
Director General for Regulation

Ms. Dorothy-Grace Elder
(by email)

25 September 2017

Dear Dorothy-Grace,

Thank you for writing to me, on behalf of the Cross-Party Group on Chronic Pain, about NHS Scotland's Information Services Division (ISD) Chronic Pain Waiting Time Statistics¹. You raised concerns about ISD removing some commentary, that patients returning for treatment are not counted, that policy officials at Scottish Government request changes to the statistics and that this amounts to inappropriate political interference. My team have looked into your concerns in detail (outlined in Annex A).

These statistics are important. They should shine a light on the waiting time experience of those needing to access chronic pain health services in Scotland. The time waiting to access these services is particularly significant given the nature of chronic pain and the impact on those who live with it.

I have concluded that ISD have made a series of misjudged decisions on the commentary and coverage of these statistics. These decisions have reduced the usefulness and accessibility of the statistics for users. My conclusion is that these misjudged decisions are the product of a narrow process of user engagement undertaken by ISD, which has led to the statistical commentary catering more for the needs of policy officials than those outside government. However, I do not consider that this narrow engagement amounts to direct politically-motivated interference. My concern is rather that the user input ISD seeks is too narrow in terms of the range of voices heard.

I also consider that ISD should continue to look into the case for the inclusion of data on return patients. ISD has not been transparent on what it plans for these statistics, which is important as these statistics are still in development, and has not communicated well with the users who have asked for return patient information to be included.

Whilst I think the misjudged decisions stem from narrow user engagement rather than political interference, these allegations are serious, and can have a detrimental impact on people's confidence in statistics. I do intend to meet with policy officials at Scottish Government working in health to discuss the benefits of the Code of Practice for Statistics in terms of trustworthiness, quality, and public value. I will highlight this case as an example of where public confidence in health statistics needs to be improved and what their role should and should not be in this.

This case highlights the need for statisticians to be transparent in their plans and reasoning when developing new statistical series, and the need for a wide range of users to be involved in the development of statistics. If ISD had done this, the erosion of user confidence in these statistics may well have been avoided. I recommend that ISD considers these points in terms of the next steps taken with Chronic Pain Waiting Time Statistics, and also for other statistics ISD develop.

¹ www.isdscotland.org/Health-Topics/Waiting-Times/Chronic-Pain/

I have also asked my team to:

- A. follow up with ISD on how they have acted on our recommendations;
- B. review a wider selection of ISD publications in the autumn. We had always planned to review² a selection of ISD publications this year, and I have now asked my team to look at the changes in commentary across different editions of statistical publications. Our conclusions will be published for all to see, and I will let you know when they are published.

The essence of this situation is the importance of wide user engagement in the development of statistics. I would encourage ISD to seek regular input from the Cross-Party Group, and I hope that this can create a more constructive process to achieve what we all want: the clearest and fullest possible picture of the experience of those living with chronic pain.

Thank you for bringing this to my attention and for your patience while my team has taken time to investigate your concerns. I have copied in Scott Heald, Head of Profession for Statistics at ISD, and Roger Halliday, Scottish Government Chief Statistician.

Yours sincerely



Ed Humpherson
Director General for Regulation

² Through a series of compliance checks: www.statisticsauthority.gov.uk/osr/assessment/programme-of-assessment/compliance-checks/

Annex A

Ms Elder, on behalf of the Cross-Party Group on Chronic Pain, raised the following points for investigation:

1. ISD removed main points from their summary between the December and March publication of Chronic Pain Waiting Time Statistics, making it difficult for some users to find the information they need. There is a concern that these main points were removed to hide bad news relating to the length of time patients are waiting for treatment.
2. Patients returning for chronic pain treatment are not included in Chronic Pain Waiting Time Statistics. There is a concern that without this information those patients returning for treatment won't get timely appointments as attention is turned to patients who have been newly referred in order to meet the referral for treatment target.

Both points 1 and 2 reflect a concern that ISD makes decisions as a result of pressure from policy officials in Scottish Government, and there is a concern that this undermines the integrity and public value of the statistics. We address this concern in our analysis of the first two points.

3. In an article published in the Herald newspaper Ms Elder raised the concern that ISD are not including patients still waiting for an appointment in their analysis of chronic pain waiting times. ISD's Head of Profession for Statistics has responded to this concern by stating publically on their website that the analysis was inappropriate. There is a concern that this response was inappropriate.

