

BMJ Open The UK Freedom of Information Act (2000) in healthcare research: a systematic review

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ABSTRACT

Objectives: To assess the use and utility of the Freedom of Information Act (2000) in healthcare research since 2005 and to determine if any particular feature of studies found led to greater data acquisition.

Design: PRISMA compliant systematic review.

Participants: An extensive literature search was performed of EMBASE, MEDLINE, CINAHL, psychINFO, BNI, AMED, HMIC and Health business elite databases from January 2005 to January 2013 using terms 'Freedom of information', 'Freedom of information act' and 'Freedom of information act 2000'. Papers were considered for publication if they described utilising the UK Freedom of information act to gather data for healthcare research. 16 articles met these criteria.

Primary and Secondary outcome measures:

Primary outcome was the number and characteristics of studies utilising the Freedom of Information Act to collect the data for healthcare research. Secondary outcome measures were any features that improved data acquisition rates (including to whom the request was made, the number of questions asked per request, etc.)

Results: 16 articles described utilising the Freedom of Information Act for healthcare research, and these investigated a broad range of topics. The median number of requests made was 86 (range 1–172), the total number of requests was 1732. A total of 15 817 pieces of data were retrieved by all studies. The amount of data collected was defined as the number of questions asked multiplied by the number of full responses. A median of five questions were asked per study (range 5–6.5) and the overall response rate was 86%. The National Health Service litigation authority responded to 100% of requests, while Primary Care Trusts had the lowest response rate of 81% for healthcare bodies. A positive correlation between number of requests made and data obtained (0.508, $p < 0.05$) and number of requests made and increased response rate (0.737, $p < 0.01$), both reached the statistical significance.

Conclusions: Researchers should make greater use of the Act to access the information they need that is not otherwise disclosed. We discuss the issues with the research utilising the Act and how future research of this type could be optimised.

Strengths and limitations of this study

- Systematic review; adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline and a thorough literature search.
- Lack of studies currently using the Freedom of Information Act and there is an element of publication bias within the available literature, as those that had minimal findings are unlikely to achieve publication.
- Difficulty in determining whether or not studies utilised the Freedom of information act and the amount of data obtained by those studies.

INTRODUCTION

The UK Freedom of Information Act (FOI) passed into law in 2000, coming into full force in 2005.¹ This made provision for “the disclosure of information held by public authorities or by persons providing services for them”.¹ Under the Act, a request for disclosure of information can be made to any number of public bodies. There are over 100 000 organisations which include education authorities, local government, publically owned companies and the National Health Service (NHS).¹

A written communication asking for release of information is all that is needed; no reference to the FOI act itself and no explanation of why the information is being sought are required.¹ When an FOI request is made, the body being requested must state whether or not it holds the information being requested and must disclose that information, unless the data are exempt, within 20 working days.¹ The Act itself is implemented and maintained by the office of the Information Commissioner, who has the power to force the disclosure of information when a request is being unfairly rejected.²

Use of the FOI Act potentially provides access to a significant amount of information for a variety of research purposes. In

particular, research into healthcare systems, where data obtained from multiple NHS trusts can provide a rich corpora of data swiftly. The FOI Act has been used extensively by the mass media, requesting large sets of information, not only from the NHS but also from many other parts of the government.³ In 2006, private individuals made the majority of requests (60%), journalists made 20%, and the remaining 20% was made up by businesses and other groups.³ In this systematic review, we investigate the use and utility of the FOI Act in healthcare research since its implementation in 2005 and discuss its possible uses in the future.

METHODS

Search method

An online search of the EMBASE, MEDLINE, CINAHL, psycINFO, BNI, AMED, HMIC and Health business elite databases was conducted from January 2005 to January 2013 using the terms 'Freedom of information', 'Freedom of information act' and 'Freedom of information act 2000'. A manual search through the references of articles located by the search strategy and meeting inclusion criteria was also performed. The search was restricted to the English language papers only. Abstract results were manually searched by one of the authors (AJF) to exclude duplicates and those studies not utilising the FOI Act specifically to obtain information related to healthcare. Studies were included if they described utilisation of the FOI Act to obtain data. Papers were excluded if they lacked formal research methodology, if they reported findings made by another group's FOI request or if the data obtained by the FOI Act request was not specified (ie, if they used FOI to fill the gaps in the datasets and did not report on the outcome of these requests).

