

## **Freedom of Information Act 2000 (FOIA)**

### **Decision notice**

**Date:** 5 January 2022

**Public Authority:** National Institute for Health and Care Excellence

**Address:** Level 1A City Tower  
Manchester  
M1 4BT

#### **Decision (including any steps ordered)**

---

1. The complainant has requested the evidence that was used to inform the latest National Institute for Health and Care Excellence (NICE) guidelines for chronic pain (NG193) that were published on 7 April 2021.
2. NICE withheld the requested information in accordance with section 21 (information accessible to applicant by other means).
3. The Commissioner is satisfied that the requested information is reasonably accessible to the complainant by other means and therefore the exemption is engaged.
4. Furthermore, on the balance of probabilities, the Commissioner is satisfied that NICE holds no further information within the scope of the request.
5. The Commissioner does not require any steps to be taken.

#### **Request and response**

---

6. On 29 April 2021, the complainant wrote to NICE and requested information in the following terms:

*"Please May I request the evidence that was used for the Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain - NICE guideline [NG193] that was published on the 07 April 2021.*

*I would like the references to the research studies, literature reviews, randomised control trials and similar please."*

7. NICE responded on 17 May 2021. It stated that the requested information was exempt from disclosure under section 21.
8. The complainant requested an internal review on the same day, stating:  
*"Surely as a government/public funded services, the public have a right to know what evidence was used to make these decisions. Please provide detailed evidence of how NICE came to these decisions in the discussed guidelines including all references (Literature reviews, Randomised control trials and similar). What is available to the public is not sufficient and does not enable anyone to look at the studies for themselves."*
9. Following an internal review NICE wrote to the complainant on 18 May 2021. It upheld its original position.

## **Scope of the case**

---

10. The complainant contacted the Commissioner on 18 May 2021 to complain about the way that their request for information had been handled.
11. Specifically, the complainant was concerned that, in order to access the withheld information, *'the public would have to pay for all the subscriptions and or individual journal costs which would go in to thousands of pounds.'*
12. The complainant was also concerned that *'In addition NICE have used unpublished data in their decision making and we are unable to access them at all.'*
13. The Commissioner therefore considers the scope of his investigation to be to determine whether NICE has appropriately withheld the requested information in accordance with section 21. The Commissioner will also consider if NICE holds any further information that would fall within the scope of the request.

## Reasons for decision

---

### Section 21 – Information reasonably accessible to the applicant by other means

14. Section 21 of the FOIA states that:

*"(1) Information which is reasonably accessible to the applicant otherwise than under section 1 is exempt information."*

15. The purpose of section 21 is to protect the resources of public authorities. Public authorities do not have to respond to requests for information where the requestor could have found the requested information elsewhere. Section 21 also acts as an incentive for public authorities to be proactive in publishing information as part of their publication schemes.

16. It is reasonable for a public authority to assume that information is reasonably accessible to the applicant as a member of the general public until it becomes aware of any particular circumstances or evidence to the contrary.

### The complainant's position

17. To reiterate, the complainant is concerned that in order to access the withheld information, *'the public would have to pay for all the subscriptions and or individual journal costs which would go in to thousands of pounds.'*

18. It is clear to the Commissioner that this complaint stems from a misunderstanding between NICE and the complainant regarding the information to which section 21 is being applied.

### NICE's position

19. NICE has explained *'We interpreted the complainant's request for "the evidence that was used for" NICE guideline as a request for the information that was actually used, that is, considered by the guideline development committee (the "committee") when developing the guideline.'*