We have considered 1) the chronic pain waiting time publications; 2) our own discussions with ISD, and 3) Freedom of Information (FOI) material provided related to Chronic Pain Waiting Time Statistics. We have also kept in mind that these statistics are new and are still in a development stage in terms of improving the quality of data provided by NHS Health Boards to ISD for publication.

Summary of the Office for Statistics Regulation investigation

1. ISD removed main points from their summary between the December and March publication of Chronic Pain Waiting Time Statistics, making it difficult for some users to find the information they need. There is a concern that these main points were removed to hide bad news relating to the length of time patients are waiting for treatment.

1.1 Changing information presented in statistical commentary is not unusual, and in many cases encouraged, as long as the changes aren't put in place to hide 'bad news' stories or because statisticians have been put under undue political pressure to change information. In fact Government Statistical Service (GSS) guidance on *writing about statistics*³ encourages statisticians to avoid simply inserting new figures into standard, unchanging text and promotes the need for commentary that provides valuable insight to users. Any changes made should of course be appropriate, with the core principles of the Code of Practice for Official Statistics in mind. We are aware that ISD do refresh their commentary through a group of senior staff who review all statistical summaries before publication to keep the commentary useful and interesting for users.

1.2 In terms of Chronic Pain Waiting Time Statistics we know that ISD removed summary information commentary on 1) patients still waiting for their first appointment at a chronic pain clinic and 2) patients still waiting for their first appointment at a pain psychology clinic. We can see that these statistics are important in terms of understanding the experience of those chronic pain patients who are still waiting for their first appointment. These statistics are still published in excel tables, and therefore are still available for various users (such as patients, the health service, government) to understand better the experience of patients waiting to be seen for chronic pain services.

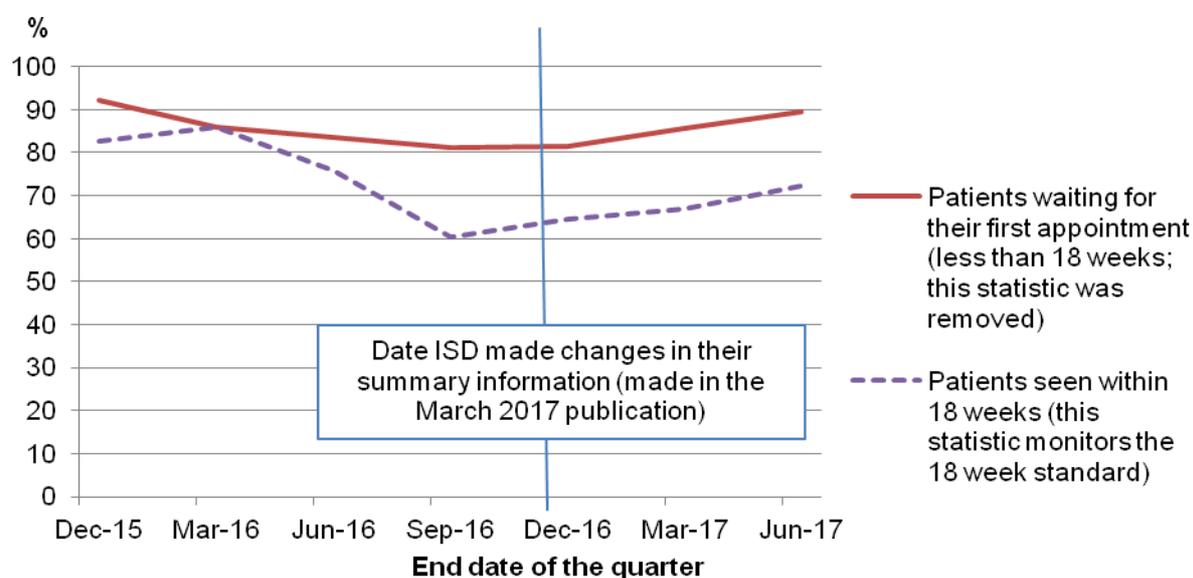
1.3 We conclude that whilst the removed information is still available in excel tables, the prominence of and access to this information may have been reduced (it may not have been clear to some users that the statistics could be found in the excel tables as ISD did not signpost users to the removed statistics).