Data extraction

Data were extracted from articles once they were deemed to be suitable for inclusion by two authors (AJF and CFC). Data extracted were divided into two major groups, background information regarding the paper and factors that may be related to improved response and data acquisition rates. Background data included the place of publication, year of publication, year in which the FOI Act request was made, the number of requests made and to whom the request was made. The specific factors that were believed to be related to improved response and data acquisition rates included: the number of questions posed per request, how many years worth of data was requested, the response rate, the amount of data collected and the specific area of the research.

Statistical methods

All data were compiled using Microsoft Excel 2007 (Microsoft, Redmond, Washington, USA) and descriptive statistics were obtained using this software. Spearman's r was used to establish the association

between the number of questions asked, response rate, amount of data received and the number of requests sent. This analysis was performed using SPSS V.21 (IBM Corporation, New York, USA); two-tailed Spearman's r test was used and the association was considered significant if $p < 0.05$.

RESULTS

The initial literature search retrieved 122 records. One additional paper was identified from manual search. After screening and eligibility stages 16 records remained and were included in the analysis (see PRISMA flow chart in figure 1).⁴

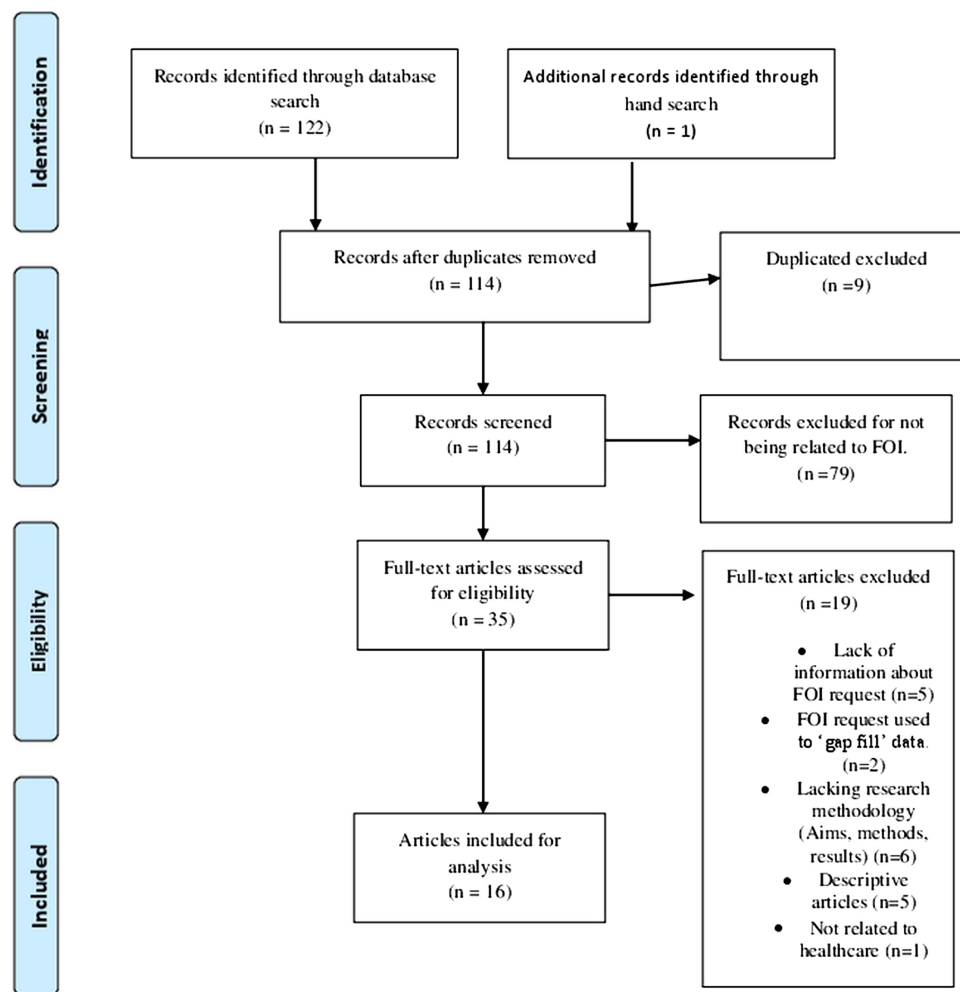
Across the 16 papers included in the analysis 1732 requests were made. The median requests made were 86 per paper (range 1–172). A median of five questions were asked (range 4–6.5) per request. A number of different subject areas were investigated. The median number of years data requested for was 3 (range 2–6), and these years ranged from 1995 to 2012.

