

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

### **Decision notice**

**Date:** 24 May 2022

**Public Authority:** The NHS Commissioning Board (NHS England)

**Address:** Quarry House  
Quarry Hill  
Leeds  
LS2 7UE

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

---

1. The complainant requested information about the members of the NHS England SMA Clinical Panel and eligibility criteria for administration programmes related to the medication Risdiplam. By the date of this notice, NHS England had not issued a substantive response to this request.
2. The Commissioner's decision is that NHS England has breached section 10(1) of FOIA in that it failed to provide a valid response to the request within the statutory time frame of 20 working days.
3. The Commissioner requires NHS England to take the following step to ensure compliance with the legislation.
  - NHS England must provide a substantive response to the request in accordance with its obligations under FOIA.
4. NHS England must take this step within 35 calendar days of the date of this decision notice. Failure to comply may result in the Commissioner making written certification of this fact to the High Court pursuant to section 54 of FOIA and may be dealt with as a contempt of court.

## Request and response

---

5. On 23 February 2022, the complainant wrote to NHS England and requested information in the following terms:

"I would like to request the following information under the FOI Act:

1. Identities of the members of the NHS England SMA Clinical Panel. The general information about the panel composition is available at <https://smauk.org.uk/england-sma-clinical-panel> However, there is no information publicly available regarding the names of the members. If there has been any changes in the composition of the panel since 1st January 2020, that'd also be useful information. Ideally, this information should be published somewhere.

2. What has been discussed about the eligibility for the Risdiplam managed access agreement between NICE, NHS England SMA Clinical Panel members and other interested parties (SMA patients and families, patient organisations, clinicians across NHS England) from 1st November 2021 till date, with regards to patients who previously had treatment with onasemnogene abeparvovec. Most of these discussions are likely to exist in emails, or transcripts of telephone conversations.

3. What was discussed about eligibility for the Risdiplam EAMS programme and the compassionate use programme among the NHS England SMA Clinical Panel members, and the other interested parties (SMA patients and families, patient organisations, clinicians across NHS England) between 1st January 2020 and 31st March 2021."

6. To date, a substantive response has not been issued.

## Scope of the case

---

6. The complainant contacted the Commissioner on 16 April 2022 to complain about NHS England's failure to respond to their request.
7. The Commissioner has considered whether NHS England has complied with its obligations in relation to the time for compliance at section 10(1) of FOIA.

## Reasons for decision

---

8. Section 1(1) of 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

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

9. Section 10(1) of FOIA states that a public authority must respond to a request promptly and “not later than the twentieth working day following the date of receipt”.

10. On 29 April 2022 the Commissioner wrote to NHS England, reminding it of its responsibilities and asking it to provide a substantive response to the complainant’s request within 10 working days.

11. Despite this intervention NHS England has failed to respond to the complainant.

12. From the evidence provided to the Commissioner in this case, it is clear that NHS England did not deal with the request for information in accordance with FOIA. The Commissioner finds that NHS England has breached section 10(1) by failing to respond to the request within 20 working days and it is now required to respond to the request in accordance with FOIA.

## Right of appeal

---

13. 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)

14. 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.
15. 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 .....**

**Michael Lea**  
**Team Manager**  
**Information Commissioner's Office**  
**Wycliffe House**  
**Water Lane**  
**Wilmslow**  
**Cheshire**  
**SK9 5AF**