1.4 In terms of motivation behind removing information on patients still waiting for their first appointment at a chronic pain clinic:

³ <https://gss.civilservice.gov.uk/wp-content/uploads/2012/12/Writing-About-Statistics-National-Statisticians-Guidance1.pdf>

- The FOI material⁴ shows that ISD statisticians were thinking about how to make the commentary clearer to users as they had realised people reading the summary were getting confused by what was presented. ISD statisticians had suggested focusing solely on the main measure of waiting times – the percentage of chronic pain patients who have attended their first appointment within 18 weeks – which would entail removing commentary on patients still waiting for their first appointment. These actions would bring the commentary on Chronic Pain Waiting Time Statistics in line with commentary on 18 Week Referral for Treatment Statistics. The FOI material⁵ also shows ISD discussed their proposed changes with Scottish Government policy officials in a meeting subsequent to ISD discussing how to change the summary. Scottish Government policy officials agreed that the commentary was confusing and that as long as the information removed from the summary was still in the excel tables the changes would be fine.
- The statistics in question are presented in Figure 1. There was little change between the December 2016 (period ending September 2016) and March 2017 (period ending December 2016) publication in the percentage of patients still waiting for their appointment who had been waiting for less than 18 weeks.

Figure 1: Chronic Pain Waiting Times Statistics in Scotland, patients waiting for an appointment or have attended a first appointment at a chronic pain clinic



Source: OSR analysis of Chronic Pain Waiting Time Statistics, NHS Scotland's Information Services Division, September 2017

1.5 On the question of why this information was removed, we consider that the decision to change the main points was made by ISD statisticians themselves and they were aiming to reduce user confusion.

1.6 However, it is clear from this investigation that the changes made have caused further confusion. We think that the way ISD chose to address user confusion was misjudged – they needed to think about and engage with a wider range of users, and how they would be able to access and interpret the statistics removed from the summary. It may have been better for ISD to find a way to explain more clearly the information that was previously published in the summary, rather than choosing to remove the information entirely.

1.7 In terms of the motivation behind removing information on waiting times for patients who are waiting for their first appointment at a pain psychology clinic:

⁴ 6 January 2017, email titled 'Chronic Pain Publication' sent by the Principal Statistician in ISD to another member of ISD.

⁵ 13 January 2017, email titled 'Chronic pain waiting times publication – unofficial statistics and developmental labelling' sent by the principal statistician to various members of ISD.

- We can see that the FOI material shows Scottish Government⁶ policy officials suggesting to ISD to reduce the number of main points on pain psychology services, as these statistics weren't their main focus.
- ISD have told us that they chose not to include these main points in the summary publication because the data underpinning the statistics were incomplete and of poor quality. ISD said this decision was in response to patient representative feedback gained in January 2017 following up from a Chronic Pain Waiting Time Ministerial meeting held in October 2016. This feedback did not include a suggestion to reduce the number of main points on these statistics but outlined the need to caveat pain psychology services waiting times information, due to data quality problems.
- ISD removed a number of points on pain psychology clinics after receiving this feedback. These changes occurred in the March 2017 publication.

1.8 We cannot say why ISD chose to remove information on pain psychology clinics – whether it was because of the comments Scottish Government policy officials gave, or because of patient representative feedback, or both. In this case we recognise that people could well draw conclusions about political interference from the FOI material. It is difficult to conclude concretely what motivated various decisions from FOI material alone. What we can say is that ISD should be engaging with Scottish Government policy officials as an important user. But ISD should also be engaging with users outside government to make sure the needs of other users are met. In particular, whilst ISD did gain feedback from one patient representative, one piece of feedback does not represent the range of users who will use these statistics. The user input is too narrow.

1.9 The statistics removed are based on incomplete data and may not fully reflect the experience of patients still waiting for an appointment at a pain psychology clinic. To choose not to highlight these statistics, in this case, may have been a sensible decision. However, we think that ISD could have been a lot clearer to a wider range of users, such as the Cross-Party Group on Chronic Pain, on their judgement about the quality of these data – both in terms of highlighting to those looking at the excel tables still presenting the statistics and for those reading the summary information⁷.

1.10 **Recommendation 1:** ISD should ensure that future user engagement is strengthened by engaging with a wide set of users, through a variety of avenues. For example, we can see real value in establishing regular contact with the Cross-Party Group on Chronic Pain who have built up insight on chronic pain, which could be used to strengthen the public value of these statistics. By broadening user engagement and making sure that a wide range of users needs are catered for ISD could in future avoid allegations that the needs of Scottish Government policy officials are catered for above other users. We believe this will increase user confidence in Chronic Pain Waiting Time Statistics.

2. Patients returning for chronic pain treatment are not included in Chronic Pain Waiting Time Statistics. There is a concern that without this information those patients returning for treatment won't get timely appointments as attention is turned to patients who have been newly referred in order to meet the referral for treatment target.

