First-tier Tribunal
(General Regulatory Chamber)
Information Rights

Appeal Reference: EA/2019/0285P

Determined, by consent, on written evidence and submissions
Considered on the papers on 15 January 2021.

Before
Judge Stephen Cragg Q.C.

Tribunal Members
Mr Andrew Whetnall
and
Mr Dan Palmer-Dunk

Between

Collette Lloyd

Appellant

And

The Information Commissioner

Respondent

DECISION AND REASONS

DECISION

1. The appeal is dismissed.

MODE OF HEARING

2. The parties and the Tribunal agreed that this matter was suitable for determination on the papers in accordance with rule 32 Chamber's Procedure Rules.

3. The Tribunal considered an agreed open bundle of evidence comprising pages 1 to 76 and a closed bundle.

INTRODUCTION

4. On 12 February 2019 the Appellant requested information relating to numbers of Down syndrome births from the Airedale NHS Foundation Trust (the Trust). The Trust refused to provide the requested information citing the exemption under section 40(2) FOIA (third party personal data) as its basis for doing so. The request read as follows: -

> 'Please could you tell me the total number of live births, the number of prenatal diagnoses of Down Syndrome and the number of live births with Down syndrome in your Trust in the past 8 years? If you collect data in financial years please fill in table A, if you collect data in calendar years please fill in table B [from 2010-2017].'

5. On 28 February 2019 the Trust disclosed information about the total number of live births per year in the Trust but stated that the actual numbers of live

births with Down syndrome was under five per year and again cited the exemption under section 40(2) FOIA as preventing the disclosure of further information.

6. On 17 April 2019 the Trust provided the outcome of an internal review. It upheld the decision to refuse the suppressed numbers citing section 40(2) FOIA.

7. The Appellant contacted the Commissioner on 18 April 2019 to complain about the way the request for information had been handled.

8. During the investigation the Trust disclosed the data for the years 2011 and 2013 to the Appellant as the values were zero in those years. The Trust also offered to provide the total number of live births with Down syndrome over the whole of the remaining years: 'this would provide the requester with a more accurate figure'.

THE STATUTORY FRAMEWORK

9. Section 40 (2) FOIA reads as follows: -

> (2) Any information to which a request for information relates is also exempt information if—
> (a) it constitutes personal data which does not fall within subsection (1) (personal information of the applicant], and
> (b) the first, second or third condition below is satisfied.

10. Section 3(2) of the DPA 2018 defines personal data as '"any information relating to an identified or identifiable living individual".

11. The relevant condition (as referred to in s40(2)(b) FOIA) in this case is found in s40(3A) (a): -

(3A) The first condition is that the disclosure of the information to a member of the public otherwise than under this Act—

(a) would contravene any of the data protection principles.

12. Under s40(7) FOIA the relevant data protection principles in this case are to be found, first, in Article 5(1) of the GDPR. Materially, Article 5(1)(a) reads: -

> Personal data shall be:
> (a) processed lawfully, fairly and in a transparent manner in relation to the data subject ('lawfulness, fairness and transparency').

13. Further, by Article 6(1) GDPR: -

> Processing shall be lawful only if and to the extent that at least one of the following applies:
>
> (a) the data subject has given consent to the processing of his or her personal data for one or more specific purposes;
>
> …
>
> (f) 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…

14. Lastly, information relating to special category data is given special status in the GDPR. Article 9 of the GDPR defines 'special category' as being personal data which reveals racial, political, religious or philosophical beliefs, or trade union membership, and the genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.

15. There are only very strict exceptions which would allow disclosure of special category information, as set out in Article 9(2). The only two that could apply in this case are that the data subject has given explicit consent to the processing

of those personal data for one or more specified purposes, or that processing relates to personal data which are manifestly made public by the data subject.