20. NICE explained that *'To assist the requester we provided a link to the evidence that was considered by the committee in reaching its recommendations<sup>1</sup>.*'
21. NICE has gone onto provide the Commissioner with information about its methods for developing guidelines, including NG193<sup>2</sup>. The Commissioner notes that NICE also provided this information to the complainant on 17 May 2021 as part of its refusal notice.
22. The Commissioner understands that in order to develop NG193, NICE commissioned the National Guideline Centre<sup>3</sup> (NGC) to review any potentially relevant studies, papers, articles and information.
23. NICE has explained that *'In this case, after potentially relevant studies had been identified, the NGC obtained the full papers via open access (freely available online) and via the Royal College of Physicians (RCP) library and they were evaluated by the NGC against pre-specified inclusion and exclusion criteria.'*
24. The NGC reviewed all of the evidence and then produced summaries of that evidence. These summaries were then provided to NICE's guidelines development committee and used to formulate and inform NG193.
25. For clarity, NICE has confirmed to the Commissioner that *'The NICE committee was not presented with the individual papers (which may, or may not, need a subscription for access) but instead considered these evidence summaries.'* This process is outlined in more detail in pages 34-36 of the methods for NG193<sup>4</sup>.
26. The evidence summaries that the committee considered in order to develop NG193 can be found on NICE's website.<sup>5</sup> This is the information that NICE directed the complainant to in response to their request.
27. NICE has explained that *'Given that the complainant contacted NICE by email using the website 'Whatdotheyknow.com' we considered that links*

---

<sup>1</sup> <https://www.nice.org.uk/guidance/ng193/evidence>

<sup>2</sup> [NG193 Methods \(nice.org.uk\)](https://www.nice.org.uk/guidance/ng193/evidence)

<sup>3</sup> [National Guideline Centre \(NGC\) | RCP London](https://www.nice.org.uk/guidance/ng193/evidence)

<sup>4</sup> [NG193 Methods \(nice.org.uk\)](https://www.nice.org.uk/guidance/ng193/evidence)

<sup>5</sup> [Evidence | Chronic pain \(primary and secondary\) in over 16s: assessment of all chronic pain and management of chronic primary pain | Guidance | NICE](https://www.nice.org.uk/guidance/ng193/evidence)

*to publicly available documentation on the NICE website would be accessible.'*

### **The Commissioner's view**

28. NICE has explained to the Commissioner how it came to identify the information that would fall within the scope of the request. NICE states *'The original request was unambiguous in seeking the information in fact used by the committee, rather than the underlying studies...The requester has access to the same information that was used by the committee that developed the guideline, as requested.'*
29. The Commissioner acknowledges that NICE, its refusal notice of 17 May 2021, directed the complainant to its website which discusses how NICE guidelines are developed,<sup>6</sup> including the use of evidence summaries which are provided to the committee by the NCG, known as 'evidence reviews'.<sup>7</sup>
30. The Commissioner agrees with NICE's interpretation of the request. He also agrees that the information that falls within the scope of the request is reasonably accessible to the complainant. The Commissioner concurs with NICE that all of the information the committee has considered, in order to develop NG193, is reasonably accessible to the complainant. Since section 21 is an absolute exemption, the Commissioner does not need to consider any public interest in disclosure and is satisfied that NICE can rely upon section 21 to withhold the requested information.
31. The Commissioner notes the complainant's internal review request which states, *'Surely as a government/public funded services, the public have a right to know what evidence was used to make these decisions. Please provide detailed evidence of how NICE came to these decisions in the discussed guidelines including all references (Literature reviews, Randomised control trials and similar).'*
32. NICE has confirmed to the Commissioner that *'we understood the above as reiterating that the complainant sought the information actually considered by the committee in coming to its decisions.'*

---

<sup>6</sup> [How we develop NICE guidelines | NICE guidelines | NICE guidance | Our programmes | What we do | About | NICE](#)

<sup>7</sup> [6 Reviewing research evidence | Developing NICE guidelines: the manual | Guidance | NICE](#)

