

Dear

FREEDOM OF INFORMATION REVIEW – MEDICAL TEST RESULTS

I write in response to your request for review of NHS Lothian's response to your Freedom of Information request about medical test results. Having discussed your request and our response of, 7 February 2024 I can respond as follows:

Original Request and Response:
Question:

- I am contacting you for advice on patient access to medical test results and reports (whether from hospital consultants or GPs) in Scotland.

I moved recently from England back to Scotland, and have been struck by the difference between the two countries in the extent and timing of patients' access to their health data/records.

Down south, I had become used to letters/reports from hospital consultants being written directly to the patient, and copied to their GP. Here in Scotland I have found that hospital consultants only send reports about patients to the GP, not to the patient, and, even though the GP may discuss these with the patient, the patient has no right to receive a copy. Furthermore, hospital results and reports may not even be sent to the patient's GP.

The NHS charter states that patients have a right of access to their health records. As a patient, I have applied for access in Scotland, but have been informed that access only applies to historic records. I am told that there is no way I can have access to my test results and medical reports on an ongoing basis.

Surely this cannot be correct? Denying people access to their health records on an ongoing basis is arguably a denial of their basic rights under the NHS charter. These are their own personal records, so there are no data protection issues. Their records may relate to issues of life and death, and be fundamental to their informed health-related decision making. Forcing people to wait for a consultant appointment (which can be an extremely long and anxiety provoking wait) to be told their results, and even then to be denied a personal copy of these results and reports, seems disrespectful to patients. It is also inexplicable since, In this digital age, it is no more difficult to send medical reports to two people (e.g. the GP and the patient) than to one (the GP only).

As a general rule I believe that people's right of access should mean that they receive their results/reports personally, in writing, as soon as they become available. This would allow them to reflect on, and discuss these results with friends or family before meeting with their doctor. People who do not wish to receive their reports personally could make this clear and opt out.

If I have misunderstood, and patients in Scotland can arrange to receive their medical test results and reports directly, personally and in writing, please let me know how, as a patient, I can do this.

Answer:

I understand your frustration regarding the difference between NHS Scotland and NHS England.

NHS Lothian's patient information system holds patient records relating to all NHS Lothian patient health services. Any request for automatic ongoing access to test result or correspondence should be made locally with the clinical team responsible for patient care, and may be agreed if manageable by the team. Alternatively you can make a subject access request to the NHS Lothian SAR Team, loth.sarteam@nhslothian.scot.nhs.uk, who ensure compliance with Data Protection Legislation.

NHS Lothian operates a system called eComms where patients can register and receive online access to appointment letters and you should be invited on initial hospital appointment. Currently this service covers 98% of our services but unfortunately this does not give access to clinic letters or test results at this time. Further service may be available to patient over the coming years.

I have enclosed the eComms invite letter which is attached to all new patient initial appointments for your convenience.

Review Request:

- I am writing to express my disappointment - and dissatisfaction - with this response.

According to your letter, NHS Lothian's patient information system holds patient records relating to ALL NHS patient health services. It is encouraging to know that all records are held in one system, as this suggests that patients could easily have one point of access for all their ongoing records - at least in Lothian.

However, you go on to say that any request for automatic ongoing access to test results or correspondence should be made locally with the clinical team, and MAY be granted, and only if manageable.

This is extremely disappointing, and problematic on a number of grounds.

Firstly, it runs contrary to the NHS charter, which gives patients a right of access to their health records. I understand this to be a general right, not a right which can be withheld by individual clinical departments.

Secondly, it is unclear why decision-making on access is devolved to individual clinical departments when records are held in one system for the whole of Lothian. It would be helpful to know what system you are referring to (The NHS portal? PACs? Or what?); and why it is not accessible to individual patients who request it.

Thirdly, you suggest that patients can make an access request to the NHS Lothian SAR Team. From my own experience, as noted in my original email, such requests only enable access to historic, rather than ongoing, records. Similarly the eComms system (which I joined as soon as I moved to Lothian) is irrelevant to my query as it does not - as you yourself acknowledge - provide access to medical records.

Fourthly, the arrangements you describe for ongoing access are not at all user-friendly from the patient perspective, and - most importantly - fail to guarantee access. Speaking personally, I am currently involved with 3 different departments (respiratory, orthopaedic and breast cancer) in 2 different NHS hospitals in Lothian. Do I really have to negotiate with all of these individually to get my results/records; and accept that some or all of them may deny me access? Denying patients their right to see their results/records (as opposed to being given a brief, verbal outline of them) limits their ability to make informed decisions about their health care, and flies in the face of 'No decision about me without me'.

Finally, whilst I appreciate that the NHS is currently facing extremely difficult challenges, the arrangements you describe - such as they are - for patients' ongoing access to their health records would seem to place an unnecessary extra burden on clinical staff just when they least need it.

In view of the above, I am asking that you review your response, which attempts to justify arrangements in place in Lothian which prevent me from having automatic ongoing access to my medical test results, correspondence, reports etc.

Review Response:

I am advised by our Data Protection Department that we do not have any additional information or comment to add to the original response. Under FOI(S)A we can only respond in relation to factually recorded information. They further advise that you may wish to escalate this matter via our Patient Experience Team - loth.feedback@nhs.scot who are more likely to be able to address your specific concerns which cannot be dealt with under FOI(S)A.



If you are not satisfied with this response you still have the right to make a formal complaint to the Scottish Information Commissioner who you can contact at the address below or using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

Scottish Information Commissioner
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St Andrews, Fife
KY16 9DS
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Yours sincerely

**Freedom of Information Reviewer/
NHS Lothian**
cc: Executive Nurse Director