There was a significant correlation between the number of requests made and the number of data obtained (Spearman's r 0.508, $p < 0.05$), and as the number of requests increased, so did the response rate (Spearman's r 0.737, $p < 0.01$). This correlation calculation was carried out utilising all included studies ($n = 16$).

There were 1480 responses that included the full data requested (provided the data were available) for 1732 requests made, representing a response rate of 86%. Response rate was calculated as the number of full data responses divided by the number of requests made. In total, 15 817 pieces of data were retrieved by all studies—a median of 387 pieces of data (range 188–1232). A 'piece' or unit of data was calculated as the number of full responses multiplied by the number of questions asked in the initial request. In the case of the NHS Litigation Authority (NHSLA), it was the number of cases disclosed, as the involved studies only requested this data from them. Data collected for a number of distinct annual periods were multiplied by the number of such periods. The total pieces of data therefore represents the number of fully answered questions. Table 1 is a summary of included studies. Table 2 summarises to whom requests were made, the number of requests made, number of responses with full data, the calculated response rate and the actual amount of data obtained. Three articles (18.8%, 3/16) noted the average response time, and one left an arbitrary cut-off of 52 days. The average response time was 29 days in the three studies reporting it (table 2).

Requests have grown each year since 2007, after an initial surge in 2005 and numbered over 45 000 in 2011 to centrally monitored bodies—not including specific NHS trusts or any outside agencies providing services privately.²¹ Centrally monitored bodies are a large part of the central government that have their FOI activity and responses frequently monitored, for example, the

Figure 1 Preferred reporting items for systematic reviews and meta-analyses flow chart of paper selection for this systematic review.



Department of Health. Table 3 shows the number of requests made to centrally monitored bodies each year.

DISCUSSION

Across the 16 studies judged to be eligible, the majority of data was obtained from (30%, 4934/15817) and most requests (44%, 757/1732) were made to Primary Care Trusts (PCT). A total of 15 817 pieces of data were retrieved by the combined studies and they covered areas as diverse as litigation, surgical provision and surveillance, costs and funding of rarer cancer, laboratory provision, pharmacological safety and midwifery discipline. The median number of pieces of data received per study was 387, a relatively large dataset, especially given the ease of access to it. The response rate was 86% (1480/1732) for all included studies. This is comparatively favourable than other methods of data collection.^{23 24}

Three studies reported the reasons why they felt data were not obtained, but none provided actual reasons.^{9 17 18} One study reported the cost and commercial interests as being barriers to full information disclosure.¹⁸ One other study felt there were difficulties in

interpreting the request by the bodies.⁹ Finally, two studies felt that trusts were unable to compile the data due to unavailability of information.^{17 18} The average response time of 29 days is longer than the 20 working days outlined in the Act but only three articles reported response time and did not clarify if they were working days.¹

The positive correlation between the number of data obtained and the number of requests made is to be expected. Obviously, as the number of sources from which data are requested increases, the number of data obtained from such requests should increase. The improvement in response rate as more requests are made indicates that the large majority of providers respond well and the effect of those that do not is reduced. As such, more data may be obtained by maximising the number of requests made, as may the response rate.

No other feature was significantly associated with obtaining more information, but the lack of a significantly negative correlation between the number of questions asked and the response rate indicates that there is no optimal number of questions. This was examined to see if higher numbers of questions led to a reduced response rate. It is possible that by asking too many

Table 1 Summary of included papers

Author	Year	Number of requests made	Number of questions/request*	Years of data requested	Number of full data responses	Number of data†
Grewal <i>et al</i> ⁶	2013	179	7	2012	175	1225
Matthew <i>et al</i> ⁶	2013	1	1	1995–2009	1	1253
Gulati <i>et al</i> ⁷	2012	1	1	1995–2010	1	318
Milligan <i>et al</i> ⁸	2011	1	1	2005–2009	1	768
Gan ⁹	2012	299	5	2008/2009, 2009/ 2010, 2010/2011	247	3705
The Royal College of Surgeons of England ¹⁰	2010	164	3	2007–2009	96	288
Raine ¹¹	2011	1	1	2005–2010	1	195
Buhanan <i>et al</i> ¹²	2012	1	1	1995–2008	1	126
Kalejaiye and Pear ¹³	2012	129	3	NOT DOCUMENTED	122	366
Chaudhari and Kilby ¹⁴	2011	161	4	2007–2010	102	408
Goldenberg and French ¹⁵	2011	170	5	2008–2009	167	1670
Rigbye and Griffiths ¹⁶	2011	327	13	2008–2009	327	4251
Aujla <i>et al</i> ¹⁷	2011	195	5	2005–2008	150	750
Payne-James <i>et al</i> ¹⁸	2009	43	4	2000–2008	41	164
Agha ¹⁹	2012	36	6	2005–2009	27	162
The Royal College of Midwives ²⁰	2012	24	8	2010–2011	21	168
Total	–	1732	–	–	1480	15817

*Questions put to the NHS Litigation Authority were requests for case reports, as such only one question was asked, and the number of data was calculated as the number of reports received.