2.1 The FOI shows that ISD had asked NHS Health Boards whether they collected information on patients returning for chronic pain treatment. After telling Scottish Government that they had asked this question of NHS Health Boards, the policy official replied that they would not want this data published. We can see that this reply could give the impression that ISD is not able to determine what they do and don't publish. We asked ISD about this comment, and they stated that it was likely given in the context of previous conversations about thinking "*carefully about the benefit of collecting and publishing this information versus the cost of collection/changes to extracts and IT systems*". Whilst data may exist in the system at health service provider level, ISD have told us that at this point in time only two NHS Health Boards collate these data centrally.

2.2 We cannot say whether ISD chose to go no further in exploring the inclusion of return patient information in chronic pain waiting time statistics because of Scottish Government's comments. We

⁶ 13 January 2017, email titled 'chronic pain waiting times publication – unofficial statistics and developmental labelling' sent by the principal statistician to various members of ISD.

⁷ We note that since this investigation started ISD have now included a caution alongside the excel tables to try and ensure that users don't miss the message that pain psychology statistics are of poor quality. They have also included more information on quality in the summary commentary.

recognise that people could well draw conclusions about political interference from the FOI material; however, it is difficult to conclude definitively what motivated various decisions from the FOI material alone, as it presents only one part of the whole picture. Again, we are concerned that important decisions are made by ISD on the basis of a narrow base of user engagement largely with policy officials. In addition to wider discussions with users, such as the Cross-Party group, we believe that ISD could have protected themselves better from any allegation of political interference by publishing their plans and priorities for these statistics, and stating what they plan to do in understanding the need for return patient information publically as well as explaining to those users who want it why this information is not published.

2.3 These statistics are still in development, and we think that ISD should continue to consider the case for the inclusion of return patient information. ISD has informed us that their current priority is to work with NHS Health Boards to improve the quality of the data already collected, but they will consider the value of including return patient data in future. We welcome this commitment.

2.4 **Recommendation 2:** ISD should be more transparent about their plans and priorities for Chronic Pain Waiting Time Statistics to a wide range of users. This should include publishing plans for the development of Chronic Pain Waiting Time Statistics outlining ISD's current and future priorities. These plans should include information on whether and how ISD will consider the public value of including patients returning for treatment in the Chronic Pain Waiting Time Statistics – and if they decide not to consider this they should explain to users the reasons behind their own decision.

3. Ms Elder raised the concern that ISD are not including patients still waiting for an appointment in their analysis of chronic pain waiting times in an article published in the Herald newspaper. ISD's Head of Profession for Statistics has responded to this concern by stating publically on their website that the analysis was inappropriate. There is a concern that this response was inappropriate.

3.1 ISD's Head of Profession for Statistics published a letter⁸ on ISD's website, which responded to an article published by the Herald on 6 March 2017⁹. ISD outlined their view that the analysis published was misleading due to the calculations used. In this instance, we support the decision of the Head of Profession in ISD to write this letter clarifying that patients are only included in the overall measure of waiting times once they have been seen for their first appointment. The Code of Practice requires statistical experts to comment publically on statistical issues.

3.2 Having said that, we also know that Ms Elder checked her calculations with ISD statisticians, who did confirm the calculations to be mathematically correct, but also provided further information explaining why the calculations in the context were inappropriate. We think that ISD, while clearly striving to be helpful in their responses to Ms Elder, should have been clearer in explaining why the calculations were inappropriate. ISD should consider developing guidance on handling customer queries of a technical nature to avoid this situation happening again.

3.3 We also think that the commentary provided in the summary of the Chronic Pain Waiting Time Statistics could be clearer on what is and is not measured, why waiting times are measured in a specific way, and how to interpret the specific measures published. For example, a rise in people still waiting for a first appointment for longer than 18 weeks, might indicate that demand for chronic pain services is higher than supply. Or it may even suggest (in some cases) that patients waiting less than 18 weeks are chosen over those waiting more than 18 weeks to ensure that the 18 week target is met.

3.4 **Recommendation 3:** Ensure that ISD describes these statistics clearly and accurately in all forms of communication, including when dealing with technical enquiries and in its commentary, so that everyone can understand what these statistics represent and how they can be used to gain valuable insight into chronic pain waiting times.

⁸ www.isdscotland.org/Health-Topics/Waiting-Times/Chronic-Pain/20170307_Ltr_The_Herald_SH_updated.pdf

⁹ www.heraldscotland.com/news/15135533.Revealed__Hidden_scandal_of_chronic_pain_wait_times/