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The Campaign for Freedom of Information

Broken commitments on access to health records

The Department of Health has agreed to publish the previously secret papers of a group advising ministers about the fees charged to patients asking to see their health records, following a challenge by the Campaign.

The Department initially refused to release the working papers of the Health Records and Data Protection Review Group, citing an exemption in the open government code on harm to the frankness of internal discussions. The Campaign argued that the exemption had been wrongly applied, and the Department has now made the papers available on its web site.

It has also revised its guidance on access to health records, after the Campaign pointed out that it broke ministerial promises that patients would be able to have their own views about a disputed matter added to their records, and NHS bodies would be urged to deal with requests within 21 days, instead of the 40 day limit set by the Data Protection Act.

The Campaign for Freedom of Information

Suite 102, 16 Baldwins Gardens, London EC1N 7RJ



Open Government Correspondence
Department of Health
Room 3E58
Quarry House
Leeds LS2 7UE

January 10, 2003

Dear Sir/Madam,

Open Government Code Request: Health Records and Data Protection Review Group

I would be grateful if you could supply me with (a) agendas (b) minutes, and (c) papers supplied to the Health Records and Data Protection Review Group, from the date of its establishment in May 2002 to the present.

With thanks.

Yours sincerely,

Maurice Frankel
Director



Mr Maurice Frankel
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7 February 2003

Dear Mr Frankel

Thank you for your letter of dated January 10th 2003 requesting agendas, minutes and papers for the Health Records and Data Protection Review Group.

I regret to inform that I am unable to provide you with the information you have requested. The Health Records and Data Protection Review Group is in the process of developing options for new or changed government policy. It is not possible to release the meeting papers as this would harm the frankness and candour of internal discussion, which is supporting the development of policy. Part Two, point of the Code of Practice on Access to Government Information "Internal discussion and advice" provides an exemption from the commitment to provide such information under the Code.

Yours sincerely,

Raj Kaur
Chair of the Health Records and Data Protection Review Group

**The Campaign for
Freedom of Information**

Suite 102, 16 Baldwins Gardens, London EC1N 7RJ



Raj Kaur
Department of Health
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February 17, 2003

Dear Raj Kaur,

Health Records and Data Protection Review Group (HRDPRG)

Thank you for your letter of February 7 explaining that you are withholding all agendas, minutes and papers of the above Group on the grounds that they are all exempt under Exemption 2 of the Code of Practice on Access to Government Information. I am writing to ask you to review this decision, in accordance with the code.

I believe that a significant part of the materials are not covered by Exemption 2 of the code at all. Any information which does fall within the exemption should in my view be disclosed under the code's public interest test.

I say this partly because a series of explicit commitments by officials and ministers on the question of access to health records have been broken, creating a substantial public interest in ensuring that these issues are now dealt with openly. These commitments are directly relevant to the work of the HRDPG, but may not be known to its members. **I would therefore be grateful if you would circulate this letter and attachments to the Group.**

On the code itself, the Parliamentary Ombudsman has held that Exemption 2 is not a blanket exemption which can be applied to an entire class of documents, as appears to have been done in this case. It must be applied with reference to the particular contents of each document involved. In particular, the Ombudsman has repeatedly made it clear that this exemption does not apply to purely factual information.¹

I would be surprised if the papers of the HRDPG did not include factual information about the background to the issues, or on questions such as the numbers of requests made for health records, the charges imposed, the conditions under which access is allowed, the exemptions cited, the steps taken to facilitate access, the identification required from applicants and the costs to NHS bodies. Such information cannot be withheld under Exemption 2.

The exemption itself only applies where disclosure would harm the frankness and candour of internal discussion. But if members of a committee would *not* be inhibited by openness, and would offer comments with the same robustness, whether or not they were made public, it is less likely that this exemption would apply. The Group is primarily made up of independent experts, rather than civil servants, who I would not, on the whole, expect to be inhibited by the prospect of disclosure.

