

Risk of Disclosure – Children and Young People with an Eating Disorder Waiting Times

Coverage

This paper assesses confidentiality and data disclosure issues of the provider/commissioner based “Children and Young People with an Eating Disorder” collection.

Background

1. Statisticians have a professional duty to protect the confidentiality of individual level data obtained to produce statistics. The Code of Practice for Official Statistics sets this out in Principle 5: “Private information about individual persons (including bodies corporate) compiled in the production of official statistics is confidential and should be used for statistical purposes only”. The Code of Practice also states arrangements for confidentiality protection should be sufficient to protect privacy but not so restrictive as to limit unduly the practical utility of statistics. The main legal instruments governing this balance are the Data Protection Act, which places obligations on organisations to protect personal information and the Freedom of Information Act, which creates a public right of access to information. There is also a common law duty of confidentiality.
2. The design of a statistic should meet the obligation to protect against disclosure, but should then be optimised to include as much detail in the statistic as reasonably possible, to fully meet the needs of the users.
3. There is a need to assess whether this data is potentially disclosive.

Guidance from ONS – the structure of this assessment

4. Guidance from ONS¹ on confidentiality sets out guidelines for any assessment of disclosure risk. It stops short of setting out hard and fast rules, but is clear on the need to protect patient confidentiality while at the same time maximising public access to official data. This guidance summarises the six main steps for ensuring access to non-disclosive statistics as shown in Figure 1.

¹ GSS/GSR Disclosure Control policy for tables produced from administrative data sources (the document is available at the following link: <http://www.ons.gov.uk/ons/guide-method/best-practice/disclosure-control-policy-for-tables/index.html>)

