## Reflecting on the use of freedom of information requests in mental health research

*Background*: Freedom of information (FoI) legislation has been represented as a valuable but underused means of generating otherwise unavailable data from public authorities in health and social care research.

*Aim*: To provide reflections on the use of FoI requests in mental health research.

*Discussion*: Relevant literature and the authors’ experience deploying FoI requests in research studies are drawn upon.

*Conclusion*: Advantages to this research approach are identified, as well as challenges and ethical considerations. FoI requests may be particularly valuable in research enquiry investigating inequities in access to treatment provision.

*Implications for practice*: Experience-based accounts addressing the use of FoI requests as a primary or complementary means of generating data provide insights into obstacles and dilemmas that may be encountered with this research approach.

*Keywords*: data collection, ethics, freedom of information, mental health nursing research, research methodology, survey studies

Why you should read this article:

* To learn more about how freedom of information (FoI) requests have been used to generate relevant data in health and social care research
* To learn more about the types of research projects that FoI requests may be particularly useful in
* To understand some of the advantages that a FoI-based approach affords researchers compared to traditional survey methods and questionnaires
* To better understand some of the ethical considerations that need to be addressed when utilising this research approach

Key points:

* FoI legislation has been represented as an undervalued means of generating relevant data from public organisations in healthcare research.
* The use of FoI requests is more cost-effective than traditional survey methods.
* The use of FoI requests can be particularly valuable in research enquiry investigating inequities in access to treatment provision.
* To send a FoI request is to exercise a citizenship right. Consequently, it is not the prerogative of institutional ethical review committees and research ethics officers to decide whether a researcher should or should not deploy them as part of their investigations. Nonetheless, submitting protocols for FoI-based research for institutional ethical review can be beneficial to ensure propriety and safeguards against that potential harm.

Passed into law in 2000 before coming fully into force as to January 2005, the Freedom of Information (FoI) Act (England and Wales) provides a ‘right of access’ to information held by public authorities. Like other FoI or access to information legislation in the UK and internationally, the act enables members of the public to request information directly from public authorities without cost. This legislation has been represented as undervalued by researchers in healthcare and social science (Bows 2017, Brown 2009, Fowler et al 2013, Johnson and Hampson 2015, Savage and Hyde 2014) – an ‘overlooked means of data production’ (Walby and Larsen 2011) and ‘a powerful tool available to researchers’ (Savage and Hyde 2014). Savage and Hyde (2014) describe a freedom information-based approach as ‘not tied to epistemic and ontological commitments’ and therefore able to ‘play a role in research projects of all types, and at all phases of those projects’, complementing data obtained via other methods, and adding validity and enriching findings.

This article complements other literature on the use of FoI requests for research purposes. Reflections are provided on the challenges and ethical considerations with this approach drawing on relevant literature and the authors’ experience undertaking studies addressing different topics in mental health and child welfare. The article is practically orientated and aimed primarily at nurse researchers, particularly those in the field of mental health, who may have limited knowledge of how FoI requests might be utilised in their investigations but be curious about this method’s application.

**The FoI Act and mental health research**

A review of literature published between January 2005 and January 2013 identified just 16 articles reporting research in which FoI requests were used to obtain data from healthcare authorities (Fowler et al 2013), including NHS trusts - primary care, acute care, foundation and mental health, constabularies, strategic health authorities, the NHS litigation authority and the national reporting and learning service. Only one article included in the review was directly concerned with mental health, specifically addressing problem gambling treatment (Rigbye and Griffiths 2011). The modest number of studies identified overall led Fowler et al to conclude their review by encouraging healthcare researchers to make the most of the provisions of act to access data that is not otherwise disclosed by healthcare organisations.

There is indication that this advice has been heeded by mental health researchers, with a steady increase in published work in which FoI requests have been utilised since Fowler et al’s review. This has covered diverse topics, including, but not limited to, online therapies for common mental health problems (Bennion et al 2017), clinical supervision in mental health nursing (White and Winstanley 2021), the implementation of Department of Health guidance regarding the assessment of sexual violence and abuse in mental health services (Brooker et al 2016), direct commissioning of healthcare input in probation services (Brooker 2015), and treatment provision for sex addiction (Griffiths and Dhuffar 2014).

