

Freedom of Information Act 2000 (FOIA)

Decision notice

Date: 13 May 2024

Public Authority: National Institute for Health and Care Excellence (NICE)

Address: Level 1A City Tower
Manchester
M1 4BT

Decision (including any steps ordered)

1. The complainant has requested the identities of several individuals who corresponded with NICE following circulation of a guideline document to stakeholders prior to publication. NICE considered the information was personal data and therefore exempt under section 40(2) FOIA.
2. The Commissioner's decision is that NICE is entitled to withhold the personal data requested under section 40(2) FOIA.
3. The Commissioner does not require any steps.

Request and response

4. On 11 September 2023, the complainant wrote to NICE and requested information in the following terms:

"I ask that NICE confirm, by reply, the names of all those involved in this behind-the-scenes correspondence: [Misuse of influence – Hole Ousia](#). It is entirely reasonable for the public to expect this information in interests of transparency. Otherwise the public might ask if NICE guidelines give priority to unacknowledged influences."
5. NICE responded on 4 October 2023 refusing to provide the requested information under section 40(2) FOIA. Following an internal review NICE

wrote to the complainant again on 30 October 2023 upholding its position.

Scope of the case

6. The complainant contacted the Commissioner on 4 December 2023 to complain about the way their request for information had been handled.
7. The Commissioner considers that the scope of his investigation is to be to determine if NICE has correctly withheld the requested information under section 40(2) FOIA.

Background

8. The complaint relates the NICE guideline "[Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#)", published by NICE on 29 October 2021.
9. Alongside the published guidance NICE also published information on how NICE guidelines are produced generally and specifically in this case. This includes information on how the process happens, the evidence considered and the stakeholders that contribute to guideline development.
10. The request is concerned with events that took place in the last stages of finalising the guideline that is the subject of this request and the influence/impact of what the complainant describes as "unacknowledged influences".
11. The link provided in the complainant's request leads to a blog which asserts that an embargoed copy of the NICE guidelines was sent to registered stakeholders in August 2021 for a final check. Following this, just prior to the original scheduled publication date, the publication was paused with NICE issuing a statement stating the recommendations needed to be supported by professionals and the NHS and a roundtable would be held to understand any issues raised.
12. The blog also includes copies of correspondence obtained under a different FOIA request which show exchanges between individuals and NICE on this matter (in a letter and text messages) with personal data redacted. It is the identities of the individuals in this, as the complainant describes it, "behind-the-scenes correspondence" that they are looking to obtain to ensure there is not undue influence being exerted by

individuals on behalf of stakeholders, potentially without the knowledge of the stakeholders they are engaging on behalf of.

Reasons for decision

13. Section 40(2) of FOIA provides that information is exempt from disclosure if it is the personal data of an individual other than the requester and where one of the conditions listed in section 40(3A)(3B) or 40(4A) is satisfied.
14. In this case the relevant condition is contained in section 40(3A)(a). This applies where the disclosure of the information to any member of the public would contravene any of the principles relating to the processing of personal data ('the D principles'), as set out in Article 5 of the UK General Data Protection Regulation ('UK GDPR').
15. The first step for the Commissioner is to determine whether the withheld information constitutes personal data as defined by the Data Protection Act 2018 ('DPA'). If it is not personal data, then section 40 of FOIA cannot apply.
16. Secondly, and only if the Commissioner is satisfied that the requested information is personal data, he must establish whether disclosure of that data would breach any of the DP principles.

Is the information personal data?

17. Section 3(2) of the DPA defines personal data as:

"any information relating to an identified or identifiable living individual".

18. The two main elements of personal data are that the information must relate to a living individual and that the person must be identifiable.
19. An identifiable living individual is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of the individual.
20. Information will relate to a person if it is about them, linked to them, has biographical significance for them, is used to inform decisions affecting them or has them as its main focus.
21. In the circumstances of this case, the withheld information is names of individuals. Clearly this is identifiable information.

22. The fact that information constitutes the personal data of an identifiable living individual does not automatically exclude it from disclosure under FOIA. The second element of the test is to determine whether disclosure would contravene any of the DP principles.
23. The most relevant DP principle in this case is principle (a).

Would disclosure contravene principle (a)?

24. Article 5(1)(a) of the UK GDPR states that:

“Personal data shall be processed lawfully, fairly and in a transparent manner in relation to the data subject”.

25. In the case of a FOIA request, the personal data is processed when it is disclosed in response to the request. This means that the information can only be disclosed if to do so would be lawful, fair and transparent.
26. In order to be lawful, one of the lawful bases listed in Article 6(1) of the UK GDPR must apply to the processing. It must also be generally lawful.

Lawful processing: Article 6(1)(f) of the UK GDPR

27. The Commissioner considers that the lawful basis most applicable is basis 6(1)(f) which states:

“processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child¹”.