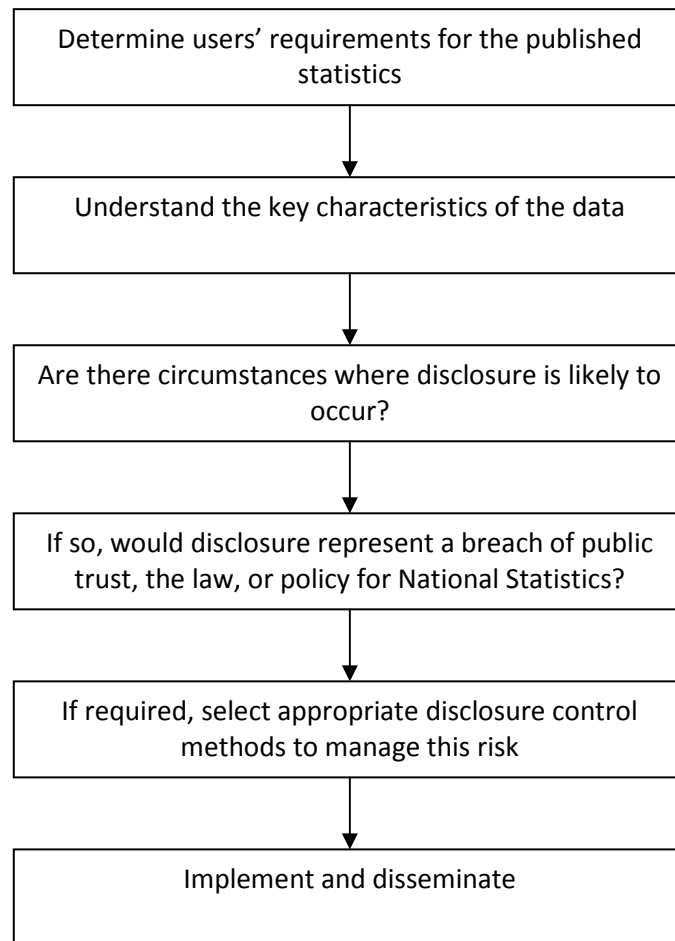


Figure 1: Main steps for ensuring access to non-disclosive statistics

Step 1 – Determining users' requirements

5. The requirements for this data were set out in **“Children and Young People with an Eating Disorder”** published in January 2016. This document includes the standard which the collection was created to monitor.
6. A collection was established using Unify2, to collect this data on a quarterly basis from all English providers/commissioners.
7. The current collection allows members of the public and those working within the system to have access to up-to-date information. This leads to an implied need to publish data subject to any confidentiality constraints in a timely way.
8. **Children and Young People with an Eating Disorder (CYP ED) Referral to Treatment (RTT) Waiting Times** data is published to give patients and commissioners an insight into the performance of their local provider and CCG, and allows them to compare against all other providers/ CCGs in England. The areas covered in CYP ED include:

- **Urgent Cases - Patients started treatment:** RTT waiting times for children and young people with an eating disorder whose wait ended during the quarter by starting NICE-approved treatment following an urgent referral.
 - **Routine Cases - Patients started treatment:** RTT waiting times for children and young people with an eating disorder whose wait ended during the quarter by starting NICE-approved treatment following a routine referral.
 - **Urgent Cases - Patients still waiting for treatment:** RTT waiting times for children and young people with an eating disorder who are waiting to start NICE-approved treatment following an urgent referral at the end of the quarter.
 - **Routine Cases - Patients still waiting for treatment:** RTT waiting times for children and young people with an eating disorder who are waiting to start NICE-approved treatment following a routine referral at the end of the quarter.
9. There is converse public interest in ensuring that information about the experience of individuals is safeguarded in an appropriate way. A balance must be struck between measures to protect confidentiality and the public good arising from publication.

Step 2 – The characteristics of the data

10. This is an aggregated data source. The data is submitted by providers based on patient level information that is taken from an administrative data source within the trust. The collection covers children aged up to 19 years old. It is collected from providers at provider level but split down further to commissioner (CCG) level. The data collected consist of counts of the number of children who started treatment and who are waiting for treatment, broken down by whether the treatment is urgent or routine and the time waited. The counts are not broken down further beyond provider, commissioner, urgency and time waited. Of particular note, the counts are not broken down by other characteristics of the children such as age or gender.
11. There is a process of data cleaning and validation within the collection system. Prior to the publication, the central data team undertakes some basic checks to identify if data is significantly out of step with other trusts and previous submissions. Also, representatives from commissioners make their own checks in regard to the data submitted by provider trusts.

Step 3 – Evidence of risk of disclosure

12. Publication of any detailed data may increase risks of disclosure of information relating to an individual patient. It is important to note that these data do not include any personal identifiers, so it is not possible to identify patients directly from the published data. Instead the categories of disclosure risk (situations in which disclosure might arise) are as follows:
- **Self-identification risk:** When a patient recalls their circumstances during the time period of the data collection and can recognise, from the context,

which data refers to them. This would only likely cause distress within smaller counts.

- Motivated intruder risk: Where there are reasons for a third party to seek further information about cases of a patient, for example where a 'celebrity' case arises or where cases in a particular organisation happen with a newsworthy frequency or pattern. This type of risk can be broken down further into two types:
 - a. Identity disclosure: Where a third party is able to determine who the data relates to using the data itself and other information available to that third party.
 - b. Attribute disclosure: Where a third party is able to infer additional information about an individual.

It can be concluded that there is no material risk of identity disclosure, as the size of the population underlying the collection is large. As providers do not have defined geographical catchment areas, the availability of provider information alongside commissioner information does not materially increase the risk of disclosure. For this age group and range of information, the main route to identity disclosure is through attendance at educational institutions. However, the collection covers children aged up to 19 years old, who will be attending a sufficiently high number of secondary and higher education facilities even within the smaller CCGs to create no material risk of identity disclosure. Instead, the risk from motivated intruders relates to the risk of attribute disclosure.