Some studies have focussed on quantitative data and statistical analysis. Notable examples of this are annual reviews of access arrangements and waiting times in child and adolescent mental health services undertaken by the Education Policy Institute (Frith 2016, 2017, Crenna-Jennings and Hutchinson 2018, 2020), and Griffiths and Steen’s (2013) analysis of primary care trust budget data to examine session cost-estimates in Improving Access to Psychological Therapies (IAPT) provision. Conversely, other research relies primarily on documentary evidence for qualitative and content analysis. Ashmore and Carver (2017) for example, contacted all NHS mental health trusts in England and seven equivalent health boards in Wales requesting copies of any written information provided to informally admitted mental health patients regarding their legal rights. Their analysis revealed variability in the depth and range of information provided to patients, with inconsistency and contradictions in the way the terms informal and voluntary were used, as well as regarding the right to discharge against medical advice and refuse treatment, and freedom of movement.

In this body of work, as in other literature concerned with the use of FoI requests for research purposes, there is comment on the benefits of this approach, particularly in enabling savings in cost and time and ensuring exceptionally high response rates compared to traditional questionnaire methods, as well as scope for further correspondence since authorities are legally obliged to respond and, outside of certain exemptions, provide requested information (Fowler et al 2013, Griffiths and Dhuffar 2013, Savage and Hyde 2014). A more immediate data set and representative sample are a highly attractive proposition for researchers. Fowler et al (2013) cite one of the most striking examples in the healthcare research literature: an enquiry undertaken by Agha (2012). In this study, which examined standardised metrics for surgical surveillance via a cohort of acute care trusts, a simple ‘polite letter’ was sent to some trusts, but only 11 percent responded. Following this up with a FoI request drastically improved the overall response rate to 83 percent.

Another advantage of the use of FoI requests, consistent with the principles of FoI legislation more generally, concerns participation in the doing of research and how requests can democratise the research process (Savage and Hyde 2014) - not just, this is, by enabling access to significant amounts of data previously been held by public authorities but also by ‘enabling wider participation of the public in research’ (Parsons et al 2019). This is a salient point for nurse researchers and other health and social care professions where principles of participatory ethics and a commitment to service user perspectives are foundational in some traditions of research enquiry.

**Experience-based reflections on using FoI requests in research**

Over the past seven years or so, the authors of this article have used FoI requests in three studies, all conducted with English health and children’s services by requesting data from mental health trusts and clinical commissioning groups, and local authorities (Lucas et al 2018, Lucas and Archard 2021, Archard et al 2022). The studies have been concerned with:

* the provision and commissioning of mental health services and care pathways for the homeless population;
* arrangements and specialist services for the treatment of posttraumatic stress disorder in adults; and
* the nature, range and scope of local authority early help services for children and families.

This research has either been unfunded or supported by small internal (research development) grants. The initial impetus to use a FoI-based approach was motivated by a lack of available resources, and the potential requests afforded to maximise response rates from organisations and provide data on issues with which the authors were concerned. The authors also believed that FoI requests would potentially be particularly valuable in research enquiry investigating inequities in access to treatment provision with recourse to a traditional survey approach.

One source of reference used early on in this research was guidelines developed by Bourke et al (2012), which offer a range of practical pointers. For example, they advise that researchers dedicate adequate time to write a clear FoI request and refine, if necessary, before sending them to information governance professionals. In the authors’ research, requests were drafted and redrafted multiple times to ensure clarity and succinctness. They were also usually trialled with a subsample of organisations before further revision depending on how the request was responded to and information provided.

***The need for flexibility***

Nevertheless, and likely due to the relative inexperience of the authors in using FoI requests, some flexibility was exercised in developing analyses. For example, requests that were sent to mental health trust representatives as part of the enquiry regarding homeless mental health referred specifically to provision for the adult single homeless population, that is for the specific population of adults without a home, but who do not meet priority need criteria for local authorities to accommodate them under homelessness legislation. However, the responses from trusts did not tend to distinguish between single homelessness and adult homelessness more generally (and other population groups that may be covered by this category, for instance vulnerably accommodated parents with dependent children). Reference was made to arrangements by way of a variety of, often more general, terms, for example rough and street sleepers and statutory and non-statutory homelessness. While the initial FoI request could have been followed up and more specific information sought, a decision was made to, instead, broaden the scope of the analysis to consider, more generally, arrangements for the adult homeless population based on the information provided (Lucas et al 2018).