†Number of data is calculated as the number of questions asked multiplied by the number of full data responses.

questions, the cost limit of £600 outlined in the Act might be reached and therefore data not obtained. We cannot comment on the optimal number of questions or of requests. To encourage data collection, it seems sensible that questions should be carefully considered, stated clearly and simply. Before a request is made, a thorough search of the existing national databases and the public bodies own website should be made to determine if such information is already in the public domain.

Questions were being asked across a cross-section of NHS, indicating that these studies are investigating the wider scope of NHS. Previously, obtaining such

information apart from official reports and documents was challenging. One of the included articles attempted to obtain data by a simple letter, and achieved a response rate of 11%; this improved to 83% after making the FOI Act request.¹⁹ A similar act passed in the USA in 1966 led to a vast public health and medical research output.²⁵ The FOI Act in the UK now enables researchers to access a similarly large amounts of data pertaining to the entirety of the health service at minimal expense—both financially and with respect to time for researchers.

While the use of FOI may be financially beneficial for those performing research, questions have been raised

Table 2 Showing bodies, the requests made to them, their full data responses, response rate and actual number of data received by authors

Body	Requests made	Responses with full data	Response rate (%)	Data received
Primary Care Trusts	757	615	81	4934
Acute Care Trusts	636	541	85	4402
Foundation Trusts	213	203	95	2811
Mental Health Trusts	58	58	100	754
Constabularies	43	41	95	164
Strategic Health Authorities	20	17	85	92
NHS Litigation Authority	4	4	100	1892
National Reporting and Learning Service	1	1	100	768
Total:	1732	1480	86	15 817

NHS, National Health Service.

Table 3 The number of requests made to centrally monitored bodies since 2005^{5 22 *}

Year	Number of requests to centrally monitored bodies
2005	38 108
2006	33 668
2007	32 978
2008	34 950
2009	40 548
2010	43 921
2011	47 141
2012	37 313*

*2012 Includes the first three-quarters of 2012.

about the collective cost of the FOI Act.^{26 27} Cost is one of the exemptions made in the Act, where a request must cost under £600 to respond to.¹ If requests are made to multiple trusts then the cost of the research to the NHS would be larger, rather than relying on the funding received by researchers.¹⁴ A report compiled investigating the financial impact of the FOI Act estimated that over £24 million was spent by the central government on FOI requests in 2006.³ Requests going to those outside of central government (including Social Health Authorities) were estimated to cost £8 million. Such estimations are limited due to the variable local costs in response to requests.³ If every request included in this analysis cost half the recommended amount of £600, then the total cost to the NHS of such research would be over £450 000.

There have been many criticisms of the FOI Act. These include the ease of 'fact fishing' where huge amounts of data can be obtained and trawled for any discrepancy.²⁸ As with any retrospective analysis, proper methodology with a hypothesis formed before obtaining data should help allay such concerns for medical literature. Indeed, such data mining may lead to serendipitous results. There have been many prominent critics, including many members of the government that introduced the initial white paper.²⁹ Former Prime Minister Tony Blair himself described it as a 'dangerous act', and while he felt it would empower people by shining 'light' on the government and making them more accountable, it has had some unintended consequences, such as the extensive use by the media to investigate all aspects of the government.³⁰

A report by a former senior civil servant into the FOI Act found that it had improved transparency and accountability, but had reduced trust and participation in government.³¹ The importance of government being able to debate in confidence, to allow civil servants to give frank analysis and the negative reporting employed by the mass media were other key issues that the former Prime Minister raises in his memoirs.¹⁷

In the era of open access research and preregistration of trial information and protocols on publically

accessible databases, having raw data available openly is a key aspect of academic freedom.³² In an increasingly connected world, data being easily available allows timely dissemination of important advances and findings. Having data available for scrutiny is a key part of the scientific method, just as having a protocol and ethics are. Data should be made available for independent assessment and analysis; the *BMJ* has made this a requirement for clinical trials of drugs and devices as of 2013.³³