This is a point also made in the Cabinet Office Guidance on the code which states: "*there is less need for confidentiality in respect of advice from expert advisory committees, especially where the members of the committees are not civil servants*".²

It is particularly significant that the Group has been told that it is free to circulate some of its papers. Its terms of reference state: "*Unless papers are marked as restricted policy members are free to share papers with colleagues within their organisation*".³ The

membership of the HRDPG includes representatives from the medical, legal, records management and social work professions, as well as a number of important patient organisations. If papers can be made available to all these bodies, why should they be withheld from anyone else?

Exemption 2 is also subject to the code's public interest test, which states that: "*In those categories [of exemption] which refer to harm or prejudice, the presumption remains that information should be disclosed unless the harm likely to arise from disclosure would outweigh the public interest in making the information available*".⁴

There is an obvious public interest in the question of the charges made for allowing patients to see their own health records. But there is a more important issue here, relating to the breaking of government commitments.

As you know, access to manual health records was originally provided under the Access to Health Records Act 1990 (the result of a private member's bill promoted by the Campaign for Freedom of Information). The 1998 Data Protection Act repealed most of the Act and incorporated its provisions. The Government indicated that individual rights would not be weakened by this change. A 1998 Home Office consultation document *expressly* stated that existing fees and response periods would not be changed.⁵

This undertaking was broken. Under the revised arrangements:

- The £10 maximum fee under the Access to Health Records Act was replaced by a £50 maximum.
- The accelerated 21-day response period required where a request was limited to information recorded in the previous 40 days was dropped.⁶
- A further change was that patients lost the right to have a note setting out their disagreement with the facts *or opinions* in a health record added to the record itself.⁷

Although the DPA also improved patients' rights in certain ways, there was no acknowledgement at the time that these particular rights were being weakened.

When we realised what had happened we raised these issues in correspondence with the Department of Health in 2000. The NHS Executive told us "*we are keen to ensure that the rights that previously existed are not lost*" and said this would be done through NHS Guidance which "*will include recording disagreements with the content of manual records, rapid response to access requests and fees being determined on a cost recovery basis only*".⁸ These commitments were amplified in the House of Lords by the then Home Office Minister, Lord Bassam, when Baroness Masham of Ilton raised the issues in amendments to the Freedom of Information Bill.⁹ Lord Bassam repeated the commitments in subsequent correspondence with Baroness Masham.

Department of Health guidance was published in July 2002.¹⁰ It refers to only one of the three issues on which action was promised. (This is the question of the £50 access

fee, about which we remain concerned). The other undertakings have been broken.

For example, Lord Bassam told the House of Lords: "*The Government are in the process of preparing guidance on access to health records. As part of that guidance, we shall make it clear that it is good practice to comply with the subject access requests, especially those to newly compiled records, within 21 days*".¹¹ In his letter to Baroness Masham he stressed that the 21 day recommendation would apply "*to all medical records, not merely newly compiled records*". The DH guidance makes no reference to responding in 21 days.

Lord Bassam also told Parliament that the DH guidance "*will make clear that data controllers should allow individuals to include a statement of their views on the relevant records if they disagree with the content of those records*". No such advice appears in the guidance.

The NHS Executive told us that the charging arrangements would be the subject of a "major review" and "*I will ensure that your views are sought in the associated consultation process*".¹² We now discover that the review itself, though it involves external bodies, is taking place in private, its papers are secret, the options under consideration are confidential and there is no way for us to contribute to the process.

It seems an astonishing collapse of accountability for all these commitments - made in a consultation document, in correspondence with us, in correspondence with a peer and in ministerial undertakings to Parliament - to be broken. Whether this was done deliberately or through oversight, there are serious implications for the work the HRDPG, which is now taking these issues forward. The deficiencies revealed by these events are also likely to be reflected in the briefings and guidance which the Department has provided to the Group, and may not be limited to the specific points described above. I believe the public interest in disclosing the present materials must now substantially outweigh any argument to the contrary. If the issue is the need for "frankness and candour" this too would now best be served by openness.

