

# HSC Neurology Services

Summary of Feedback on Care Opinion Platform

August 2020 – April 2023

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## 1.0 PURPOSE

The purpose of this briefing paper is to demonstrate how the current Care Opinion database can be used to inform the Health and Social Care system on the experiences of service users, families and carers who use **Neurology Services** across Northern Ireland.

The following information reflects on stories published via Care Opinion from **03 August 2020 to 30 April 2023**.

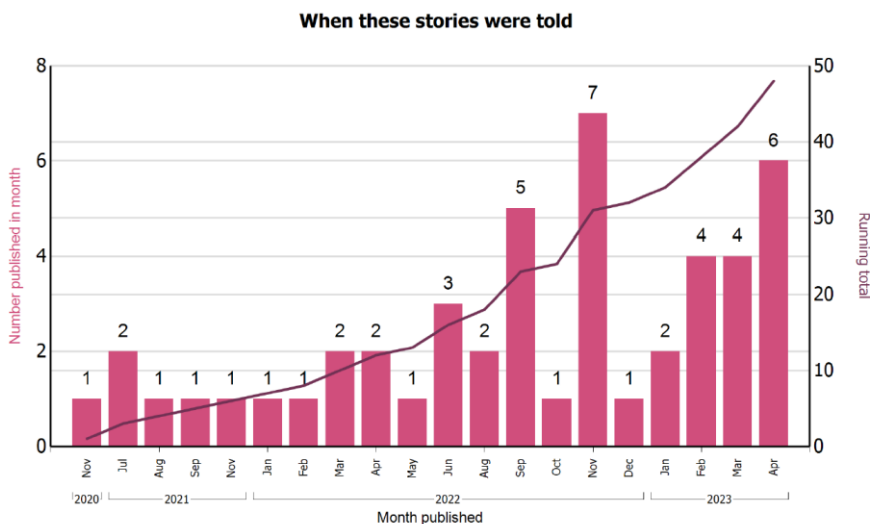
## 2.0 BACKGROUND

Commissioned by the Department of Health (DoH) the Online User Feedback Service (OUFS), Care Opinion was launched in Northern Ireland on 03 August 2020. This service provides an open and transparent platform to give service users, families and carers the opportunity to share feedback on their experiences of any service within Health and Social Care in Northern Ireland (HSCNI). The Care Opinion platform enables services to engage with the author of the stories through a two-way feedback mechanism. This platform supports feedback to be shared safely as stories are independently moderated prior to publication on the website ([www.careopinion.org.uk](http://www.careopinion.org.uk)).

## 3.0 CONTEXT

In total **48** stories have been shared on Care Opinion which relate to Neurology Services. Figure 1 displays the number of stories published per month since the launch of Care Opinion on 03 August 2020 up until 30 April 2023.

**Figure 1: Number of stories submitted each month on Care Opinion**

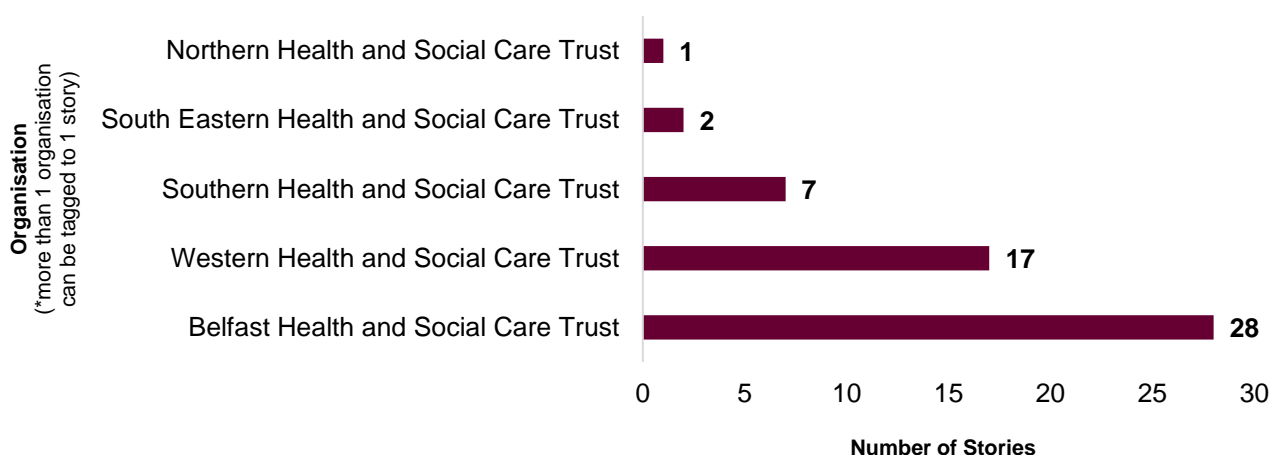


The methods used to submit these stories were:

- Website - 90% (n=43)
- Leaflet - 6% (n=3)
- Telephone - 4% (n=2)

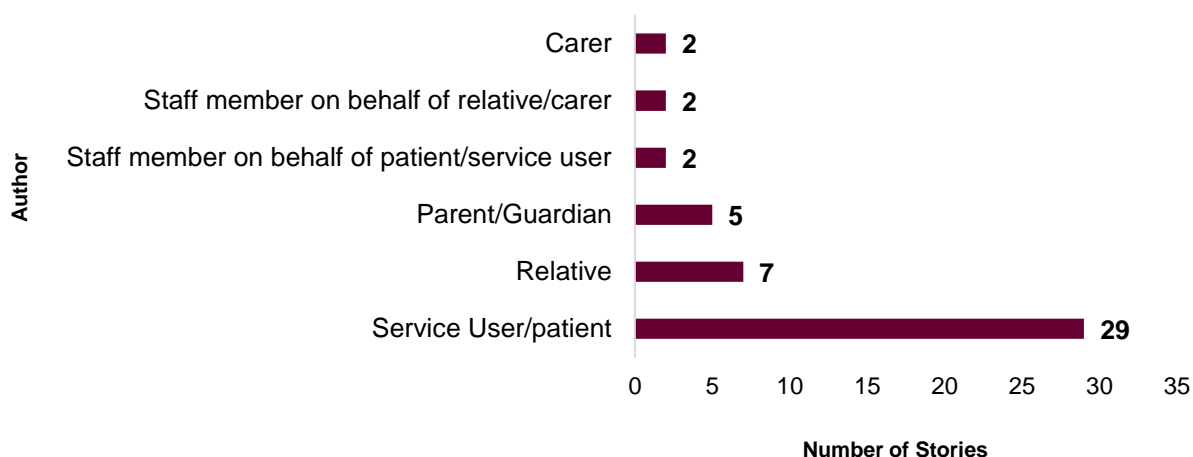
The stories relating to Neurology Services have been submitted from across all Health and Social Care Trusts in Northern Ireland as outlined in Figure 2, with the majority of stories being generated within the Belfast Health and Social Care Trust. It is important to note that seven stories relate to more than one Health and Social Care Trust.

**Figure 2. Number of stories per organisation**



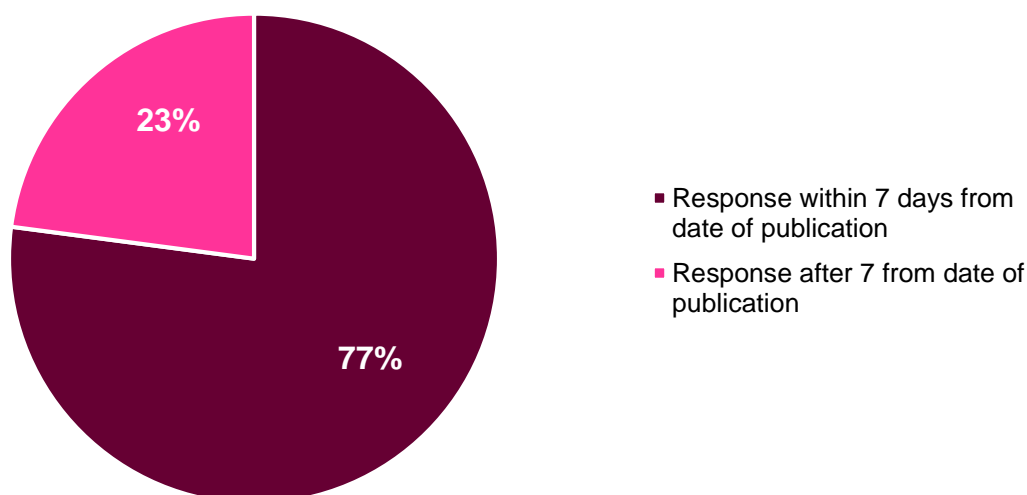
Authors are asked to identify if they are a patient/service user, relative or carer etc. The responses are shown in Figure 3. The majority of stories have been submitted from the perspective of the patient/service user 60% (n=29).