33. However, the Commissioner disagrees that the request is unambiguous and is mindful that the complainant also wrote '*...What is available to the public is not sufficient and does not enable anyone to look at the studies for themselves.*'
34. The complainant appears to be requesting access to all underlying studies in relation to NG193 so they can be independently scrutinised, not just the evidence reviews considered by the committee. It is worth noting at this stage that, according to the Commissioner's guidance '*Information reasonably accessible to applicant by other means*<sup>8</sup>' information may be regarded as reasonably accessible to the applicant even though it is accessible only on payment. This means that, even if the underlying studies fell within the scope of this request, it is likely that NICE would be able to withhold this information under section 21.
35. The Commissioner appreciates that NICE has signposted the complainant to its processes for creating new guidelines, including what information is and is not considered by the committee. However, the Commissioner also considers that NICE could have been clearer to the complainant about what information it was withholding under section 21 in this instance.
36. NICE has explained to the Commissioner '*We regret that our responses to the request and internal review do not appear to have clarified the position sufficiently for the requester...if the complainant now wishes to see copies of the underlying individual studies (rather than the actual information considered and used by the committee who developed the guidelines), she may wish to make a new FOIA request for those paper and we would of course consider what information could be provided in response to such a request.*'

## **Section 1 – general right of access to information held by public authorities**

37. Section 1(1) of the FOIA states that:

*"Any person making a request for information to a public authority is entitled –*

*(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and*

---

<sup>8</sup> [Information reasonably accessible to the applicant by other means \(section 21\) \(ico.org.uk\)](https://ico.org.uk)

*(b) if that is the case, to have that information communicated to him.”*

38. In this case, the complainant disputes NICE's position that it did not review, and does not hold, any unpublished data in relation to the development of NG193.
39. In cases where a dispute arises over the recorded information held by a public authority at the time of a request, the Commissioner, following the outcome of a number of First-tier Tribunal decisions, applies the civil standard of the balance of probabilities. This means that the Commissioner will determine whether it is likely, or unlikely, that the public authority held information relevant to the complainant's request at the time that the request was received.
40. In order to reach his determination, the Commissioner asked NICE to provide detailed explanations as to why all of the information that would fall within the scope of the request has been identified. The Commissioner also asked NICE to explain the searches it had undertaken to locate any information that would fall within the scope of the request and to explain why these searches would have been likely to locate all of the information in scope.

### **The complainant's position**

41. The complainant is concerned that NG193 includes references to Cochrane reviews. *Cochrane is 'a collection of databases that contain different types of high-quality, independent evidence to inform healthcare decision-making.*<sup>9</sup>The complainant is concerned that Cochrane studies are often based on unpublished data.
42. The complainant has also identified the following studies, Fontaine (2007) and Mannerkopi (2010), referenced in NG193's evidence reviews that have both been conducted using published and unpublished data.
43. Furthermore, the complainant notes that NICE itself states that unpublished reports will be considered as part of a call for evidence that may occur during the revising, or writing, of NICE guidelines.
44. The complainant believes that the above proves that the NG193 guidelines have been developed using unpublished data.

---

<sup>9</sup> [About the Cochrane Library | Cochrane Library](#)

## **NICE's position**

45. NICE has explained to the Commissioner that *'As stated in the searching for evidence section of the methods document<sup>10</sup> (page 16, section 2.2.1), 'searching for unpublished literature was not undertaken' for this guideline.'*
46. NICE has also explained that *'Additionally, the sections on inclusion and exclusion criteria (page 17, section 2.3.1 and page 31, section 2.4.1.1) state that 'Literature reviews, posters, letters, editorials, comment articles, unpublished studies and studies not in published in English language were excluded.'*
47. The Commissioner notes that once information relevant to this review was identified it had to meet the inclusion criteria for it to be considered by the committee. Information could be excluded for a variety of reasons, for example, if it was an unpublished study or the definition of 'chronic pain' used within that study differed from that used by NICE.
48. At this point, it is worth clarifying that NG193 is one document. However, there are approximately ten evidence reviews (A-J) that accompany it. Each evidence review discusses how evidence was considered, for the purposes of NG193, in relation to different aspects of chronic pain.
49. Page 7 of *'Evidence review for psychological therapy for chronic primary pain (F)<sup>11</sup>* discusses the clinical evidence that was included, and excluded, from the reviewal process. It states *'Nine potentially relevant Cochrane reviews were identified and assessed for eligibility, but none were included.'*
50. Furthermore, each evidence review includes a list of excluded studies and the Commissioner notes that further Cochrane reviews and both Fontaine (2007) and Mannerkopi (2010) are included within these exclusion lists.
51. Furthermore, NICE have confirmed that *'In accordance with our published methods and processes, unpublished data may be considered as part of a call for evidence. However, I can confirm that no call for evidence was undertaken during development of this guideline.'*