By making public the papers of the HRDPG, the Department would be following a well-established precedent. The Lord Chancellor's Advisory Group on Implementation of the Freedom of Information Act, chaired by a minister, has analogous functions to those of the HRDPG. Its agendas, minutes and papers - including draft LCD reports submitted to the Group for comment - are publicly available from the LCD's web site, in full, in precisely the form in which they are circulated to the Group's members.¹³ The minutes and papers of a preceding body, the Home Secretary's Advisory Group on Openness in the Public Sector, were similarly public.¹⁴ The HRDPG is itself dealing with freedom of information issues, and the case for it to follow suit is self-evident.

Regardless of any decision about the wider publication of HRDPG papers, could I ask that they be supplied to me as soon as possible in accordance with the code.

Could you also let me know what steps will be taken to bring the current guidance on access to health records into line with ministerial undertakings.

With thanks.

Yours sincerely,

Maurice Frankel
Director

Enclosures:

1. **Letter from CFOI to DH, 16/5/00**
2. **Letter from NHS Executive to CFOI, 19/6/00**
3. **Extract from Lords Hansard, 25/10/00**

Endnotes

1. See, for example, Parliamentary Ombudsman, Case A.8/00, May 2000: "Exemption 2 is intended to protect advice, not factual information."
2. Cabinet Office, "Guidance on Interpretation of the Code of Practice on Access to Government Information", 2nd edition, 1997, para 2.21
3. Terms of Reference for the Health Records and Data Protection Review Group, www.doh.gov.uk/ipu/ahr/tor.htm.
4. Code of Practice on Access to Government Information, 2nd Edition, 1997, Part II, 'Reasons for Confidentiality'.
5. Paragraph 12 of the 1998 Home Office consultation paper 'Data Protection Act 1998, Subordinate Legislation' stated: "The subject access rights under...the Access to Health Records Act 1990...are brought within the scope of the 1998 Act. The Government intends to use the section 7 powers *to maintain their present fees and response periods.*" (*my emphasis*)
6. Access to Health Records Act 1990, section 3(5)(a)
7. Access to Health Records Act 1990, section 6(2)(b)
8. Letter dated 19 June 2000 from P D Walker, Information Policy Unit, NHS Executive.
9. Hansard [Lords], 25.10.00, cols 464-466
10. Department of Health 'Guidance for Access to Health Records Requests under the Data Protection Act 1998', July 2002. <http://www.doh.gov.uk/ipu/ahr/index.htm>
11. Hansard [Lords], 25.10.00, col. 464
12. Letter of 19 June 2000
13. <http://www.lcd.gov.uk/foi/agimpfoia.htm>
14. <http://www.lcd.gov.uk/foi/foiadvvp.htm>



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26 February 2003

Dear Maurice Frankel

Thank you for your letter of 17 February requesting a review of the department's decision not to release papers of the Health Records and Data Protection Review Group (HRDG). I am responding as the new chairman of the Group.

Before she left Raj Kaur had already asked the HRDG to review the Department's original decision to withhold. At its meeting on 13 February members decided that as much information as possible should be disclosed. They did however recognise that there may be some, albeit very limited, circumstances where restrictions may be appropriate. I have therefore set out below how I intend to proceed.

I will separately send you by email all agendas for the 5 meetings so far. The minutes will also be released but the Group has asked that members and, in particular external contributors, should be given an opportunity to confirm that they are content for quotes attributed to them to be released into the public domain.

To date there have been 24 papers prepared for the HRDG. In addition a number of information papers have also been issued. Those (effectively the majority) prepared by the Department of Health will be reviewed for restricted material but I anticipate that very little will be held back. As with the minutes, I will consult with the authors of the papers prepared by contributors outside the Department. Subject to their agreement these will also be released.

