



Association of British  
Dispensing Opticians



ASSOCIATION OF  
OPTOMETRISTS



THE COLLEGE OF OPTOMETRISTS



Federation of Ophthalmic  
and Dispensing Opticians

## **Consultation on Public, Patients, and other interested parties views on Additional Uses of Patient Data**

Together ABDO, AOP, the College and FODO represent the 10,699 optometrists, the 5,303 dispensing opticians and optical businesses in the UK, who provide high quality and accessible eye care services to the whole population.

Thank you for inviting the optical representative and professional bodies to participate in this important consultation. Our responses to the consultation questions follow. However, first, we would like to raise three broader issues.

First, optical practices are independent businesses operating under contract with the NHS to provide a single nationally defined service - the NHS sight test. They maintain practice records about their own patients for their own clinical management and administrative purposes. These records, and the information they contain, are funded by and owned by the practices, not the NHS. However, by definition, they will contain epidemiological and other research data of value to the NHS and others.

As we move to the introduction of a comprehensive electronic record for all NHS Patients – which we entirely support – appropriate negotiations would need to be held with the Department of Health therefore about the value of these data and how practices should be remunerated for making them available to the NHS.

Second, we have seen repeatedly over the past 10 years the burgeoning of multiple organisations (often duplicating existing ones) with the launch of every new Government initiative, most of which organisations are either abolished, merged or disbanded after a couple of years. We would be concerned if the current initiative followed a similar path.

We therefore highlight our concerns in our comments below about the necessity of having a “Information Custodian” and a new Patient Information Advisory Group (PIAG) organisation, and we query the interface between the two.

Moreover we cannot but help wondering whether Research Ethics Committees do not already have sufficient independence and high standards to be able to make decisions about information themselves (subject to some kind of simple appeals process to an independent body e.g. the Information Commissioner). This might simplify the system as well as removing the need for additional bodies and public expense.

Finally, we also highlight in our comments our concerns about data lapses in centrally-held systems, particularly public systems. The NHS is the largest employer in the UK and, by definition, will have its full complement of the good, the bad and the incompetent. Given that so many officials will potentially have access to these personal data, the risks of mis- or simply lax - use are proportionally higher than in any other sector.

What seems to us to be missing from the consultation document therefore is any statement about the punitive regime there ought to be for any person/body:

- who mis-uses the data (e.g. for criminal or personal purposes)
- who manages the data without due care and attention (e.g. lapses in security, encryption not used, passwords not used, etc.).

Criminal sanctions ought to apply to any breaches of the uses of these data the severity of which ought to increase for those misusing or misappropriating data from “sealed envelopes”.

We have limited our response to those questions that are most relevant to our sector.

**Do you have any concerns or comments about the use of data held in sealed envelopes for research or other purposes apart from care?**

No, providing it is entirely anonymised and can never be traced back to the patient, however unlikely that may be.

**Although strictly speaking individuals have no legal right to restrict how information that has been effectively anonymised may be used, it is important that we understand and where possible address people’s concerns. Do you have any concerns or comments about the use of anonymised data for research or other additional uses?**

No, providing it is entirely anonymised and can never be traced back to the patient, however unlikely that may be.

**If people should be asked for their consent to share linked anonymised data in a ‘sealed envelope’, when should they be asked?**

When the sealed envelope is set up so that it is flagged electronically and also again, if possible, when specific requests to use the data are made.

**Do you have any concerns or comments about the use of patient identifiable data for research or other purposes without your consent?**

The public interest needs to be considerable to justify such uses, but there are circumstances in which this would be justifiable. Having a group like PIAG review it would enable each situation to be considered on its own merits.

**Should it be possible to put flags on records to show whether patients are willing to be contacted directly by researchers?**

Note above “Yes possible but only for certain types“ is for certain types of research or researchers.

**Do you have any concerns or comments about the use of patient identifiable data for the purpose of inviting patients to join future studies or the use of flags?**

We are concerned that the information may fall into the wrong hands and be used for alternative purposes. There is also the concern that life or health insurance companies may

find the information useful and may penalise certain patients if they know who they are.

**Do you agree that the idea of an 'Information Custodian' is a useful one?**

We are not clear how this would interface with PIAG, and what the respective organisations would do. The last bullet point states that the Custodian might 'receive applications from researchers and others who want to use patient data and decide which ones to allow'. This presumably is currently done by PIAG. Recent lapses in security with government-held personal information do not inspire confidence in another central organisation such as the Custodian.

**Below are some of the tasks that the 'Information Custodian' might do:**

**manage the way patient data is anonymised**

**link data from different sources using a code and then remove the identifiers**

**perform data quality checks**

**receive applications from researchers and others who want to use patient data and decide which ones to allow**

**Are there any other tasks that you would like the Information Custodian to do? Please write in:**

No

**Have you any concerns or comments about the use of an 'Information Custodian'?**

We would like clarity on how this role would interface with PIAG. Consideration would also need to be given to how to regain the public's confidence in the storage/use of their personal data after recent breaches.



Sir Anthony Garrett  
**General Secretary**  
Association of British  
Dispensing Opticians

[tgarrett@abdo.org.uk](mailto:tgarrett@abdo.org.uk)  
t: 020 7298 5100



Bob Hughes  
**Chief Executive**  
Association of  
Optometrists

[bobhughes@aop.org.uk](mailto:bobhughes@aop.org.uk)  
t: 020 7207 2192



Bryony Pawinska  
**Chief Executive**  
College of Optometrists

[Bryony.pawinska@college-optometrists.org](mailto:Bryony.pawinska@college-optometrists.org)  
t: 020 7839 6000



David Hewlett  
**Chief Executive**  
Federation of Ophthalmic  
and Dispensing Opticians

[david@fodo.com](mailto:david@fodo.com)  
t: 020 7298 5151