**Figure 3. Which term best describes you?**



A unique function of Care Opinion is the two way feedback mechanism which ensures authors receive a response from the service. In line with research, stories should be responded to within 7 days from publication. This indicates to the author that services have engaged with the feedback (Bains et al 2018). Figure 4 represents the responsiveness of Neurology Services in relation to feedback via Care Opinion. 77% (n=37) responded within the 7 day timeframe which reflects a commitment by the service to meaningful engagement with the stories shared.

**Figure 4. Percentage of stories relating to Neurology Services responded to within 7 days**

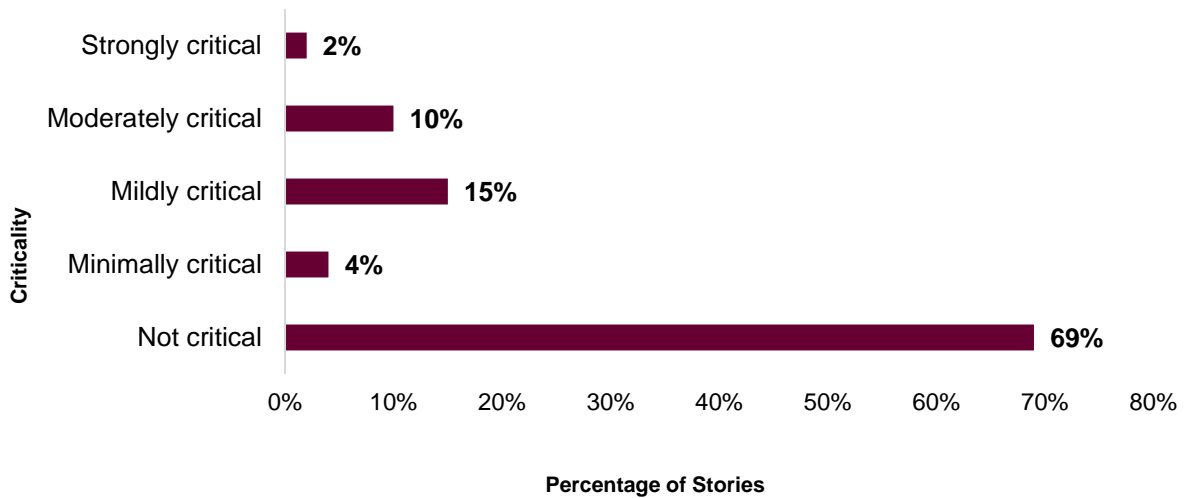


## **4.0 SUMMARY OF STORIES**

### **4.1 Criticality Scores**

Care Opinion is built upon the concept of “what’s your story” and supports the author to highlight what matters most to them using their own words. As part of the analysis through Care Opinion each story is assigned a criticality score by an independent moderator to highlight the level of critique included in the story. Figure 5 illustrates the scores for the 48 stories submitted relating to Neurology Services. The majority of stories 69% (n=33) have been assigned a “not critical” scores which indicates a wholly positive experience.

**Figure 5. Criticality rating of stories submitted on Care Opinion relating to Neurology Services**



NB: criticality scores are assigned by moderators (not the public) to stories to support our alerting service. They are assigned *per story* not *per service*, so may reflect criticism of services other than your own. We provide them here purely for information, with these caveats in mind.

The definition of criticality scores is summarised in Appendix 1 supporting an overview of the main content of the stories. Learning from the critical stories is included in Section 4.3.

#### 4.2 Summary Questions

The stories are also summarised through three supporting questions included on the platform: -

1. What was good about your experience?
2. What could have improved your experience?
3. What are your feelings and emotions relating to your story?

Responses relating to Neurology Services are summarised in Table 1 and further illustrated in the word clouds in Appendix 2.

