clear pathways exist for stroke but not for other neurological conditions – this exacerbates inequalities.

There seems to be lots of bureaucracy to get a proposal together, and then within the CCG in finding funding even if the case has been made. Barriers are put in the way such as 'can't do something for MS if not for all neuro'.

What is the handover/transition process to the ICS? There are concerns that things will be lost either through people changing roles, knowledge or expertise lost or existing work ceasing.

Uncertainty about the ICS set up is causing issues because people are not able to renew contracts that end in April 2022 and there is a knock on effect on recruitment to vacant posts if you can't say that the post will continue beyond March 2022.



Can we tap into the extra Government funding for physios in GP surgeries for some neuro physios based in the community? Would need some lead from the CCGs? National physiotherapy organisations are working with Public Health England and groups feeding in – neuro-physios could be part of a Primary Care Network cluster as patient numbers too small to justify one for each GP practice. Maybe they could be based in a Therapy Centre?

### **Question 3**

Sharing expertise is important

The importance of the exercise programme was stressed as a crucial thing keeping people going.

Also the benefit of physio is not given enough importance in health systems in terms of prevention and rehab – it is very cost effective but no money put into it.

### **Key feedback - How do we motivate people and keep them activated in a cost effective way?**

We need standard outcome measures and a benchmark for minimum service levels and use these to assess services – we already have national standards framework, NICE guidelines and the neuro pathways – we should combine the regional mapping with standards to put together a business case for an equitable service.

### **Key question - Will the ICS be mapping services?**

We could feed in but if not mapping then variation and inequality will not be addressed.

There is also variation in voluntary sector services – this depends on what CCGs commission if charities are providing services or on what decisions and funding local groups make on gaps and need. Can be very variable.

The ability to influence CCGs is limited and variable and depends a lot on individual relationships.

**We need from the ICS:**

- Communication and transparency about processes and structures
- Respond to existing data and research about what's needed rather than asking for new research every time a business case is made.
- Working groups to be more inclusive – real co-production BUT this would need training for Health Care Professionals on how to deliver this as it's not just an add-on to their usual work and may need some changes in attitude – Healthwatch can help with this.

## Group 3 - write up

### **What are your thoughts about information presented? In particular what are the priorities to focus on?**

- There was a focus initially on what wasn't included in the presentations, the gaps that are important to address so people can access services:
  - Transport is a barrier – Need to look at ways to address this and other barriers
  - Changing places in particular and accessible toilets / general public toilets are in short supply.
  - Local groups for people linked to neuro conditions need to be listened to so that the information on the support they can offer is included.
  - Cost of getting to activities and appointments can be prohibitive
- A question was asked - 'do you have to join Brio and whether you are penalised if on the day of a class you can't make it.'

Following points were made in discussion:

- There is a charge for Brio Leisure services
- There is no longer a charge for Neuro Therapy Centre (NTC) opportunities it is donation only.
- There is an agreement with Brio that providing you have a neurological condition on your membership then if you are unable to make a class you will not be charged. That may not apply to other leisure centre providers.
- It is positive there has been a good response to the digital classes as this overcomes the transport problem. Recent engagement work with people who have and haven't used the NTC showed many people were keen to continue with some digital classes because of the transport problem. However some people at home would need some support to set up equipment at first, or for some all the time.

## **What potentially could people present be involved in developing to meet the need?**

- One of the big priorities the presentations showed was the importance of commissioners and service planners making the links between different services e.g. mental health, community long term conditions and public health to support emotional and psychological support and activity and exercise at a community level to ensure they meet the needs of people living with neuro conditions where they live.
- Part of the problem with this integration is the service providers are pulled in so many different directions between teams.
- Existing 'rules' prevent integration e.g. therapists can't refer to social prescribing link workers only primary care.
- If we could get over some of these barriers then OT and physios could do joint visits with link workers and know that they were supported on the actions to take to meet the needs of someone with a neuro condition
- Merseycare life rooms can provide some of the support that the NTC provides over in West Cheshire including exercise sessions, relaxation, singing etc.
- Need to prioritise getting info out about services available e.g.
  - Local group activities
  - Life rooms and other similar services
  - Nurse advice line from Walton
  - Neuro nurses and their local clinics
  - Access to social prescribers and wellbeing coaches

How do we get all this information in one place? Even when it is in terms of various on line hubs it is only up to date for a period of time. Need a living, breathing person to keep this up to date and ensure info is disseminated.