In a somewhat similar vein, for the study of early help provision (Lucas and Archard 2021), with no standard recording process, there was a lack of uniformity in figures that were made available about the numbers of children and families in different localities who were accessing early help support. From the FoI request, the figures local authorities provided were not necessarily for the same periods of time and only some local authority representatives provided a sufficient level of detail. Often, figures covered the activities of multiple agencies within a locality, meaning the possibility of duplication. Indeed, some local authority representatives commented that they could not respond to the request with accurate figures as the early help strategy involved voluntary sector organisations being engaged for targeted provision and no arrangement was in place for the formal recording of early help services across the agencies involved. This was not the data that would have initially been anticipated, but these responses nonetheless revealed a diverse methodology at work across England in recording early help intervention and support. In this way, while it was possible to surmise some things about numbers of children and families supported, the data obtained primarily demonstrated a lack of clarity regarding early help provision, indicating that difficulties establishing which children and families are engaged in early help arrangements relate to local authorities coordinating different partner agencies in this process, the extent of whose work they may not be fully aware. This finding was related how government guidance announces a clear expectation that local authorities engage in strategic partnerships to ensure early help input is available for referrals to children’s services departments, but this is not accompanied by a statutory obligation to provide statistical returns with no universal protocol for recording this work (Department of Education 2018).

This experience completing the studies may, on one level, be taken as further evidencing how the use multiple FoI requests can be a beneficial strategy in maximising the potential of getting the most relevant data for their concerns or that any data retrieved is only as good as the available records and capabilities of the professional retrieving it (Agha 2012, Fowler et al 2013). On another, it demonstrates that requests can be used not so much to generate a uniform dataset but more so a means of investigating what relevant data is held by organisations and the systems in place for recording certain information either as a basis for further investigation or an end in itself.

***Complications and linked questions that may or may not be best served by FoI requests***

The experience of the authors was also that there can be other complications in using FoI requests. As Bennion et al (2017) note based on their experience as part of a study examining access to online therapies, some IAPT services, as private and third sector organisations commissioned by the NHS, are not obliged to respond to FoI requests as they are not public authorities, and this can be an obstacle in obtaining information about treatments they provide. Bennion et al question whether FoI legislation needs to be revised. With the study regarding specialist treatment provision of posttraumatic stress disorder (Archard et al 2022), this also proved to be an issue and restricted whether some data could be accessed. In planning the study, it was also evident that utilising FoI requests would not be a suitable methodology for exploring certain linked questions around what treatments are being used.

There were obvious advantages, but also clear limitations. Combining the use of a FoI request to trusts and clinical commissioning groups with a voluntary survey to private providers enabled to authors to extend earlier surveys and see how much psychological treatments endorsed by the National Institute for Health and Care Excellence (NICE) (NICE 2005, 2018) were made available as compared to those that are not. However, consideration of the reasons why certain psychological treatments are opted for is not entirely amenable to research using a FoI-based approach and would be better served by interviews or surveys with clinicians and managers within services, as well as users of services. Nevertheless, FoI requests may still be valuable in helping to generate accounts of circumstances in which specific therapies are offered to patients instead of those recommended by NICE. For example, a FoI request would enable access to written information (leaflets and standardized letters) provided to patients regarding these modalities, which can influence user choice of treatment (Tarrier et al 2006). Again, time would be significant in pursuing this so as to ensure relevant data can be made available – a factor that is even more important to consider owing to the exigencies of the COVID-19 pandemic (White and Winstanley 2021).

