Abstract

The concluding statement of the Burns Commission, established to evaluate whether changes are needed to the Freedom of Information Act (FOI), ruled no major legislative changes were required. As such FOI legislation still enables anyone to obtain information from public authorities. In this brief report article we explore arguments regarding FOI as an instrument for healthcare research using an international research programme as a case study.

Freedom of Information Act: scalpel or just a sharp knife?

INTRODUCTION

The Freedom of Information Act 2000 (FOIA) [1] and the Freedom of Information (Scotland) Act (2002) [2], enable the public to obtain defined information from United Kingdom (UK) government departments and public bodies, including the National Health Service (NHS). There is similar legislation internationally, for example in US [3], but its potential use for healthcare research is more limited outside universal healthcare systems such as the NHS. “Anyone, anywhere in the world can make a FOI request to NHS England” [4], yet a FOI request may be seen differently by those who use them and those who have to comply with them. Differences in views about uses of the FOIA can be compared to the different uses of a scalpel. In skilled hands a scalpel can improve lives, in unskilled hands it becomes ‘just a sharp knife’. Clearly the context, perceived intent and precision with which such tools are employed, influences how their use is viewed. Similarly, using an FOI request may be seen as either a legitimate means of gaining information or a crude weapon of coercion.

In healthcare, the use of FOIA by private companies carries connotations of making financial gains, notably when a tobacco company previously used a FOI to request a university’s research findings [5]. The use of FOI requests by academics in healthcare research has been questioned with regard to economic detriment, lack of potential for scientific gain and ethical issues around the voluntary nature of compliance [6, 7]. In a systematic review of FOIs in healthcare research, the authors conclude with a call for greater use of FOIA by researchers [8]. This perspective is congruent with other disciplines where FOI requests made by researchers is more frequent [9, 10, 11] and where guidance for academics has been published [12].

We used an FOI request to access NHS Trusts’ guidance and policies for dementia services in January 2014. This experience suggests that use of FOI requests as a research tool in healthcare remains a divisive issue. As the Burns Commission report [13] recommended no legal changes be made to the FOIA, debates regarding its deployment by researchers re-emerge. We explore our experiences and consider their implications when using FOI requests with NHS Trusts.

DEMENTIA AND HIP FRACTURE: GLOBAL ISSUES NEEDING GLOBAL ANSWERS

Worldwide figures indicate 47 million people are affected by dementia [14]. Hip fracture is one of the largest challenges facing modern medicine. The risk of hip fracture for people living with dementia is four times greater than for those without [15]. In the UK, caring for patients with hip fracture and dementia costs around 0.4bn more than caring for hip fracture patients deemed ‘psychiatrically well’ [16]. Clinical outcomes are also poorer [17, 18], with 45% of patients with dementia requiring institutionalised care post-fracture, compared to 7% of patients without dementia [19].

Providing care for this group is challenging, but elements of good care do show beneficial patient and economic outcomes [16]. The challenge of innovating sustainable services to support vulnerable elderly patients, including but not exclusively those living with dementia, relies on developing good practice care delivery options into integrated pathways capable of transcending health and social care divides [20, 21]. The (*name removed for peer-review*) is a five-year research programme that seeks to use Enhanced Recovery Pathway (ERP) principles to address this challenge. It aims to develop a specific ERP for people with dementia who fracture their hip. As part of this programme we used an FOI request to collect hard to access data.

FOI as part of a multimethod research approach

Within (*name removed for peer-review*), we required an overview of current and innovative practices in hip fracture care for patients with dementia to identify potential components for the ERP. This was part of a larger work package which included a Cochrane and systematic literature review (*references removed for peer-review*), plus an international telephone survey using chain-referral sampling. In the original research design, the systematic nature of our evidence collection was expected to demonstrate the variety of evidence needed to populate the ERP. However insufficient grey literature was identified for us to be confident we had fully captured practice. This dilemma prompted the use of FOI requests to ask UK NHS Trusts for their policies for caring for people with dementia. This enabled us to access unpublished policy documents.

Using FOI requests alongside an international telephone survey reduced the limitations of chain-referral sampling, including community bias and inaccurate anchoring of target population. It facilitated access to grey literature otherwise unattainable as expected, but significantly, we found that FOI requests created opportunities for positive dialogue with clinicians seeking further clarification regarding study purposes and an interest in gaining timely access to study outputs. Others sought increased participation, contextualising their policy documents by participating in the telephone surveys or attending stakeholder events.

Precise scalpel or just a sharp knife?

Tools need to be handled with precision to yield high quality results. With FOI requests, precision is determined by what, how and to whom questions are asked. Conversations held with initial FOI responders assisted question refinement. However, NHS Trust FOI departments determine who responds and in doing so make judgements about who is appropriate. This contrasts with survey methods where the research design determines key characteristics of respondents.

Table 1: FOI response metrics demonstrates how using FOI requests could be a focused addition to research strategies eliciting grey literature. Employing key terms in our requests elicited 343 documents, in addition to the 79 from the domestic

telephone survey and 59 from the international telephone survey, each method producing similar documents. Nonetheless, FOI requests may be perceived as an unplanned disruption by those receiving the request.

	England n(%)	**Northern Ireland, Scotland, Wales n(%)**	**Total n(%)**
Number of trusts contacted	154[1] (100)	26 (100)	180 (100)
Number of responses	136 (88)	25 (96)	161 (89)
Number of non-responses	18 (12)	1 (4)	19 (11)
Total number of trusts which sent no documents	72 (47)	11 (42)	83 (46)
Number of trusts which sent documents	82 (53)	15 (58)	97 (54)

Table 1: FOI response metrics

Legal requirements for FOI requests set minimum response standards with demanding timelines. In deploying FOI requests as a research method we were permissive with late or non-responders. As illustrated in Table 1, such trusts were not followed up and we complied with wishes to rescind FOI requests. The majority of trusts who asked that requests were rescinded were happy to share their documents. We made such decisions based on conversations with clinical partners. However, we are not suggesting other researchers using FOI requests should not pursue non-responders.