---

<sup>10</sup> [NG193 Methods \(nice.org.uk\)](https://www.nice.org.uk/guidance/NG193/methods)

<sup>11</sup> [NG193 Evidence review F \(nice.org.uk\)](https://www.nice.org.uk/guidance/NG193/evidence-review-f)



52. NICE has confirmed to the Commissioner that it does not hold, and has not held in the past, or destroyed, *'the kind of information that the complainant is referring to (that is, unpublished evidence used in the development of guideline NG193). Given that this is the case, NICE has not undertaken any searches for unpublished information in response to this request.'*

### **The Commissioner's view**

53. The Commissioner is satisfied that no call for evidence was conducted during the development of NG193 and unpublished studies were not used in the development of NG193. Whilst there are multiple references to unpublished studies contained within the evidence reviews, this is only to confirm their exclusion from the study.
54. Returning to paragraphs 22 and 23, the NGC obtains full papers of relevant studies with a view to evaluating them against the inclusion and exclusion criteria. Since unpublished studies would automatically be excluded in accordance with the aforementioned criteria, it would not have been provided to the committee for it to consider in its development of NG193.
55. The Commissioner therefore considers it reasonable that NICE has not conducted any searches for any unpublished data used in the development of NG193. Such searches would be fruitless.
56. Again, the Commissioner considers that more clarity from NICE regarding the NGC, evidence reviews, its guidelines development committee and the overall process for developing NICE guidelines, could have avoided this complaint being brought to the Commissioner.

### **Other matters**

---

57. The Commissioner acknowledges that NICE's processes are complex. He is also mindful that this complaint has stemmed from differing interpretations of what the request is asking for. The Commissioner considers that NICE's interpretation of the request is a reasonable one and he notes that NICE explained its position to the complainant on more than one occasion.
58. However, NICE may find it useful to consult the Commissioner's guidance *'Interpreting and clarifying requests'*<sup>12</sup> which states *'The*
- 

<sup>12</sup> [interpreting-and-clarifying-a-request-foia-eir-guidance.pdf \(ico.org.uk\)](https://ico.org.uk/interpreting-and-clarifying-a-request-foia-eir-guidance.pdf)

*authority must answer a request based on what the requester has actually asked for, and not on what it thinks they would like, should have asked for or would be of most use to them.'* If there is any doubt as to what information is being requested, a public authority should clarify this with the requestor.

59. The Commissioner would bring the complainant's attention to paragraph 36 of this notice. The Commissioner would urge the complainant to use the contextual information within this decision to inform any future request they may wish to make.

## **Right of appeal**

60. 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](mailto:grc@justice.gov.uk)

Website: [www.justice.gov.uk/tribunals/general-regulatory-chamber](http://www.justice.gov.uk/tribunals/general-regulatory-chamber)

61. 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.

62. Any Notice of Appeal should be served on the Tribunal within 28 (calendar) days of the date on which this decision notice is sent.

## **Signed**

**Alice Gradwell**  
**Senior Case Officer**  
**Information Commissioner's Office**  
**Wycliffe House**  
**Water Lane**  
**Wilmslow**  
**Cheshire**  
**SK9 5AF**