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24 November 2017

[redacted]

By email

[redacted]

Dear [redacted]

Request under the Freedom of Information Act 2000 (the "FOI Act")

I refer to your email of **30th October 2017** in which you requested information under the FOI Act from NHS Improvement. Since 1 April 2016, the Patient Safety functions under section 13R of the NHS Act 2006 have been exercised by the NHS Trust Development Authority, as part of the integrated organisation known as NHS Improvement.

Your request

You made the following request as a follow up to the FOI response we sent to you on 16th October 2017:

"Dear NHS Improvement,

Thank you very much for the information that you have sent to me on the delayed diagnosis of breast cancer. Could I just quickly query three parts of the information.
1. Out of the 4,826 incident reports, 1,291 say that "Patient Sex" is not stated/unknown. This seems rather unlikely. I would not have expected 1 in 4 oncologists / breast surgeons to be unable to tell the gender of their patients. Could you just doublecheck that your information is correct because this doesn't make sense.

2. Out of 4,826 incident reports, 520 have "missing" information on patient gender. However, if the gender part of the form wasn't filled in and the information was missing then the incident report could not be submitted. If the form couldn't be submitted how do you know any information about the incidents? Again, could you doublecheck that your information is correct because it doesn't make sense.

3. Out of the 1,010 incidents reported involving delays in diagnosis and clinical assessment, there were only 8 deaths and 79 cases of severe harm. The majority were categorised as no harm and yet we know that delays in cancer diagnosis cause serious harm, reduced life expectancy and death. The issue is that we don't always know what harm will be caused until months (or even years) after the delayed diagnosis has taken place. Can medical professionals alter their incident report at a later date to take account of any changes in the patient's prognosis? Would it also be important to find out whether a patient's treatment has changed as a measure of harm? It may be that the patient needs further chemotherapy in

the light of a delayed diagnosis because the cancer has grown, or perhaps a patient's cancer might have become too advanced to treat in which case they might need less or no chemotherapy. Is there a way of checking these questions against your data?
With many thanks,"

Decision

Please see our following responses to your questions:

1. The National Reporting and Learning System (NRLS) is a central database of patient safety incident reports and as such incident reports are uploaded from local risk management reporting systems such as Datix. Therefore when the "Patient sex" is listed as "not stated/unknown" this doesn't mean that the patient sex was unknown to the clinician reporting the incident, but that a local system logged it under that category (potentially as a default when reporter didn't actively select sex of patient). A breakdown of Patient Sex across all incidents in 2016 was run and found that "Not stated / unknown" amounted to 30.8% and "Missing" was 8.6%, so the breakdowns are fairly similar to the data from your previous request, and we have no reason to think that the data is incorrect.

2. It is possible to submit an incident form without filling in every field and "Patient Sex" is not one of the mandatory fields, as stated in the previous answer when the patient sex is not added this may appear as "not stated/unknown".

3. All incidents submitted to the NRLS via local risk management systems can be updated at any time if/when further information becomes available, this includes the degree of harm. We encourage all organisations to update their incidents, although this is not a requirement, it is not always possible to determine the degree of harm where possible delays in treatment have occurred. Incident data extracted from the NRLS will show the latest information that has been uploaded at that time.

We hope that these answer your questions satisfactorily and as stated in our previous FOI response you may find it helpful to know that NRLS data can also be requested through our data request process via nrls.datarequests@nhs.net. When a data request is made we can help a member of the public, clinical staff or researcher to identify what information might best meet their needs, and discuss the best way to search for it within the NRLS.

Review rights

If you consider that your request for information has not been properly handled or if you are otherwise dissatisfied with the outcome of your request, you can try to resolve this informally with the person who dealt with your request. If you remain dissatisfied, you may seek an internal review within NHS Improvement of the issue or the decision. A senior member of NHS Improvement's staff, who has not previously been involved with your request, will undertake that review.

If you are dissatisfied with the outcome of any internal review, you may complain to the Information Commissioner for a decision on whether your request for information has been dealt with in accordance with the FOI Act.

A request for an internal review should be submitted in writing to FOI Request Reviews, NHS Improvement, Wellington House, 133-155 Waterloo Road, London SE1 8UG or by email to nhsi.foi@nhs.net.

Publication

Please note that this letter will shortly be published on our website. This is because information disclosed in accordance with the FOI Act is disclosed to the public at large. We will, of course, remove your personal information (e.g. your name and contact details) from the version of the letter published on our website to protect your personal information from general disclosure.

Yours sincerely,

NHS Improvement