

[Redacted]

From: Carson, Alan
Sent: 15 July 2024 17:51
To: [Redacted]
Subject: Re: Data Breach

Follow Up Flag: Flag for follow up
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I m sorry I m totally lost- in what way is this a IG data breach - what does that mean and what has it to do with my organization's data protection lead- I m sorry I don't understand
a

From: [Redacted]
Sent: Monday, July 15, 2024 4:47 PM
To: Carson, Alan [Redacted]
Subject: Re: Adverse Event- PoTs Pathway

Hi Alan,

I am sorry to message you as I know you've been off, but following on from our email on 11th July this reply is now an IG data breach. Therefore, it should be managed with your organisation's Data Protection lead accordingly.

Kindest regards,

[Redacted]
Programme Support Officer
National Strategic Network for Long term effects of COVID-19
National Specialist and Screening Services
NHS National Services Scotland



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www.nss.nhs.scot



[REDACTED]

Subject: Re: Adverse Event- PoTs Pathway

I do wonder about the wisdom of such a response in taking the advice down- this has become a known approach to distorting the scientific literature and it is all too pervasive in management of poorly understood syndrome like POTS- I think far too much credence is given to single author/ support group letters soften espousing an unbalanced view of the literature and the system frequently over responds rather than taking time for sober reflection.

Whilst I personally think the methodology underpinning the POTS pathway was weak it was fairly innocuous. More importantly we can see clear trial evidence that the idea that long covid can be rehabilitated in part via exercise has been systematically stifled- with the with that exercise is dangerous if post exertional malaise PEM (an as yet undefined condition) is present, despite numerous studies in fatigue in general showing that appropriate exercise strategies can be used to rehabilitate in PEM with level 1a evidence in support. This reached its zenith in a NICE guideline from which all the physicians on the board felt compelled to resign, royal colleges could not support, and has been subject of major critiques in Lancet and JNNP. I think it is important that advice that comes out from the center is regarded as evidence based but also mainstream - it is unhelpful if GPs are referring to me suggesting the latest paper saying patients with brain fog should have fdg PET. Almost all are too sensible to do so but it doesn't make the GPs job easier when there are papers suggesting it from colleagues who should frankly know better.

Best wishes

alan

(White P, Abbey S, Angus B, et Anomalies in the review process and interpretation of the evidence in the NICE guideline for chronic fatigue syndrome and myalgic encephalomyelitis *Journal of Neurology, Neurosurgery & Psychiatry* 2023;**94**:1056-1063.)

From: [REDACTED]

Sent: Monday, July 8, 2024 10:41 AM

To: [REDACTED]

Cc: [REDACTED]

[Redacted content]

Subject: Re: Adverse Event- PoTs Pathway

Thanks all noted Mairi

On Fri, 5 Jul 2024 at 16:18, NSS longCOVID [Redacted] wrote:

Dear all

An individual has written to a wide range of senior NHS Scotland figures and to the Minister for Public Health raising concerns in relation to the Long Covid POTS Management Pathway that was developed and endorsed by the network.

A review of the situation by NHS National Services Scotland has identified clinical and other governance concerns and this is being managed as an adverse event in line with NHS NSS policy.

In the first instance the pathway has been removed from the network SharePoint site and you are requested to delete any copies you may hold locally. Work on the review of the pathway is also paused for the time being. This will allow us to review the concerns raised and ensure any corrective action is in place.

A Problem Assessment Group has been convened and will meet on 9 July to identify further corrective /preventive action to be taken and a timetabled plan for implementation. This will include a communication plan that will guide and govern all communications on the matter. We therefore also request that you do not enter into individual correspondence.

We are liaising with Scottish Government and will ensure a co ordinated response.

Thank you for your ongoing support for the network at this time.

Isaac

Programme Manager
National Strategic Network for Long term effects of COVID-19
National Specialist and Screening Services
NHS National Services Scotland



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