**Table 1. Top 5 author tags for stories relating to Neurology Services**

What's Good?		What could be improved?		Feelings and Emotions Tags	
Staff (inc nurse & doctor etc)	34	Communication	3	Thankful (inc grateful)	16
Compassion (inc kind etc)	16	Appointments	4	Reassured	6
Professionalism	13	Advice	2	Supported	5
Communication	7	Appointments	2	Respected	5
Delivery of care	5	Access to Support	2	Relieved	3

### 4.3 Thematic Analysis

Framing each story with the lens of “what matters to you” the following themes have been identified in the narrative. The values of Health and Social Care and Standards for Patient Client Experience (respect, privacy & dignity, communication, attitude and behaviour) are also echoed in the themes. Each theme is illustrated using quotes directly from the story to ensure the voices of the authors are heard. Names have been removed from each quote and replaced with a letter to support anonymity. It is also important to highlight that the themes are not mutually exclusive and a number of themes can be identified within the quotes.

#### 4.3.1 Clear explanations to service user and family

*“...Our experience here has been a good one. The clinic is very good, with all the doctors being extremely helpful. They have really been very good in helping us learn as we go along. All the nurses are excellent as well - really very good...the clinic has been exactly what we expected and needed it to be!...”*

<https://www.careopinion.org.uk/877563>

*“...I want to extend my thanks to RVH ED & Urgent Care, the medical team and her team of nurses for the care that was provided to my husband on his attendance. The staff were friendly, accomodating and professional and helped make a difficult, daunting experience much easier. A special mention to the Doctor and the Neurology registrar that took great care in explaining his symptoms as they sought a diagnosis...”*

<https://www.careopinion.org.uk/929638>

*“...I am in my fifties, and this is the first time in my life, that my issues were explained to me in a concise, professional, friendly and using lay-mans-terms, facts that I could understand. The gentleman [consultant] took me through my treatment thus far and the prognosis...”*

<https://www.careopinion.org.uk/1011966>

*“...I had a review appointment in the Neurology clinic in Belfast City Hospital I seen Dr McMullan at the clinic I have been diagnosed with MS for over 10years and I can honestly say this was the best appointment I have had with a consultant since diagnosis. He spent time explaining everything to me and my husband and answered all our questions. I have to say his empathy and listening skills were exceptional throughout the appointment. I left this appointment with a clear understanding of what to expect and he also made a follow up call...”*

<https://www.careopinion.org.uk/1029523>

*“...He showed me my scans and explained in simple jargon free language what was happening. He encouraged me to ask as many questions and even when I took out my list of questions which I had written out to ask in case I forget anything but he had covered*

everything...”

<https://www.careopinion.org.uk/1056837>

#### 4.3.2 Empathy and Understanding

*From domestic, auxiliary nurses, ward nurses, doctors, and not forgetting the patience of the ward manager :) I cannot praise them highly enough. They continued to reinforce that things would improve. Naturally I also would like to thank the neurology staff who helped me see light at the end of the tunnel and with whom I am currently engaged. Having identified something was not just right they have been diligent in offering me time and space to come to terms with potential changes...All those staff I encountered whilst working in challenging conditions, always had time for a word, to check, are you ok?, is there anything you need?, a smile, an acknowledgement of my situation, a reassurance...”*

<https://www.careopinion.org.uk/943503>

*“...Secretary in Neurology-understanding, kind and empathic to concerns of a parent. Followed up phone call to me this morning to advise on outcome. One relieved parent...”*

<https://www.careopinion.org.uk/964946>

#### 4.3.3 Professionalism

*“...I had to take a relative to the neurology clinic in Altnagelvin Hospital yesterday. From arrival we were treated with respect and professionalism by everyone we met, from the Consultant to the Nurse Specialist, and also R who was organising the clinic...”*

<https://www.careopinion.org.uk/974979>

*“...we were taken into an office where a different nurse did a verbal assessment with my help due to my Fathers hearing issues. She was fantastic, asked a number of questions relating to his condition and then also asked how I was feeling as I am his sole carer. I found the whole process very easy and also very calming, the nurse then left to talk to the Doctor who assessed the information and recommended a number of therapies which will hopefully help my Father.I cannot recommend the nurse we saw enough, she was very caring, intuitive and professional...”*