A frontline clinical insight into receiving a FOI request is provided in Table 2. We have also included the view of a patient/carer representative, a perspective not previously attended to in discussions of the FOIA in healthcare research.

An NHS consultant perspective: *"Pity the overworked and under resourced NHS consultant who receives an FOI request email from his/her trust's legal department. Decisions must be made. Is it safe to release the information? Remember - first do no harm. A mandated timescale is no respecter of other clinical priorities. What other work will be eclipsed by this? For me an FOI request from a researcher carries with it an underlying presumption – "We (the researchers) are using this method because you (the recipient) are too (choose your own adjective) to respond". Suddenly I feel guilty for all the "Survey-Monkey" requests I've deleted. Regardless, for me the initial negative emotional response to the perceived stick of an FOI*

[1] At the time of the FOI, 160 acute trusts were identified in England. We were unable to find an email for 1 Trust, 4 were specifically for children and 1 was specifically for women and babies. These 6 Trusts were excluded.

request is hard to reconcile. Does this put future engagement with research in jeopardy?"
An NHS patient/carer perspective: *"I'm not an academic. Had I personally been able to access more information on the dementia care policies of local hospitals, I would have perhaps felt more empowered to enact or challenge practices earlier. Maybe this is why some hospitals policies are not freely available on the Internet? If patients/carers do not know the rules of the game how can we play on a more equal footing? As a member of the public, familiar(ish) with research, The idea that researchers and clinicians need to share non-sensitive information which may help improve patient care efficiently makes sense. Working together for patients surely stretches beyond the NHS? How can improvement happen if this does not?"*

Table 2: An NHS consultant perspective and patient/carer perspective

Frontline clinicians may not welcome FOI requests for research purposes and central to arguments opposing the use of FOI in this manner are the issues of coercion, cost and perceived lack of scientific value [6, 5, 7].

Ethical principles governing research mandate that participation in research is voluntary and accompanied by the right to decline and withdraw. For some a FOI request: "…allows researchers to force other clinicians to provide data…" [6]. Hence as part of a publicly accountable body the individual is obliged by law to comply. The point of principle is that this is not a request to an individual whose rights to withdraw or decline access to their personal information would be protected in research. A FOI request to an organisation does not override one's rights to safeguard their confidential data. It simply asks for organisation-level information from a public body legally-obliged to provide that information to the public on request. An organisation responding to a FOI request is not comparable to an individual being forced to take part in research. Whilst an organisation might be reluctant to provide some kinds of information, the use of a FOI requests does not constitute coercion, nor is it contrary to the ethical principles of research. Organisations however, can, and do, refuse to provide data under one of the legal exemptions detailed in the FOIA (https://ico.org.uk/for-organisations/guide-to-freedom-of-information/refusing-a-request/).

FOI requests nonetheless carry a cost burden for public organisations. Using calculations indicated by previous commentators in this field, we estimate processing our FOI requests cost the combined healthcare services over "…£75,150, equivalent…a consultant's yearly salary…" [6]. This figure is not small yet this commentary implies all NHS Trusts responding reached the maximum cost limit of £450 for public authorities. Not all requests will cost this much. This assumption does not take into account the role of trust-employed information governance and FOI administrators dealing with this specific task, nor the amount of clinical input needed. Our FOI requests entailed locating existing documents; hence clinical time burden was

likely to be small. Should research findings be implemented and produce cost savings then the economic burden argument could be challenged [6].

Not all FOI requests made for ‘research’ have the potential for scientific gain. In this case study, a clear rationale was presented to ensure completeness in evidence synthesis. Thus FOI requests were the next logical step. We now need, to ensure some propriety in academic use of this avenue of enquiry, perhaps prioritising “the public good”. Academic research institutions need to issue guidance regarding if, and when, FOI requests are appropriate.

In our case it is pertinent to understand why a UK-wide FOI request of NHS Trusts was needed to access policy documents. If the information were available by other means such as being already ‘realistically accessible’ or ‘in the public domain’, both of which are FOI exemptions, such requests would not have been necessary.

Closing remarks

Researchers retain a moral responsibility in exercising FOI requests to use a ‘scalpel’ rather than ‘just a sharp knife’. Within a “risk society” where external regulation via monitoring and reviewing processes is increasingly the norm, institutional guidance may provide a more palatable answer.

FOI requests are made to public organisations and not individuals; however, how such requests are processed by individuals within organisations and managed by those making the request this may lead to a perception of coercion. The costs and benefits are complicated to calculate but a model that is predicated only on the immediate costs to organisations without considering potential public benefit may also be challenged.

In the case study presented, FOI requests were employed to ensure a systematic approach to accessing an inclusive body of literature not otherwise available to researchers. This raises the question as to why NHS trusts do not place policy documents in accessible places and why clinicians are repeatedly creating similar policies without sharing such knowledge, albeit with the potential for local modification. This calls into question whether NHS policy documents can be classed as public, private or commercial documents. In our view, competitiveness between NHS trusts encourages perceptions of commercial sensitivity and searches for sustainable competitive advantage. This environment mitigates against openly sharing documents whether for research, public information or patient empowerment.

Competing interest statement:

"We have read and understood the policy on declaration of interests and declare that we have no competing interests."

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