I expect the review of the minutes and papers to be completed by 14 March and

information will subsequently be placed on the DH website. In future the intention will be to publish as much information as possible on this website as a matter of course. I will let you have the website address when this has been set up.

In your letter you also raised three other issues -

- Access charges;
- NHS response period to comply with subject access requests; and
- The right of patients to have disagreements with facts or opinions appended to their health record.

You will be aware that only the first of these falls directly within the TOR of the HRDG where a number of options are still under consideration. Recommendations on charges will be made to ministers by summer 2003.

Rapid access to health records for patients remains a government goal and commitments such as that made in the NHS Plan to copy clinical correspondence to patients are still being taken forward. There is also a long term target to allow patients free access to electronic records over the internet. However any immediate consideration of reducing the time available to the NHS for complying with subject access requests is dependent on the outcome of the HRDG work. As you know the HRDG review will be looking at the implications of amending the Data Protection Act requirements for clinicians to review records for harmful and/or third party information before releasing information. This will include investigation of the time currently required for such clinical review.

It has always been and remains Department of Health policy that where an individual feels that information on their health record is inaccurate they are entitled to have a statement detailing their own views appended to their health record. However, having reviewed our available guidance I agree that this has not been clearly stated. I will therefore arrange for the document - 'Guidance to Access to Health Records under the Data Protection Act 1998' - to be amended accordingly. I will also include an appropriate reference in the forthcoming document - 'Confidentiality: A Code of Practice for NHS Staff'.

You may also be interested to know that the Department has recently commissioned research to support the work of the HRDG and we have specifically asked for the CFI to be approached. When completed the relevant commissioning papers will be made available on the website mentioned above.

Finally, you asked that your letter be copied to HRDG members and I will do so along with this response.

Yours sincerely,

Jim Shannon
Patient Confidentiality Issues

**The Campaign for
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Jim Shannon
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April 7, 2003

Dear Mr Shannon,

Thank you for your letter of February 26th.

I appreciate the steps that you are taking to release the HRDG's papers, and welcome the publication on the Department's web site of the various agendas, minutes and working papers.

I am pleased to hear that the Department of Health's guidance on access to health records will be amended to make clear that patients are entitled to have a note of their views added to their health record if they disagree with its contents.

However, I remain concerned that the Department has not complied with the ministerial undertaking to advise NHS bodies to respond to subject access requests within 21 days. Although your letter describes this as a "goal" it was in fact an unequivocal ministerial commitment to Parliament, which has not been complied with. I have therefore raised this with the Secretary of State, and enclose a copy of my letter.

Yours sincerely,

Maurice Frankel
Director

**The Campaign for
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The Rt Hon Alan Milburn MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
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April 7, 2003

Dear Mr Milburn,

Ministerial commitment on patient access to health records

I am writing about the breaking of an explicit ministerial commitment about patients' access to health records.

Under the Access to Health Records Act 1990 (the result of a private member's bill which we initially promoted and which was introduced by Doug Henderson MP) patients had access to their manually held health records. Where a patient's request was limited to recently recorded information, access had to be given within 21 days (as opposed to the 40 days allowed in other cases). This reflected the view that access to

records should be part of the normal doctor-patient relationship, and that information about someone's current treatment should be provided with the minimum of delay.

This Act was largely repealed when its provisions were incorporated into the 1998 Data Protection Act (DPA). In a consultation document on the secondary DP legislation, the Government stated that the existing response periods for access to health records would be retained. Unfortunately, this did not occur. The 21 day response period was dropped and replaced by a standard 40 day period for all requests.

When we realised that this had happened we wrote, in May 2000, to the Department about this and related matters. We were assured that guidance on access to health records would be issued and would deal with the issues we had raised including "*rapid response to access requests*".