<https://www.careopinion.org.uk/1036332>

#### 4.3.4 Responsiveness to concerns

*“...Following eye test on a Saturday by my opticians, which found swelling on my optic disc I was provided with appointment in Altnagelvin hospital with eye casualty that Monday morning. Within the day I had further eye tests, CT scan, Lumbar puncture and seen by a neurologist. I was obviously very nervous about getting lumbar puncture and was very appreciative of a staff member sitting with me chatting while procedure was being completed. Within a week I had MRI test. All my appointments have been quick following swelling being found to getting diagnosis of Idiopathic Intracranial Hypertension (IIH) to*



*treatment plan being put in place which has helped reduce stress and anxiety...*

<https://www.careopinion.org.uk/993775>

#### 4.3.5 Importance of MDT in the management of conditions

*"...I had my first appointment with neuro-physio. Very constructive (think I've been walking incorrectly for a number of years which has compromised my balance). Exercises suggested & follow ups scheduled. Wish I'd been aware of this service 2 decades ago. However, I'm embracing it wholeheartedly..."*

<https://www.careopinion.org.uk/995706>

*"...Furthermore, the number of tests I undertook was amazing, all intended to give the clinical staff a steer in what I was encountering, and all those involved in carrying out those procedures, from the staff who took me to and from scans and x-rays to the staff who carried them out were exemplary."*

<https://www.careopinion.org.uk/943503>

*"...The ward has a multi-disciplinary approach and fosters a strong team ethic across the different professions. The consultants are a familiar presence on the ward and are open and approachable, to their enormous credit...I have been amazed and humbled by the kindness and professionalism with which I was treated by the nurses at all levels, taking care to include the students I encountered and a small group of agency staff who are block booked, so very much a part of the ward...To my admiration for nurses I can now add the same for Occupational Therapists and Physiotherapists, of each of which a small group is attached exclusively to the ward. Something that becomes clear very quickly is that no two spinal injuries are the same, and the physios tailor a programme to optimise the potential of each patient, working mostly one-to-one with a designated physio in a way that facilitates trust and builds confidence. The team work so well together (in a way that appears almost intuitive) that it was only on my penultimate day in the ward that I found out who was in charge. The OTs also work one-to-one preparing patients to live with their new limitations, turning any physical gains made with the physios into practical techniques useful in everyday life. There is clearly an ongoing exchange of information, indeed between all the professions in the ward..."*

<https://www.careopinion.org.uk/1048708>

A proportion of stories (n=13) have a criticality rating of 2 or above. The following highlights the main issues identified specifically within these stories.

#### 4.3.6 Communication between Organisations

*"...Very impressed with all the staff we have encountered who have been empathetic, knowledgeable and professional and have continued to monitor despite COVID restrictions. Our only frustration resulted from how the different hospitals communicate in that the paper referral from one trust to another went missing in postal systems delaying diagnosis. I can't*

*believe in this day and age that services need to rely on unreliable methods such as putting a piece of paper in the post when so many technology solutions are available which are much more efficient and reliable for transfer of information and making referrals..."*

<https://www.careopinion.org.uk/801733>

#### 4.3.7 Challenge of telephone consultation

*"...I expected a reminder regarding neurology telephone consultation. No phone call! Not surprised appointments cancelled 4 times.."*

<https://www.careopinion.org.uk/868663>

*"...Extremely disappointed in the neurology review given to my father via telephone...He was anxious about the appointment for weeks as he was conscious he would have to explain his worsening tremor and its effects on his daily living, and other symptoms, on the phone. The telephone call occurred, which lasted a total 2 minutes 7 seconds. The response to reported neurological symptoms, was to discuss with his GP. Then a closing statement was that it would be best to be seen face-to-face the next time. This is an annual review!... My father felt the entire process was a waste of time and it appears us all to be merely a box-ticking exercise to mark patients off the list. What is the point of a specialist review, if in a phonecall lasting 2 minutes no specialist assessment, advice or treatment is given?..."*