THE DECISION NOTICE

16. The Commissioner recorded the reasoning put forward by the Trust for not disclosing more information in a decision notice dated 15 July 2019 as follows: -

> 21. The Trust stated that it is a small Trust in a rural area and the number of relevant patients is very small. … 'We believe that the relevant patient(s) themselves, or their family, friends, colleagues or neighbours, may be able to identify an individual to whom our figures refer if we were to disclose them as requested. This information is personal and neither the child nor the mother would have any expectation that information about their pregnancy, or outcome, could be published or examined in public in the future.'
>
> 22. The Trust explained that the nature of the syndrome to which this data refers comprises specific physical characteristics. 'We also consider that some types of data are more attractive to a motivated intruder than others – and more consequential for individuals. We believe this is the case in relation to this data which may leave an individual if identified subject to distress plus given the relatively short passage of time from the year 2010 to date, the subjects would still be young children…'

17. The Commissioner considered this reasoning and concluded as follows in relation to whether the information held was personal information: -

> 23. The Commissioner notes that these numbers relate to a number of identifiers - location, medical health, year of birth/age and physical characteristics of the individual(s). She accepts that the withheld data may link with other information or knowledge, such as information from the educational sector, media or social media, to make identification of the data subjects possible. Given the age of the children, it is likely that the families still live in the same area.

> 24. She is satisfied that this information both relates to and identifies the children. This information therefore falls within the definition of 'personal data' in section 3(2) of the DPA.

18. The fact that information constitutes the personal data of an identifiable living individual does not automatically exclude it from disclosure under FOIA.

19. Applying the framework above the Commissioner then considered the second element of the test to determine whether disclosure would contravene any of the data protection principles. Having considered the question: - 'would disclosure contravene principle (a)?', the Commissioner concluded that: -

> 28…. the information can only be disclosed if to do so would be lawful (i.e. it would meet one of the bases of lawful processing listed in Article 6(1) GDPR as well as being generally lawful), be fair, and be transparent.

20. In relation to whether the information was 'special category data' the Commissioner noted and decided that: -

> 32. Having considered the wording of the request, and viewed the withheld information, the Commissioner finds that the requested information does include special category data. She has reached this conclusion on the basis that the data relates to a lifelong health condition and a specific genetic profile of the data subjects.
>
> 33. Special category data is particularly sensitive and therefore warrants special protection. As stated above, it can only be processed, which includes disclosure in response to an information request, if one of the stringent conditions of Article 9 can be met.
>
> 34. The Commissioner considers that the only conditions that could be relevant to a disclosure under FOIA are conditions (a) (consent from the data subject) or (e) (data made manifestly public by the data subject) in Article 9.
>
> 35. The Trust has stated that the data subjects are children under 9 years and has not sought consent from them. 'The Trust does not believe it is appropriate to seek consent from the parents or guardians of the children to whom this data relates. We believe it may be distressing for them to

discover that their families are the subject of a Freedom of Information request and that there may be a risk of identification of the children by persons unknown.'

36. The Commissioner has seen no evidence or indication that the individuals concerned have specifically consented to this data being disclosed to the world in response to the FOI request or that they have deliberately made this data public.

37. As none of the conditions required for processing special category data are satisfied there is no legal basis for its disclosure. Processing this special category data would therefore breach principle (a) and so this information is exempt under section 40(2) of FOIA.

21. For completeness, the Commissioner moved on to consider whether there were any legitimate interest(s) in the disclosure of the requested personal information. The Commissioner recognised that such interest(s) can include broad general principles of accountability and transparency for their own sakes, as well as case-specific interests: -

45. In the circumstances of this case the Commissioner understands that the complainant is interested in actual numbers of live births with Down syndrome per year per Trust.

46. The Commissioner is inclined to accept that the complainant has a legitimate interest in making this request and has gone on to consider whether disclosure is necessary in order to meet the legitimate interest.

22. The Commissioner considered whether disclosure was necessary to meet the legitimate interests: -

50. The Trust also informed the Commissioner that the legitimate interest could be met elsewhere:

 The National Down Syndrome Cytogenetic Register (NDSCR) for England and Wales has already disclosed some of the requested information with a view to satisfying the public interest in its annual reports e.g. the NDSCR anonymous data reports include Down's syndrome diagnosed since January 1989 until 2013 in England and Wales. NCARDRS congenital anomaly statistics

provides annual data from 2014 onwards. We understand data collection in newly established regions started from 1 April 2017 and national coverage of congenital anomaly reporting including Down syndrome will be possible from 2019.

51. The Commissioner fully accepts that the Trust has considered at length what information it can lawfully provide to the complainant. She considers that further disclosure in the detail requested is not necessary to meet the complainant's legitimate interest in this case and could be intrusive to the data subjects.

