

Minutes of the Long Covid CPG

20/10/2021

Attendees

Rhun ap Iorwerth

Hefin David

Joseph

Mabon ap Gwnfor

Daisy N

Sarah Murphy

Russell George

Andrew Bettridge

Geraldine McCaffrey

Sian Griffiths – Long Covid Wales

Dee Montague

Lee Bowen – Long Covid Wales

Helen James

Dale Thomas

Ian Frayling – Long Covid Wales

Kathryn Tancock – Long Covid Wales

Georgia Walby – Long Covid Wales

BDA- British Dietetic Association

Calum H

Kathryn Gower

Calum Higgins

Heledd Roberts

Sharron Dutton (secretary to Dr Helen Davies)

Agenda

- Geraldine McCaffrey, Research and Development Lead Pharmacist BCUHB to speak
- Update on issues from Georgia Walby, representing Long Covid Wales Campaign team
- Hefin David speaking on the Care Navigation system in Wales.

Points from Geraldine's Presentation

- Lack of treatment options for long COVID patients. Access to services also an issue.
- The HEAL Covid study is running but this is for hospitalised patients.
- Need to capture data in robust way. Healthcare research Wales and specific studies such as HEAL aim to help capture evidence.
- Variation between the services available in England and Wales. GP's not aware of the services that they can refer to.
- Dr Ian Frayling- A forum is needed for Doctors, Pharmacists etc to access information about strategies like using common medications in some Covid patients. Experimental results can also be documented. LC clinics should be run by those with Long Covid expertise.
- Rhun ap Iorwerth- need for central collation of information on both symptom management and treatment management.
- Georgia Walby- gap between formalised research end points which are years away from completion vs informal remedies that can be trialled now. We don't have LC clinics therefore not being offered such informal remedies in Wales unlike in England.
- Daisy Norton- Welsh NHS Confederation are meeting to make an overview of the Long COVID services in Wales.
- Hefin- Wider issue he is currently addressing is care navigation, accessing alternative healthcare providers directly, and has written to the first minister about this. This process isn't happening sufficiently in Wales and patients with long COVID are affected by this.

Update from Georgia Walby

- Ongoing issue of lack of medical Long Covid Clinics in Wales
- Concerned about psychologisation of long COVID in Wales. Some services for Long Covid in Wales are run by psychologists.
- Long COVID patients are under the care of therapies in Wales. Medical care is needed not just rehabilitation.
- Many Patients now facing severe financial difficulties with sick pay, furlough & SEISS having run out out. People facing financial hardship.
- Wider recognition of the severity of this remit and relapse illness is needed
- Struggling with return to work. Many have failed a RTW multiple times. Much longer phased returns are required.
- Patient involvement needed in shaping long COVID services from the outset in Wales- Long COVID Wales have fought hard to be involved in reviewing small aspects of services in Wales but much more consultation and collaboration is needed for services to meet patient needs.

- Dr Katie Goddard relayed the following points from NHS Employees in the Cardiff and Vale Health Board with long COVID
- Long COVID is an occupational illness and should be treated as such. Some employees have had difficulty getting their employer to complete a RIDDOR report following occupational illness.
- Lack of occupational health support due to an overrun system. Some patients are facing return to work without a Occupational Health Appointment.
- Lack of guidance on return to work- very long and flexible return to work procedures required.
- Delay in guidance from the Welsh government in whether sick pay will be extended beyond one year. Currently pay beyond one year is at your managers discretion resulting in variance from employee to employee.

Action points

- There should be a pursuit of financial fairness, not limited to, but particularly in healthcare workers as they caught COVID at work. Rhun to seek press coverage on this in coming days.
- Rhun to write to the Health Minister on the need for guidance from Welsh government on pay procedures for employees with long COVID and will also mention the ongoing need for consultant led medical services for long covid.
- Rhun will look into approaching Westminster about help for people struggling due to the financial impact of long covid

Suggestions for further speakers

- Long COVID Wales proposed speakers for future CPG meetings to include Dr Helen Davies, a Delphi study author, Professor Danny Altman and healthcare worker with experience of losing job secondary to long COVID. Would be interesting to hear further from FTWW about women's health issues in Wales.