<https://www.careopinion.org.uk/924932>

#### 4.3.8 Impact of Restrictions due to COVID-19 Pandemic

*"...we are now entering week 4 of my mother having no visitation. The first 2 weeks of no visitation, for me, seemed like a reasonable reaction as a patient on my mothers ward tested positive. However the restriction to therapies being applied on the ward seemed completely counter active with physios and OTs having to think outside the box for my mother to progress, participate and hit her goals. My mother has tested negative for covid, has all her vaccinations, and her therapies, in most cases, take place in the gym or other rooms on her own with either a physio team or OTs. Therefore I cannot see the additional risk of contracting covid, in letting patients leave the ward to go to attend their individual therapies, especially when they are still interacting with the same people they would be in the gym and the various therapy rooms..."*

<https://www.careopinion.org.uk/909437>

*"... I informed the nurse looking after my bay that I was going to meet my parents and daughter to exchange dirty clothes for clean clothes and to see my father as he had just been diagnosed with lung cancer. I was off the ward approximately 20 minutes when the health care assistant came looking for me, to tell me a porter had arrived to take me for a procedure which I had no knowledge of being scheduled... I only got 5 minutes to spend with my family and returned to the ward. When I arrived I asked the nurse what test I was going for and they informed me that they just told me that to get me to come back to the ward. I was extremely upset about being lied to because at this stage I still had no diagnosis and any test was welcomed by me if I thought it would get me closer to a*

diagnosis. This upset me terribly and I ended up in tears.

<https://www.careopinion.org.uk/917565>

#### 4.3.9 Scheduling Appointments

*"...I have a neurological condition and part of the management is urinary track ultrasound annually. The majority of my condition I self manage... I understand how busy services are and how under pressure staff are due to covid [but].... The random allocation of appointments means I am scheduled my scan at times I have no ability to attend (teaching commitments) and the second time I ask to reschedule I am told I will be put to the back of the list if I don't come. I really need to attend this appointment - Is there no potential for some flexibility for people that have a full time job and self management complex conditions..."*

<https://www.careopinion.org.uk/929524>

#### 4.3.10 Inpatient experience - Lack of communication and poor standard of care

*"...The various hospital wards my mother has been in have all had serious issues. I found it extremely difficult to speak to someone regarding her medical care. My mum was very depressed and distraught. I placed a call with the patient liaison officer to have her doctor ring me to discuss and to date I still have not received a call back. I did speak with the ward sister and they stated that there are no beds available to enable mum to transfer to another non covid ward, she was feeling completely deflated and isolated...We found the neurological ward to be understaffed and at one point a nurse handed me bedclothes for me to change my mothers hospital bed myself unassisted. The ward was dirty and unkempt with used cotton swabs with blood on the floor...the standard of care has been extremely lacking and communication with us has been non-existent. When I have asked for an update on my mother's situation, I have been told no doctor is available and that they were required to ask my mother's permission before they could speak to me. The staff in charge cannot tell me whether the forms have been completed by a social worker to get mum to a rehabilitation centre..."*

<https://www.careopinion.org.uk/1007213>

#### 4.3.11 Concerns of service user or family dismissed

*"...Having waited 2 years for a Neurologist appointment, we finally got one in December 2022...I felt the doctor was dismissive when I showed videos they just said, not Parkinson's... but didn't suggest any other reason. They told me that it couldn't be Dementia 'because it's been 6 years - he'd be dead by now, and if it was Parkinson's 'he wouldn't kick in his sleep, he'd punch the pillow...I asked if he agreed with the diagnosis of MCI, the reply was that they didn't give that diagnosis. We were informed they hadn't gotten my husbands records, yet at the end whilst holding open the door to let us out, told us my husband is not allowed to drive - it's in his records...There's something wrong with my husband, and the neurologist had possibly the key to finding out what that might be, yet they didn't explore*

*any options. Instead they made me feel stupid and small. I felt their attitude was not caring nor empathetic... I certainly would not be happy to have a further appointment with this Neurologist, nor could I recommend to anyone else, my impression was that they just really couldn't be bothered..."*

<https://www.careopinion.org.uk/1031889>

#### **4.4 Areas of development**

There have been **3 changes made** (as recorded by responders) by services as a direct result of engaging with an individual story as detailed in the links below.