- People living with conditions need one point of contact to get this information from also
- Social prescribing and health and wellbeing coaches have a real role to play in supporting individuals and getting this information out

- Need to move away from piecemeal communication about services and develop coordinated communication.

### **What might you need from Cheshire and Mersey ICS / Walton Centre / Primary Care Networks etc.?**

- Positive ICS have identified neuro-rehab as a priority
- Strong basis for place based services linked to this Cheshire and Mersey wide priority as people need the support where they live.
- GP's got together in South Liverpool and made available info about services at a local level
- Need to acknowledge the role social prescribers can play in this place based approach. They can support a person in identifying what they need and promote access to other service - this will prevent social isolation, anxiety and depression.
- Local groups, networks and health care staff need the info / access / ability to refer to social prescribers. West Cheshire MS group only found out about social prescribing service when they rang to refer someone.
- Need acute service at Walton to reach out and develop a model that works much more at primary and community level for people living with neurological conditions.
- Need info about the neuro nurses and the clinics they run to be circulated - not sure how this information currently gets out to the people who need to know including people living with MS.
- Need the Cheshire and Mersey model that develops to support access for people at points of change in the development of their condition e.g. when struggling to continue working, stop walking

### **Who else needs to be involved and how do we ensure they are included? (Including people living with a neuro condition).**

- Many contact points have been lost over last 18 months. Brain Charity important and is an important point of support for many
- Local Charity groups also important – West Cheshire MS group recently had a referral from a 27 year old who was newly diagnosed who was having to wait 6 weeks for this consultant appointment. They googled

and found West Cheshire group via helpline. They needed someone to sit down with and talk about it.

- This link with other people who are able to provide support is important e.g. in MND clinic. Have about 45 minutes if the person says they are concerned about their job then that will be what is focused on.
- Acknowledged that although this information is important people are happy to receive it and use it at different times and this needed to be considered.
- Piece of work going on following on from November 2020 MS pathway workshop where a health care staff check list will be developed to support the information being given to people after diagnosis in a useful way.
- Primary care were seen as important to developing services particularly for people as their condition progresses. Link between Walton and primary care needs to develop.
- Link between local commissioners and Walton Centre needs to be strengthened so that there is joint input to the development of local provision. Walton centre do run some community services now so this is a place to start.
- Discussion that OT's need to be included and this needs to be medical OT and social services OT and it needs to be made easier for the people who are living with conditions to be in contact with the right OT.
- Bring community and medical OT's together?
- There is a real shortage of housing that is fully accessible – need to be part of discussion
- Need more adult changing rooms when out and about and public toilets

### **What are the next steps that should be taken?**

- Need the neuro rehab review to happen and report
- Need to have representation on the Neuro-Science Programme Board of all the people who have been spoken about in this discussion.

- More creative thinking about how we develop services. Employment is important. There are many skilled people who volunteer in local groups who with a bit of creative thinking about job roles could support as a paid worker.
- Re employment people need legal support and access to vocational rehabilitation (Walton has an employment clinic, Brain Charity has an employment service that can receive referrals).

**Two points to feed back:**

- Develop strong communication and information sharing that specifically focuses on reaching the people living with conditions and family / carers.
- Need to break down the barriers between services so there is a pathway that incorporates primary care, local charity condition specific groups, community services, public health wellbeing teams, acute services.



## Group 4 - write up

### **Q 1 What are your thoughts about info presented? In particular what are the priorities to focus on?**

Raise the profile of neurology so it has the same status as Coronary Heart Disease and other Long Term Conditions

Effective Communication of services essential, not just to the potential users of service but to other service providers so they have the right contacts and access routes for their patients

Encourage GP's to understand the services and make best use of them

Clarify the geographical spread of staff across the region – some areas are well served, others not so much

Review the pathway as regards referrals, making sure it's as clear as it can be

Importance of having neuro specialised link workers that patients can access - additional training etc. to non-specialised workforce

As the changes proceed (to ICS) people move on, and new roles are being developed, so its essential communication is kept up to date

Importance of local group voices to be involved and to influence the process – learned experience voice needs constant conversation to influence, particularly the PCN

Waiting times are different for different services, so the question is what can be done to support patient in the gap between referral and access, sometimes three to 4 months long – Health and wellbeing coaches/social prescribers and link workers\* can offer support during the waiting period, can work with the patient of social issues such as housing/finance/debt relief etc.