With a universal ease of access to data comes the issues surrounding research ethics and access to data obtained by research. The most prominent example of this was a request made by a major tobacco conglomerate in 2011. They requested data from a group at the University of Stirling who were investigating the opinion of teenagers about plain packing.^{34 35} Academics argued that releasing such information could jeopardise future work if young people were thinking that their opinions were being used to form the tobacco industry's marketing campaigns. If forced to disclose, as they eventually were, they argued it would have vast implications on academic freedom.²²

One prominent criticism of the FOI Act is the provision for ministerial veto.³⁶ This came to light with regard to a request for access to the NHS 'risk register'. A document was prepared outlining the potential damage caused by NHS restructuring under the white paper of 2010.³⁷ This led to the questions surrounding what data and predictions were contained within the document and worries related to the NHS changes.³⁸ This is perhaps the most worrying aspect of the FOI Act for healthcare researchers. That is the highly politicised nature of the NHS and the potential political problems of such a document's release. Data that might be useful to researchers could be held back to prevent such embarrassment.^{9 17}

The FOI Act gives access to a plethora of data and the potential of using such data is only as limited as the questions posed by researchers. In this review, the FOI Act was primarily used to investigate the metrics of performance across large portions of the NHS but should not be limited to this. Research utilising the FOI will become especially important for monitoring the impact of changes to the structure and practice of the whole NHS on outcomes following from the reforms of the NHS Bill 2012.²⁴ The possibility of utilising the FOI act itself to ask about how many FOI requests had been made for the purposes of research was considered. However, the condition that there is no requirement to state the purposes for requesting information and the broad, heterogeneous bodies from which this information were requested means this would likely have been futile.

Greater transparency itself can help improve outcomes. For instance, Bridgewater *et al*³⁹ demonstrated that publication of surgeon-specific mortality data following the Bristol inquiry led to a reduced mortality in cardiac surgery. A greater transparency in a wide range of

medical specialities may well have a similar impact and FOI could be an important tool facilitating such transparency as part of a wider information revolution.^{26 40}

This analysis is limited by the fact that the actual number of studies utilising the UK incarnation of the FOI Act for healthcare research are relatively few and there was inclusion of only English language papers. The lack of studies located limit the analysis of the FOI Act's value as a research tool. The impact of language discrimination is likely to be minimal, given the research pertained to the UK FOI Act. Inclusion of articles utilising the Scottish Freedom of Information Act—as opposed to the UK FOI Act—may have yielded further examples of FOI use.⁴¹ It is also possible that research that had no findings or found it very difficult to obtain information would not be submitted or accepted for publication and as such there may be a certain level of publication bias. Authors may also not describe their work as utilising the FOI Act for data collection, therefore meaning that research using the Act may not be characterised as doing so.²⁸

Whether or not a paper was true research, rather than just making large scale FOI requests and then scouring the data for inconsistencies was hard to distinguish, and was based on whether or not the article outlined its research methodology. This may have excluded some valid studies, although given their lack of described methodology; such papers would likely have been of poor quality. Another difficulty was in extraction of data; specifically discerning the number of data obtained. For example, one article reported over 800 000 data relating to *Clostridium difficile* infections. However, this was the answer to a question, rather than obtaining 800 000 individual data points, so was not included in the number of data obtained.^{5 9} Finally, we had no way of assessing the quality of data collected. While there is a legal requirement to disclose accurate information, the methodology of the initial collection of the data may not be uniform and therefore raises unknown biases within the data set.

To allow greater assessment on how the FOI Act has been used, the patterns of data distribution and to standardise the data collection, a formatted checklist would be beneficial. This would hopefully result in future studies of this kind having equivalent methodology to allow better comparison; and therefore more significant conclusions, to be drawn from the data. This would ideally include:

1. Which body/bodies data were requested from?
2. How many and what questions were asked?
3. The rate and timeframe of responses
4. Reasons given when data were not released
5. Amount of data received

CONCLUSION

To our knowledge, this is the first systematic review looking into the use of the FOI Act in healthcare research. The FOI Act has led to easy access to a large

amount of data across the whole of the NHS, which were previously challenging to access. As changes to this service occur, judicious use of FOI Act requests could lead to careful and accurate monitoring of a variety of measures—be they medical, legal or financial. A greater number of requests improves the overall response; both in terms of data volume and response rate.

Given the vast corpora of data that is available, the lack of published work is perhaps surprising, but we hope that through a greater understanding of what is required to make a request and what kind of data is available by request, this very valuable resource can be maximised in healthcare research.

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