##### **1. Provision of Patient Information Leaflet**

*"... We understand that a new diagnosis of epilepsy can be very difficult and there is so much information to digest. It is our aim to see people with a new diagnosis as soon as possible and within two weeks of referral to the Epilepsy nursing service. In response to your suggestion of having the epilepsy information pack within one week of diagnosis, the epilepsy service will provide epilepsy information packs and will request that the consultant neurologist will share with individuals who have a new diagnosis of epilepsy, whilst awaiting an appointment with the epilepsy nursing service..."*

<https://www.careopinion.org.uk/999531>

##### **2. MDT Event in Management of Falls – including Neurology Physiotherapy Services**

*"... Following on from successful outcomes for people attending the recent falls health event, we are committed to increasing public awareness of services that are available to support people who are at risk of having a fall. The falls integrated pathway co-ordinator has attended a number of community events providing education, advice and support with onward referrals to services that support with reducing risk of falls or putting in place a plan to manage risk factors. We aim to run a similar falls health event during Falls Awareness Week in September 2023 which should benefit lots of people..."*

<https://www.careopinion.org.uk/995706>

##### **3. Joint Clinic with Paediatrician and Epilepsy Nurse Specialist**

*"... Many thanks for your positive comments on the paediatric epilepsy service. I am pleased to say that since Jan 2021 we have been running weekly joint epilepsy clinics, where both the paediatrician and epilepsy nurse are present..."* [as suggested by the author of the story]

<https://www.careopinion.org.uk/801733>

It is also recognised stories continue to impact services, organisations and the region through collective analysis, such as the learning included within this briefing paper.

## **5.0 NEXT STEPS**

The analysis presented in this paper is based upon the stories shared from 03 August 2020 to 30 April 2023. It is anticipated the following actions will support Neurology Services within Health and Social Care Trusts to continue to demonstrate their commitment to listen and learn from the experience of service users, families and carers through Care Opinion:

- 1- Embed the concept of Care Opinion into Neurology Services through training led by Trust PCE Facilitator and opportunities through Care Opinion - this includes Care Opinion awareness training and responder training.
- 2- Expand current Care Opinion promotion campaign (through Nurse led clinics) within each organisation to reflect all services and clinical settings relating to Neurology Services. Coordinated by Regional PCE team (PHA) and supported by Trust PCE Facilitators a bespoke invitation link and promotional material has been designed. This supports services to invite feedback at defined stages of the service users' journey and facilitate regional analysis.
- 3- Identification of subscription members within regional forums to receive regular Care Opinion digests on Neurology Services and agree a schedule to undertake thematic analysis of the stories with the support of the Regional PCE team within the Public Health Agency (PHA).
- 4- Learning presented from stories on Care Opinion can support service development, quality improvement initiatives and strategic priorities such as the regional review of Neurology Services.

## Appendix 1:

### Definition of criticality scores assigned by Care Opinion moderators

Score	Definition	n=48
0	<b>Not Critical:</b> Entirely positive or neutral postings with no hint of criticality.	33
1	<b>Minimally Critical:</b> Mention of dissatisfaction with non-clinical non-personal aspects of care, typically “facilities” issues such as food, parking or waiting.	2
2	<b>Mildly Critical:</b> More specific but still mild criticism, which may also include non-clinical but interpersonal issues such as attitude of staff, compassion, politeness. This might include the timely nature of the service whether in hospital or in the community where it has caused distress, e.g., carers not turning up on time.	7
3	<b>Moderately Critical:</b> Criticism which may include alleged shortcomings in clinical or non-clinical aspects of care, the Author may not say what the effect of these are. Also includes serious comments about facilities: ‘never cleaned’; and where people’s essential basic care needs are not being met, e.g., inadequate nutrition and hydration, development of bedsores.	5
4	<b>Strongly Critical:</b> Serious criticisms of specific unnamed staff or groups of staff, or of clinical or other care or facilities. This might have had very serious consequences for physical or emotional health. These will be described by the Author. There might also have been social consequences that have increased the risk or vulnerability of an individual.	1
5	<b>Severely Critical:</b> Posting alleges or describes actions or events which may be illegal, grossly negligent, or allege serious misconduct by named members of staff or organisations.	0







## 6.0 References

Baines, R., Donovan, J., Regan de Bere, S, Archer, J. and Jones, R (2018) Responding effectively to adult mental health patient feedback in an online environment: A coproduced framework. *Health Expectations* 21 (5) DOI Open Access <http://hdl.handle.net/10026.1/11239>



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