28. In considering the application of Article 6(1)(f) of the UK GDPR in the context of a request for information under FOIA, it is necessary to consider the following three-part test:-

- i) **Legitimate interest test:** Whether a legitimate interest is being pursued in the request for information;

¹ Article 6(1) goes on to state that:- “Point (f) of the first subparagraph shall not apply to processing carried out by public authorities in the performance of their tasks”. However, section 40(8) FOIA (as amended by Schedule 19 Paragraph 58(8) DPA) provides that:- “In determining for the purposes of this section whether the lawfulness principle in Article 5(1)(a) of the UK GDPR would be contravened by the disclosure of information, Article 6(1) of the UK GDPR (lawfulness) is to be read as if the second sub-paragraph (dis-applying the legitimate interests gateway in relation to public authorities) were omitted”

- ii) **Necessity test:** Whether disclosure of the information is necessary to meet the legitimate interest in question;
- iii) **Balancing test:** Whether the above interests override the legitimate interest(s) or fundamental rights and freedoms of the data subject.

29. The Commissioner considers that the test of 'necessity' under stage (ii) must be met before the balancing test under stage (iii) is applied.

Legitimate interests

- 30. In considering any legitimate interest(s) in the disclosure of the requested information under FOIA, the Commissioner recognises that such interest(s) can include broad general principles of accountability and transparency for their own sakes, as well as case specific interests.
- 31. Further, a wide range of interests may be legitimate interests. They can be the requester's own interests or the interests of third parties, and commercial interests as well as wider societal benefits. They may be compelling or trivial, but trivial interests may be more easily overridden in the balancing test.
- 32. NICE acknowledges there is a public interest in ensuring transparency about the individuals and stakeholders involved in developing and influencing NICE's guidelines.

Is disclosure necessary?

- 33. 'Necessary' means more than desirable but less than indispensable or absolute necessity. Accordingly, the test is one of reasonable necessity and involves consideration of alternative measures which may make disclosure of the requested information unnecessary. Disclosure under FOIA must therefore be the least intrusive means of achieving the legitimate aim in question.
- 34. NICE argues there is already information in the public domain that details the process of developing guidelines and disclosing individual names would not add to this. It stated the communications referred to in the blog were not formal stakeholder submissions but that NICE's standard position is to release the identity of organisations responding to formal consultations but not the individuals submitting the comments on behalf of the stakeholders. It considers the same approach applies here even though these were not formal submissions.
- 35. NICE has also pointed out the blog already confirms the organisation the individual worked for and one of the other named individuals was corresponding a private capacity.

36. The Commissioner notes the amount of information published by NICE regarding the stakeholder challenges to the guideline before it was published, including the minutes from the roundtable organised to discuss key issues².
37. The complainant argues there is a need to know who is exerting influence on NICE and to understand if they are doing this with the knowledge of the stakeholder they represent.
38. The Commissioner does not consider that releasing the identities of the individuals who were involved in the correspondence with NICE as highlighted in the blog would be necessary to fulfil the legitimate interest in understanding how the guideline was developed and finalised.
39. There is a significant volume of information already in the public domain and NICE has a clear position on disclosing stakeholder organisations identities but not the identities of individuals corresponding on their behalf or private individuals. Disclosing names would not show that those individuals were acting on their own accord (and in one case it is already accepted they were acting in a personal capacity) or that their views exerted an undue influence on the final guidelines that were published. Any view can be expressed by any channel but it would be impossible to say how much, if any influence this had on the final outcome.
40. As the test of necessity has not been met, the Commissioner does not need to go on to consider the balance between the legitimate interests and the interests or fundamental rights and freedoms of the data subject.
41. As disclosure is not necessary, there is no lawful basis for the disclosure of the requested information. Disclosure would be unlawful and would therefore breach the first DP principle. The Commissioner finds that NICE was entitled to rely on section 40(2) of FOIA for the information it has withheld.

² [NICE pauses publication of updated guideline on diagnosis and management of ME/CFS | News | News | NICE](#)
[History | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)
[NICE announces next steps for publication of its guideline on ME/CFS | News | News | NICE](#)

Right of appeal

42. Either party has the right to appeal against this decision notice to the First-tier Tribunal (Information Rights). Information about the appeals process may be obtained from:

First-tier Tribunal (Information Rights)
GRC & GRP Tribunals,
PO Box 9300,
LEICESTER,
LE1 8DJ

Tel: 0203 936 8963

Fax: 0870 739 5836

Email: grc@justice.gov.uk

Website: www.justice.gov.uk/tribunals/general-regulatory-chamber

43. If you wish to appeal against a decision notice, you can obtain information on how to appeal along with the relevant forms from the Information Tribunal website.
44. Any Notice of Appeal should be served on the Tribunal within 28 (calendar) days of the date on which this decision notice is sent.

Jill Hulley
Senior Case Officer
Information Commissioner's Office
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