52. As the Commissioner has decided in this case that disclosure is not necessary to meet the legitimate interest in disclosure, she has not gone on to conduct the balancing test. As disclosure is not necessary, there is no lawful basis for this processing and it is unlawful. It therefore does not meet the requirements of principle (a).

THE APPEAL AND RESPONSE

23. The Appellant's appeal is dated 14 August 2019. In her Response, the Commissioner has summarised the appeal grounds, and the Appellant has agreed that the summary reflects the points made in the appeal notice. The summary reads as follows: -

(a) 'The **Personal Data Ground'**: The Appellant appears to dispute the Commissioner's finding on the facts that the data sought was "personal data".

(b) 'The **Special Category Ground**': The Appellant contends, in respect of paragraph 31 of the decision notice that 'the physical characteristics of the natural person/child in this case are the identifier and that disclosing how many children with that genetic make-up were born at a particular location in a particular year, adds nothing to their identification'. As understood, the Appellant does not dispute the finding that the data sought was special category data.

(c) '**The Necessity Ground'**: The Appellant disputes the Commissioner's findings at paragraphs 49 and 50 of the decision notice.

(i) As to paragraph 49, she asserts that " ... people with Down syndrome can be subject to prejudice and bullying, however, this would be due to the physical characteristics, not because they are one of 4 born in that year or even that they were the only one born in that year. I would strongly suspect, due to early intervention, Facebook and support groups that the parents are already very aware of other children around the same age as their own who happen to have Down syndrome. Further, it is notoriously difficult to work out what age a child with Down syndrome is, due to them often looking significantly younger than they are, and sometimes, not always, being placed out of year in an educational placement."

(ii) As to paragraph 50, the Appellant disputes that NDSCR, which is published by region (not by hospital trust) meets her legitimate interest. The Appellant asserts: "... it is important (a) to gain correct baseline data for national evaluation, and in the case of trusts that are already offering NIPT, this data may be skewed and (b) to anticipate the effects on live birth rates of this national roll-out."

24. We also note that the Appellant offered to provide an undertaking not to publish the data.

25. It appears that the Appellant has a number of similar appeal cases pending against other health care bodies raising similar issues (although we have not seen any of the papers in those cases). Case Management Directions were made in this case on 29 October 2019 (amended on 1 November 2019), in which the parties were informed that this case (EA/2019/0285) will be considered as a lead case for the purposes of rule 18 (the cases give rise to common or related issues of fact or law), behind which EA/2019/0307, EA/2019/0308, EA/2019/0309, EA/2019/0310, and EA/2019/0311 are stayed.

26. The Commissioner's Response to the appeal can be summarised as follows: -

(a) In relation to the Personal Data Ground the Commissioner notes the case law which confirms that that whether something is personal data is to be judged on the basis as to whether someone such as a 'determined intruder'

or an 'investigative journalist' would be able to identify a person from the information disclosed and submitted that the Commissioner had taken the right approach in the decision notice. The Commissioner noted that the Appellant herself recognises that her information request could lead to the direct identification of the specific individuals about whom the data refers when her Grounds of Appeal state: 'The information I would be given would, at the most, allow me to meet someone with a child with Down syndrome, and be able to say (after verbally asking where they were born and in what year) that they were the only, or one of two, three or four babies that were born with Down syndrome at that hospital trust in that year'.

(b) In relation to the Special Category Ground the Commissioner says that if the Appellant is disputing that the data sought was special category data, then that is mistaken and that the Commissioner was correct to find that 'the data relates to a lifelong health condition and a specific genetic profile of the data subjects' , such as to constitute special category data under Article 9 GDPR, and that there are no exceptions in Article 9(2) GDPR applied on the facts.

(c) In relation to the Necessity Ground the Commissioner argues that the Appellant has said contradictory things in her appeal grounds. On the one hand she says she needs the information to calculate national trends over time, but on the other hand she has commented that the data might be of limited value because of the mobility of families with a Down syndrome child, or because of late Down syndrome diagnosis in some cases after a child has left hospital. The Commissioner submits that the decision notice was correct to find that disclosure was not necessary for calculating national trends, and that the Appellant has not explained why data in the form of 'less than five' is not sufficient in any event.