\*All three used interchangeably in conversation, checked with group, similar roles different titles

## **Q2 What potentially could people in the break out group be involved in developing to meet the need?**

Continue to raise the issue, continue being the patient voice, Link workers report into the system both on an individual patient level and at a service level.

Changing commissioning landscape - networks will be instrumental and influential in developing these plans and what the development of a network should look like. (Cheshire and Mersey) Network will need lived experience

Funding issues might become apparent, however there should be enough flex in the system to do some developmental work. There's evidence about how prevention work is effective both in health outcomes and system savings, need to keep evidencing this to secure agreement to work in a different way.

There is variation in the spread of these roles currently, but as networks develop (PCNs) they will work more jointly and what might be a gap currently might change as a result of this. The ambition is that link workers work right across the PCN areas, but some PCN's may need to share resources of specialist roles according to local demand, to be cost effective

The Neuro Science network reports into the ICB and there's an opportunity to do a deep dive in aspects of services each quarter – this might be one of them?

There may be an opportunity do some piloted development work in this area, nothing can be committed as it's an uncertain commissioning landscape currently but will form part of Amanda's (Brookes) thinking

## **Q3 What might you need from Cheshire and Mersey ICS / Walton Centre / Primary Care Networks etc.?**

Lot of discussion about the link between mental and physical health that are considered separately to the detriment of patients wellbeing. Is there a way that this could be more joined up? Especially at diagnosis where mood disorders (anxiety and depression) are well recognised issues, early support at this point was vital and helped patients manage until access to other services could happen (as was peer to peer support). This is also important for carers as well as patients. Can the pathway look at where this support currently sits? Does it need to be earlier?

Workforce issues – shortages across all OT/Physio/Psychologists etc.

Importance of a wide range of partners including leisure services etc.

The ambition needs to be the right service at the right time, a single point of access, a single point of information.

**Q4 Who else needs to be involved and how do we ensure they are included? (Including people living with a neuro condition)**

Continue with involving the local groups to access lived experience

Consider other professions - care home staff, nutritionist, continence, and Health education workforce (Could target universities etc.)

A road map of services on a geographical basis needs to be plotted so differences in access can be resolved and this can be communicated to patients – who would need to be involved in this

Some areas, such as CWAC are building their local offer - 'Live Well' website to host all local information on Health, social care and voluntary sector services (and will allow live updates from stakeholders):

[www.livewell.cheshirewestandchester.gov.uk/Services/2876](http://www.livewell.cheshirewestandchester.gov.uk/Services/2876)

**Q5 What are the next steps that should be taken/ Main actions to feed back?**

Communication as ever remains the key concern – both communicating the service offer, and engaging community.

Acknowledge and support the importance of mental health support at the beginning, use this to maintain health and wellbeing and feeling of control while waiting for access into other services (physio etc.) both through formal service offer and peer to peer groups.

Road maps that plot the services geographically so variation can be managed more effectively

## Appendix 4 Comments

“The event was able to highlight some of the issues that will need to be resolved in order to make progress, but it also brought out some examples of best practise and ways that services can develop more, particularly in the community, to better support PLwNC”.

“The facilitated breakout sessions were very useful and we heard from a good range of people in the area.”

“Initially I thought the event was going to be too long, and that we would lose a number of attendees during the break. This turned out not to be the case (some professionals had to leave due to diary commitments, which is understandable) and demonstrates the importance of the event to people”.

“I think Julie Riley is already planning to follow up on the role of the Health & well-being coach/social prescribers through the neuroscience board, but it would be good to learn how well that role can work, and the difference it can make to GP appointments etc.”

“It would be good to know how other areas have structured e.g. Greater Manchester alliance to use as lessons learnt”.

“It would be good to see if anywhere has any information on the effectiveness of low-level interventions for mental well-being, such as group counselling, as these could easily be put in place at a low cost, and could even be facilitated remotely via Zoom e.g. Gab ‘n Go sessions”.

“Would benefit from a variety of representation from voluntary sector e.g. brain charity, life rooms etc.”.

“More service user feedback of experience of accessing services would be helpful”.



## **We're the MS Society.**

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

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 **Let's stop MS together**