This assurance was repeated in the House of Lords during the passage of the Freedom of Information Bill. In October 2000 Baroness Masham of Ilton tabled amendments to the Bill which would have restored the 21 day response period for recent information. In response, the then Home Office minister, Lord Bassam of Brighton, gave an explicit commitment, stating: "*The Government are in the process of preparing guidance on access to health records. As part of that guidance, we shall make it clear that it is good practice to comply with the subject access requests, especially those to newly compiled records, within 21 days*" [Hansard, 25.10.00, col. 464]

Lord Bassam later write to Baroness Masham clarifying that the 21 day recommendation would apply to requests for "*all medical records, not merely newly compiled records*".

To our great surprise the guidance, which was published in July 2002, ignored this commitment. The 'Guidance for Access to Health Records Requests under the Data Protection Act 1998' contains no suggestion that requests should be dealt with in 21 days. It merely restates the statutory requirement that they be dealt with promptly and in any case within 40 days.

We raised this, along with other issues about the work of the department's Health Records and Data Protection Review Group, with your officials on February 17. The response, on February 26, though helpful in most other respects, is extremely unsatisfactory on this point, stating only that "*Rapid access to health records for patients remains a government goal*". The Hansard makes clear that this is an explicit commitment, not a 'goal'.

The department's letter goes on to suggest that the decision on whether to honour this ministerial commitment depends on whether it is found to be compatible with whatever recommendations this review group may make. It seems astonishing that a body which ministers set up to advise them should have the power to override a direct ministerial undertaking to Parliament.

The breaking of this commitment is a important matter for patients, who are being

denied the rapid access to health records that existed until two years ago. But it has even more serious implications for the credibility of ministers. If such an explicit commitment to Parliament can be ignored in this way, why should any ministerial undertaking on any subject be taken seriously in the future?

I enclose the relevant correspondence, and would be grateful for your assurance that the department's guidance will be amended as soon as possible to reflect the undertaking given to Parliament on your behalf.

I am copying this to Lord Bassam, Baroness Masham and Doug Henderson.

Yours sincerely,

Maurice Frankel
Director



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12 May 2003

Dear Mr Frankel

Thank you for your letter dated April 7th to Jim Shannon, concerning the Department of Health's current guidance on access to health records. I have been asked to reply and

apologise for the delay in doing so.

The Department of Health is currently taking steps to review and subsequently amend guidance to NHS bodies on requisite periods for access and corrections to health records in order to comply with the ministerial commitment made to Parliament in October 2000.

We are currently in the middle of this process and would ask kindly that you wait for the preceding correspondence from this office to update you on the status on the issues you have raised.

In the meantime, please feel free to contact myself if you wish to discuss anything about these issues or the work of the Health Records and Data Protection Review Group (HRDG).

Yours sincerely,

Victoria Lowther
HRDG Secretariat

Confidentiality Issues Sections
Information Policy Unit
Department of Health



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12 June 2003

Dear Mr Frankel

In my letter dated 12th May 2003, concerning updating the Department of Health's document Guidance for Access to Health Records Requests under the Data Protection Act 1998, I mentioned that I would update you on the status of this guidance.

The document has now been amended to fulfil promises ministers made to Parliament in October 2000. The change in the guidance is part of a series of developments surrounding information governance (IG) issues including the work of the Data Protection Review Group and the introduction of an IG web-based toolkit that will take place later on this year.

The amended document can be accessed on our website at:

<http://www.doh.gov.uk/ipu/ahr/index.htm>

Information about the IG toolkit will be posted shortly on the Information Authorities website at:

<http://www.nhsia.nhs.uk/caldicott/pages/default.asp>

As always please do not hesitate to contact me if you wish to discuss anything.

Yours sincerely,

Victoria Lowther

HRDG Secretariat

Confidentiality Issues Sections
Information Policy Unit
Department of Health



[Link to the Health Records and Data Protection Review Group's web site.](#)



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