(d) In relation to the undertaking given by the Appellant the Commissioner says that if the data were provided it would be susceptible to further dissemination and being placed in the public domain and that the Appellant's proposed undertaking would not provide protection of the special category data in issue in those circumstances.

27. The Appellant has responded to these points: -

(a) She disputes the likelihood that a 'motivated intruder' would be able to identify a person from the information if disclosed. She states that if a child had stayed in the area: -

> …."a motivated intruder" would have far easier means of finding the person, including joining online support groups or arriving at one of the many events put on by local Down syndrome support groups. Having the birth data, would not change the likelihood of being able to find that person.
>
> Knowing the size of the group that a child belongs to therefore, does not constitute personal data, and could not be used for the purposes suggested in law.

(b) The Appellant says that she does dispute that the information is special category data, and that what she is asking for is the size of the group. Therefore, that is not special category data, as it does not refer to the disability.

(c) In relation to 'necessity', the Appellant says that knowing the actual numbers is important for future service planning such as the national evaluative roll out for non-invasive pregnancy testing (NIPT): -

> Knowing the "likely" size of the group would help with planning - although it would, admittedly, only be loose planning, but seeing whether the size of the group is increasing or decreasing in a particular area is important. As we are dealing with such small numbers, knowing that the group is 4 strong, as opposed to 1

> strong, or previously was 4 strong and now is consistently (for the past few years) is 1 strong, would be helpful. There is a significant difference in employing people to run specialist services or organising specialist services, if there is l child a year born in your area for the last three Years or 4.

(d) The Appellant reiterates her undertaking to keep the information confidential.

DISCUSSION

28. The first important point in this case is whether the requested information constitutes personal data. We understand the Appellant's argument that, on its face, no individual can be identified by the revelation that a particular number of children, less than five, were born in the Trust's area for a particular year.

29. However, as the Commissioner says, the interpretation by the courts as to when data is personal information needs to be considered. The case that brings together the caselaw most conveniently is *Information Commissioner v Miller* [2018] UKUT 229 (AAC). In that case it was confirmed that applying the judgment in *R (Department of Health) v Information Commissioner* [2011] EWHC 1430 (Admin): -

> 10.…the proper approach to whether anonymised information is personal data within section 1(1)(b), for the purposes of a disclosure request, is to consider whether an individual or individuals could be identified from it and other information which is in the possession of, or likely to come into the possession of a person other than the data controller after disclosure.

30. In the *Department of Health* case Cranston J said at paragraph 66 that the assessment of the likelihood of identification included 'assessing a range of every day factors, such as the likelihood that particular groups, such as campaigners, and the press, will seek out information of identity and the

types of other information, already in the public domain, which could inform the search'.

31. In *Miller* the UT noted the 'motivated intruder' test relates to '…a person who starts without any prior knowledge but who wishes to identify the individual or individuals referred to in the purportedly anonymised information and will take all reasonable steps to do so.' Again, in *Miller* the UT noted that a similar approach was taken by the Court of Session (Inner House) in *Craigdale Housing Association v The Scottish Information Commissioner* [2010] CSIH 43 at paragraph 24:

> "…it is not just the means reasonably likely to be used by the ordinary man on the street to identify a person, but also the means which are likely to be used by a determined person with a particular reason to want to identify the individual…using the touchstone of, say, an investigative journalist…".

32. Further, the Commissioner's Code of Practice on "*Anonymisation: managing data protection risk*" provides guidance at page 22-23 on the application of the "motivated intruder" test:

> "The approach assumes that the 'motivated intruder' is reasonably competent, has access to resources such as the internet, libraries, and all public documents, and would employ investigative techniques such as making enquiries of people who may have additional knowledge of the identity of the data subject or advertising for anyone with information to come forward. The 'motivated intruder' is not assumed to have any specialist knowledge such as computer hacking skills, or to have access to specialist equipment or to resort to criminality such as burglary, to gain access to data that is kept securely."

33. In our view the Commissioner in this case has applied this approach correctly. At paragraph 23 of the decision notice the Commissioner noted that the numbers sought by the Appellant 'relate to a number of identifiers - location, medical health, year or birth/age and physical characteristics of the individual(s). She accepts that the withheld data may link with other

information or knowledge, such as information from the educational sector, media or social media, to make identification of the data subjects possible. Given the age of the children, it is likely that the families still live in the same area'.

