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self help for chronic pain sufferers

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CHRONIC PAIN SUFFERERS VIEWS ON MINIMUM CORE DATASET PROJECT

In 2015 the NACCP instructed a Data and Measurement Project for Chronic Pain Services at Dundee University to inform national service improvement. This dataset has been sent to the ISD Steering Group on Chronic Pain to be used to compile data on chronic pain patients in Scotland.

Affa Sair member Fiona Robinson, who also sits on the ISD Steering Group for the project, consulted a selection of chronic pain patients and Affa Sair members on the survey which is designed to be completed by every chronic pain patient attending a pain clinic, treatment or review. The aim of the survey is to build up a record of a patient's journey through the Chronic Pain service.

All the patients who answered, felt the survey would not give an accurate picture of the state of the chronic pain service and needs considerable changes before it is released. The non-recording of delays in treatment and the very long waiting times for return appointments featured heavily in the replies.

Affa Sair urges ISD to make the suggested changes to the survey so that accurate information is recorded. Otherwise this will just confirm patients' suspicions that the survey will skew the data received making the current situation for chronic pain sufferers look far better than the bleak reality they face.

Chris Bridgeford
Chairman – Affa Sair
04 February 2020

Fiona Robinson
ISD Steering Group
04 February 2020

Comments Made:

1. The pain section would be better if patients could plot or have a table they could put in ticks (pain vs time up to 5 years in 3 month intervals) – i.e. is the treatment working or is the pain progressively getting worse.
2. Another question which should be added is - Would you say your is pain constant, intermittent or variable on a day to day basis? – This indicates the type of treatment which may be best. Not how I would've done a study.
3. Add in emotional 2 positives rather than just 2 negative leading options or change it to a 2 sided scale (like question 7 and 9) - maybe an additional question in past mental health issues.
4. There are inconsistent time scales - why 3 months for one question, 6 months for one and 2weeks for another? Especially when the lowest timescale for pain option is 3 months - as a scientist this makes no sense for analysis of data and worse if its intention is to be used by doctors/anyone, to monitor patient treatment over time.
5. Less than 3 months should be included for pain but the impact can't be quantified if you're only asking about a 2 week window. In the case of long-term sufferers in my opinion (if they haven't suffered in past 2 weeks somehow it doesn't have an impact? - maybe instead should be "during the duration of this pain have you...")
6. As for the reason behind the varying scales used for weeks/months, I can see the reasoning behind it as the minimum "less than 3 months" tells the clinicians who has been referred urgently, and those who have had to wait, but the emotional impact one is standard for psychological surveys, with either a week, two weeks or a month being typical. In this case the two week mark gives enough time to allow the pain to fluctuate and have an impact on emotional wellbeing, and the pain scale one is playing off the first "scale".
7. During my degree I've found standards can be wrong/have major problems, not saying that there is but there is absolutely nothing wrong with pain data going back further if a person has been experiencing it - it also gives patients more time to consider their actual pain at different times rather than quickly circle what they are currently at.
8. Another question to add is - Do you feel like healthcare staff address your concerns when it comes to health issues when raised?
9. Do service providers ask about pain routinely and if they do, do they take the answer seriously since they cannot measure pain. With 'invisible illness' they can be so busy 'projecting' onto the patient and trying to discern if it is real....that pain is very low on their measuring of 'relevant' symptoms in chronic conditions. There is a quality of caring in their not wanting to risk patients on long-term meds but no alternative is ever offered.
10. My experience is that if pain is given a label like CRPS and then ignored there is little reference to it again. Another useful question to discern the true effect of their pain is asking if patients have felt actively undermined or dismissed about pain?
11. There is a serious concern by some patients that continually asking for alternative methods of pain control is viewed as attention seeking.
12. The standardised depression test can make almost anyone appear depressed due to negative bias.
13. I mean look at these questions - you can't tell me that most people wouldn't score points even if it's due to a non-depression health issue - for example 3,4,5,7,8 could be due to thyroid problems when applied to this it would equal moderate depression