Self- Identification risk

13. There may be circumstances where a patient can self-identify. Current published tables can contain small numbers. This is not in itself a reason for suppressing data. An appropriate test is defined by the Data Protection Act 1998, which requires the matter to be considered (although it does not directly require all self-identification to be avoided). There is a need to confirm that the published data would not cause, or be likely to cause, unwarranted and substantial damage or distress.
14. The collection is related to performance data therefore self-identification is likely; it only requires recognition of hospital experiences during the time-period.
15. It is highly unlikely that distress would be caused by self-identification unless some sort of negative emotion is evoked from recognising the patient had entered a CYP Eating Disorder (CYP ED) pathway.
16. The patient would recognise that only someone who already knew about any of their condition, whether the condition was treated and the location of the treatment would be able to identify them, and therefore no additional information is revealed. Indeed, the patient may view such information as useful in providing evidence that can be used to improve access to treatment for themselves or others.
17. If someone had access to PAS² data then identification could be possible, but both these data sources are subject to their own security and rules concerning confidentiality.

² A Patient administration system (PAS) is core component of a hospital's IT infrastructure. It records the patient's demographics and details all patient contact with the hospital, both outpatient and inpatient.

18. The broad conclusion is that there may be a risk of self-identification; however, the consequences of this are highly unlikely to cause damage or distress to the individual patient. There is therefore no need to suppress any small numbers to avoid self-identification.

Motivated intruder risk

19. The risks of being identified by a third party are similar to those arising from self-identification, except in the following aspects:
 - The third party may not have access to information that the individual is aware of (regarding themselves), so in some areas risk is reduced.
 - However, it may be a breach of confidentiality if a third party can deduce anything about the individual.
 - We need to consider carefully the extent to which a third party might become a motivated intruder, with an incentive to explore the data and deduce information about the individual.
20. The published data does not contain any personal identifiers. The additional risk that publishing small numbers allows a motivated intruder to deduce information about an individual is considered next.
21. The incentive, and consequently the risk, may be higher when high profile individuals are known to have attended hospital during the quarter. There may also be scenarios where someone would seek information about a friend or relative.
22. The broad conclusion is that it is impossible to identify a patient from the Children and Young People with an Eating Disorder data alone. Prior knowledge or access to personal information would be required. If a third party is in possession of information that a child has been treated and knows the provider and/or CCG of treatment, there is a risk that they could infer whether the treatment was urgent or routine and the waiting time for treatment.

Step 4 – Would disclosure represent a breach of public trust, the law, or policy for National Statistics?

23. Where patients can identify themselves in the data, there is a risk that the patient could view this as disclosive. As discussed above, this self-identification risk is not a substantial one. Disclosure would not represent a breach of public trust.
24. Previous GSS protocols on confidentiality stated that disclosure control methods should be judged sufficient when, taking account of information likely to be available to third parties, it would take a disproportionate amount of time, effort or expertise for an intruder to identify a statistical unit to others, or to reveal information about that person that is not already in the public domain.
25. In this collection there is insufficient data to enable an individual to be identified from the data alone. If a third party was able to access other data sources, such as PAS, to further identify a patient, these secondary sources would have to be full disclosive in their own right in order for an individual to be identified. As discussed above, PAS have their own security protocols.

26. There is a risk of third parties inferring information about the urgency of, and wait for, treatment. In our view, whilst this information might not be viewed by many as the most sensitive type of medical information, allowing its disclosure would still represent a breach of trust and potentially the law.

Step 5 – Select appropriate disclosure control methods to manage this risk

27. To mitigate this risk;

- For young people that started treatment, national and regional totals will be displayed every quarter and will be unsuppressed. However, provider and CCG totals will be displayed using a 12 month time period and the data will only be displayed where there are two or more 'Urgent Referrals' and two or more 'Routine Referrals'. Secondary suppression of data for providers or CCGs will be applied within regions where necessary.
- For young people still waiting to start treatment, national and regional totals will be displayed every quarter and will be unsuppressed but provider and CCG totals will not be included in any form in the publication files.