34. This view is reinforced by the Appellant's own submission, as set out above, that if the information is disclosed, she would be able, with minimal additional information, to tell the child 'that they were the only, or one of two, three or four babies that were born with Down syndrome at that hospital trust in that year'. The Commissioner submits that the Anonymisation Code provides that a like course of conduct to that described by the Appellant would constitute re-identification of personal data. At page 19 the Code states: -

> There are two main ways for re-identification to come about.
> - An intruder takes personal data it already has and searches an anonymised dataset for a match.
> - An intruder takes a record from an anonymised dataset and seeks a match in publicly available information.
>
> Generally, the latter risk scenario is of greater concern for data custodians because of the confidentiality pledges that are often given to those appearing in an anonymised dataset. However, both risk scenarios are relevant and can carry with them different probabilities of re-identification. In either case though it can be difficult, even impossible, to assess risk with certainty.

35. Thus in the present case, applying the Appellant's own approach, if the numbers in this case are disclosed, she will know exactly how many children were born in the area with Down syndrome. As the Appellant says, if she takes that information and obtains further information from a Down syndrome child or the child's parents (or obtains the information from social media platforms as the Appellant suggests could happen), the Appellant (or anyone else) would be able to tell the child and/or their parents the exact size of the cohort of those born with Down syndrome in that year, and place the child in

that cohort. In our view the Commissioner has correctly identified, therefore, the information as personal data.

36. If the information is personal data, then the question arises as to whether it is also special category data. The Appellant's case is that as she is simply asking for the 'size of the group' then that is not special category data. However, it seems to us clear that on the face of the request the information must 'relate' to lifelong health condition and a specific genetic profile of the data subjects', and therefore Art 9 GDPR applies. The Appellant has not contended that any of the exceptions in Art 9(2) GDPR (see above) apply.

37. If Art 9 GDPR applies and none of the exceptions are applicable, then that is the end of the matter and the information cannot be disclosed. However, on the basis that the information is simply 'personal data' (and not special category data) the Commissioner went on to consider the 'Necessity Ground' as set out in Art 6 GDPR, and so do we.

38. We accept, as did the Commissioner, that the Appellant has a legitimate interest in the disclosure of the information for the purposes of considering national trends over time, and local trends which may assist in local service provision. However, like the Commissioner, we have difficulty seeing why disclosure is necessary for either of these purposes. As to long term trends, these are already considered in the National Down Syndrome Cytogenetic Register (NDSCR) as the Commissioner noted, and it is difficult to see how disclosure of the specificity required by the Appellant would improve the position. In relation to local services, as recorded above, the Appellant is already concerned about late diagnosis and families moving away such that again, and it is not clear why the exact figures (rather than the 'less than five' approach) would assist.

39. In *South Lanarkshire Council v Scottish IC* [2013] UKSC 55 at paragraph 27, Lady Hale stated that a 'measure would not be necessary if the legitimate aim could

be achieved by something less'. Applying that to the context of this case, in our view the 'legitimate aim' of the Appellant as described by her can be met by the disclosure of the information she has already received.

40. We agree, therefore, that disclosure is not necessary to meet the Appellant's legitimate interests. On that basis we do not go on to consider where the balance might lie between the Appellant's legitimate interests and the fundamental rights and freedoms of those to whom the personal data relates.

41. Finally, we mention the Appellant's offer to give an undertaking not to disseminate the information further. However, neither the Commissioner nor the Tribunal have any powers under FOIA to ask for or to enforce such an undertaking. Thus, in *Office of Government Commerce v Information Commissioner* [2010] QB 98 Stanley Burton J said at paragraph 72 that: -

> 72 Disclosure under FOIA is always to the person making the request under section 1 . However, once such a request has been complied with by disclosure to the applicant, the information is in the public domain. It ceases to be protected by any confidentiality it had prior to disclosure. This underlines the need for exemptions from disclosure.

42. For all these reasons the appeal is dismissed.

Stephen Cragg QC

Judge of the First-tier Tribunal

Date: 11 February 2021.

Promulgated Date: 16 February 2021