14. As a former social science student from a course focused on research this severely disappoints me as a survey. I could have easily made this type of survey in my NC6 days, and it also fails to include questions such as known triggers, such as having to travel to said appointment, stress etc, which could be posed as an open question or a quantitative question with tick boxes and an option for other, also wait time to get appointment, and also whether you had to fight in the first place to get an appointment should be noted. Also to be noted should be it should be anonymised in some form or another or the health care staff collecting the data, could use it against the patient. This so called survey is not fit for purpose at this stage and could have been made in 5 minutes.
15. This is a joke right? Which patient with chronic pain has had pain less than 3 months and could potentially have excellent health? Takes at least a year to go back and for to the GP with symptoms to get referred to the pain service, then wait for an appointment and then finally get to see someone only to be sent back to GP with a list of drugs for them to prescribe. Who wrote this?
16. I think a lot of us don't see our doctors as much as we should due to physical and mental problems. If things were recorded, it's good for the doctor to have a quick glance as it will save time for them by going through everything again, and it will save us the embarrassment of relaying the same things over and over.
17. What is the actual return patient time scale – There isn't one! Without it then this cannot move forward.
18. Everyone is different but the time scale should be the clinical decision, therefore this is the guarantee.
19. I was referred to the Pain Clinic so I could be sent to the Residential Pain Management Course in Glasgow. 15 months later I have had no word of a return appointment to see what effect it had on my pain levels.
20. Where does this survey allow for data on the waiting times of return appointments or how pain has altered in that time?
21. It doesn't reflect the changes in pain between appointments.
22. Why doesn't it mention delays or return waiting times? Is this not the reason for it?
23. Surely delays in treatment times should be recorded otherwise the data collected will make out that the pain has increased because the treatment is not working, not that the increase is due to delays in the actual treatment.
24. How else will this be used? Will it be used to boot me off the list? I am already getting letters asking if I still want to be on the list as the delay between treatment is huge.
25. I have had 2 suicide attempts due to a now 2 year delay getting my injection, where do I put this on the NHS questionnaire?
26. How do they measure new patient delays? There is no questionnaire for new patients that tell health boards this, the health boards already measure it, therefore why can't they measure return patients and delays, the onus should not be on us. Why are there 3 different time scales? In the last 2 weeks, 3 months and 6 months. Seems a bit weird.
27. Why is it our responsibility to make health authorities aware of the delay. Surely they already know the delays. I can phone consultants secretary and she can immediately tell me what the time scales are for treatment.
28. I was prescribed Capsaicin cream to use for 6 weeks and it really helped, but when I got my next appointment it was for 7 weeks after I stopped the cream and the pain was as bad as ever, how does your questionnaire show this?

29. I'm supposed to get 2 injections a year. I've not had an injection for 20 months due to lack of appointments. It's going to take years for the injections delay to build up and show the true picture to the health board and government.
30. Can I change this survey to add that the delay in my treatment made my pain worse!
31. I'd happily complete it if I can get seen sooner, but I fail to see how this questionnaire does this, it doesn't mention deterioration due to delays. Paper exercise to shut us up!
32. My private physio has a better questionnaire than this, can we change it to reflect the needs of chronic pain patients?
33. Who is going to add all these surveys to a national system? My consultant is the only one in Highland, I would prefer getting my infusion on time than him wasting time on this.
34. If I repeatedly say my pain is bad on the questionnaire, will I get removed from the pain service as clearly the treatment is not being shown to work? If I actually got my treatment on time and there was "context" to this questionnaire then I wouldn't be scared to complete it accurately.
35. I waited 49 months for an injection (supposed to get 2 per year), just had an injection in January which failed. I have phoned my pain consultant to see how long I have to wait, this is being reviewed. Why should anyone have to wait 49 months (4 years 1 month). An utter disgrace.
36. I would love to fill this in if I can get an appointment with anyone in the pain clinic. I have fibro and have been ping-ponging all over the NHS, no one wants to help me.
37. My GP is trying to help but I urgently need specialist pain care. I am on the scrapheap of the NHS, that seriously is how I feel. My GP has 2 letters from the pain clinic saying I don't meet their criteria and 3 letters from Rheumatology saying the exact same thing.
38. Is this being used for psychology appointments? Good luck getting an appointment in ARI, I'd never get to fill it in.
39. How will completing this get us more staff? More staff, less delays. NHS delay the inevitable by getting us to complete this, waste of time and money as usual. Just get more staff.
40. We desperately need services in Elgin and travelling to Aberdeen makes my pain ten times worse, so I'm not showing a true picture of my pain and I'll be in additional pain filling this in, how can I be objective?
41. I moved house 5 miles (to a bigger house where I can care for my dad) and I am no longer in the NHS catchment area for Lignocaine. My new health board doesn't offer this and it's the only thing that works.
42. Treatment types need to be nationalised not just up to local boards. Postcode lottery shouldn't exist in Scotland.

All of the Affa Sair members who replied answered **YES** to the following questions:

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|---|--------------------|
| 1. Type of treatment recommended by health professional should be recorded: | Yes/ No |
| 2. Frequency of treatment given should be recorded i.e. weekly, fortnightly, monthly etc: | Yes/ No |
| 3. Any delays in treatment should be recorded | Yes/ No |