**Ethical considerations in using FoI requests with health and social care organisations**

There can be conflicting advice regarding the level of ethical clearance required in undertaking research via FoI requests. This has something to do with the fact that the common distinction between primary and secondary research commonly used to categorize ethical issues in research does not apply straightforwardly to research in which FoI requests are used as the principal means of data generation (Savage and Hyde, 2014). Information obtained via requests is publicly available, but this is only due to a request being submitted and responded to. Savage and Hyde (2014) point out that there are practical similarities with established methods of data collection, like interviews and questionnaires, where data are generated at the behest of the researcher, at the same time, the researcher does not hold the same level of responsibility for ensuring confidentiality or assessing potential risks involved as they would with these methods. This relates to the point that it is a citizenship right to submit a FoI request and thus debatable whether it is the prerogative of institutional ethical review committees and research ethics officers to make decisions about a researcher or research team utilising them (Walby and Luscombe 2018).

While this is rightfully the case, submitting study protocols for institutional ethical review should not necessarily be viewed as a bad thing. The process may be beneficial to ensure safeguards against that potential harm and a check that FoI requests are being used efficiently and sensibility. Researchers may allow their enthusiasm for generating data to lead them and fail to spend adequate time accessing and analysing any data that has already been made publicly available by an organisation, thus using requests irresponsibly.

With the FoI Act, there are certain harm and class-based exemptions that apply and, under the Act, public authorities have a right to charge a fee to cover the cost of any administrative work necessary to search for and provide the information requested (with the applicant being provided with a fees notice of any intended charge). There is also an exemption from providing information where the administrative cost to the authority would exceed £450 (£650 in the case of government departments) albeit where this is the case, the authority should give an indication of the information it could provide within the cost limit.

In the studies carried out by the authors, following Savage and Hyde’s (2014) example, approval for the research was sought in all cases from institutional research governance and ethics board of the university department in which the principal investigators were based during the planning stage of each study. Protocols were also developed to respond to information governance professionals in the case of personal data being released. In the case of the survey of treatment provision for posttraumatic stress disorder, this was necessary due to voluntary survey component. However, interestingly, in the case of the other two studies, there were markedly different responses. For one, a lengthy amount of information was provided to the ethical review officer to educate them around the application of this approach and ensure safeguards were put in place. Conversely, the other was swiftly reviewed, and the principal investigator was informed that institutional ethical clearance of the study was unnecessary.

In the healthcare research literature, concerns have been voiced about the need ‘to ensure some propriety’ with FoI-based approach as more researchers become familiar with its value (Hammond et al 2016), and so as to avoid relationships with healthcare organisations being jeopardised by researchers using FoI legislation aggressively to access additional data (Hughes et al 2000). Hammond et al (2016) liken FoI requests to a scalpel: a tool that can improve lives when used skilfully, equally something that is simply a sharp knife in unskilled hands. Requests, they say, ‘may be seen as either a legitimate means of gaining information or a crude weapon of coercion’. In their estimation, context, intent and precision are crucial. Competitiveness between NHS trusts encourages perceptions of commercial sensitivity and searches for competitive advantage - an environment which militates against openly sharing documents for research, public information, or patients’ interests. Given requests may, directly or indirectly, impinge on the provision of services, they suggest that a clear rationale needs to be made regarding the potential for scientific gain in using them for research purposes.

The experience of the authors, to some degree, validated the arguments of Hammond et al (2016). However, it bears remembering that their recommendations are inconsistent with an acknowledgement that the use of FoI requests is a citizenship right. The level of consideration they recommend will also vary from project to project, according to the aims and scale. While it is obviously good practice to complete thorough searches of the websites of authorities and organisations prior to any FoI requests being made to ensure that the information sought is not already in the public domain, information requested for a study may still be fairly minimal, and thus not costly for authorities provide. FoI-based research is also, like all empirical enquiry, a process of trial and error, and authorities and information governance professionals’ handling of requests and the level of information they are able to provide varies. Researchers are not responsible for how a FoI request is responded to.

**Conclusion**

FoI requests should not be overlooked by nurse researchers, especially those working in the field of mental health. They afford a valuable means of generating qualitative and quantitative data. Although a growing number of studies have drawn on this approach in recent times, the potential of this approach is far from fully realised, nor has sufficient attention be given by health and social researchers to FoI legislation, not just as a tool for research, but a topic deserving of study in its own right. Experience-based accounts addressing the use of FoI requests as a primary or complementary means of generating data afford insights into obstacles and dilemmas that may be encountered with this research approach. It may also be beneficial to survey variations and commonalities in the use of FoI requests by mental health and nursing researchers according to the topic and questions addressed.

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