Information: To share or not to share
Information Governance Caldicott Review

1.) Thank you for inviting us to comment on this Review. Information governance (IG) is an area with the potential both to facilitate and to create barriers to the integration of NHS services.

2.) In our experience, all too often, IG requirements have been excessively onerous for the levels of risk involved in our sector and have actually inhibited electronic information sharing between NHS providers, across primary care, and between primary and secondary care. We welcome the Review's intention to strike a more appropriate balance between the protection of patient information and the use of that same information to improve the delivery of patient care and outcomes.

3.) As we stated in previous responses to the *Liberating the NHS* consultations[1], we believe that the NHS should move swiftly to a more sensible and proportionate IG system based on the use of secure email which, with today's technology, can transfer information securely, cost-effectively, and efficiently between healthcare providers.

4.) We fully recognise the importance of having IG requirements to prevent any patient identifiable data going astray, being inappropriately accessed or ending up with an unintended recipient. It is important, however, not to overplay these risks to the detriment of patient care.

5.) It is also important to recall that IT systems for private healthcare providers (such as those who contract with the NHS to provide primary care, first point of access and referrals) have in the main been developed in isolation. IG requirements should by drafted with that reality in mind and should focus on the principles involved and maintain proportionality. Owing to this variety in IT systems it is vital to engage with providers about IG requirements at the earliest concept stage. Otherwise there is a high risk that, as in the past, IG requirements will be promulgated which are inappropriate for the providers they cover and create unintended barriers to integration of health services.

6.) As eye care professionals, the principal information flows relating to us are the referral systems for the approximately one million referrals that are made annually on paper between optical practices, GPs and secondary care[2]. A particular problem we have in terms of clinical governance is there is no effective system for feedback on

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[1]   For further information, please refer to our response to the Information Revolution: http://www.opticalconfederation.org.uk/downloads/consultations/2011-01%20Information_revolution.pdf

[2]   *Optics at a Glance,* December 2011 - http://www.opticalconfederation.org.uk/downloads/key-statistics/Optics%20at%20a%20Glance%202011.pdf

the quality or outcomes of referrals. The existing paper based system is prone to problems, and often the referring optometrist is left in ignorance of what has happened. A lack of feedback to optometrists on their referrals hinders their ability to adjust their referral criteria and reduce the number of inappropriate referrals. We strongly believe that these referral systems could be greatly improved by moving to an electronic system for referrals (detailed in paragraphs 17 to 20 below).

Explicit or Implied Consent

7.) From a community optical perspective, we strongly believe that there are instances where it is clearly in the patient's interest to share data and information electronically between primary care providers and between primary and secondary care.This would apply, for example, when a patient is referred by their optometrist following a sight test for further examinations by another health care professional. It is clearly in the patient's interest for reliable and high quality information pertaining to their condition to be shared quickly and effectively to facilitate further investigation into their clinical status. It must be in the patient's interest for this flow of information (from the original referring practitioner to the recipient practitioner) to be shared without explicit consent, so long as sensible and proportionate precautions are observed. There is evidence[3] that patients find the eye care system to be confusing and disjointed, and this can create barriers to them seeking appropriate care. Any steps that we can take to improve a patient's continuity of care should therefore be seriously considered.

8.) We believe that by applying for an NHS sight test (just as in joining a GP's list) a patient is implicitly given consent for relevant clinical information to be shared securely between relevant NHS healthcare professionals involved in their care. This could be made explicit in the application form for a sight test which the patient already has to agree to and sign. Similar arrangements could be put in place for private sight tests.

9.) Either way, implied or explicit consent under these and similar circumstances would prevent any unnecessary hold-ups to the referral process, which can in some cases be sight threatening, whilst additional consent is sought. The reasons for transferring the information would be apparent from the patient's records in the practice should it ever be needed.

10.) There might of course be instances where the patient would wish to object or withdraw their consent however, in our experience this is somewhat a rarity and adequate provisions can be made to ensure that the patient's wishes are respected by the practitioners involved.

11.) On the other hand, there are instances when it is important to maintain or seek explicit consent when sharing information. Under the Opticians Act[4], explicit consent is already rightly required should another provider get in touch to request a copy of

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[3] RNIB (2012) Preventing avoidable sight loss: Developing an evidence base to build better eye care services.

[4] The Opticians Act is available here: http://www.optical.org/en/about_us/legislation/opticians_act.cfm

the patient's prescription in order to supply their spectacles or contact lenses. We feel that this is a sensible precaution and a useful example of when explicit consent should be required.

12.) In our view it would be sufficient to provide clear guidance on implicit and explicit consent through the professional representative bodies which has the advantage that it can be tailored to sectoral clinical circumstances.

Record Shielding Requirements

13.) Protection of patient identifiable data is already established in clinical guidelines and primary care contracts. It should also be noted that the type and degree of detail held in patient records will vary considerably between health care providers and this should be borne in mind when putting in place requirements to shield patient records.

14.) In community optical practice, the type and nature of information held in patient records would rarely, if ever, include information about safeguarding of children and vulnerable adults. As a sector, we have recently issued clear guidance which stipulates that should a patient need to be referred for safeguarding considerations, a record of the referral and reasons for doing so will be held securely and separately from the patient record. It is simply flagged in the patient record that supplementary information is held by the Practice Manager. We feel that this system has served patients' safeguarding requirements well. Whilst we would be happy to incorporate the principles of record shielding in our guidance, the type of information and risks are not sufficient to include us in statutory requirements.

Transition from paper to electronic records

15.) Several community optical practices have successfully transitioned from paper to electronic records. Our best practice advice when doing so is to scan the historical paper records (to an appropriate year) to ensure that they are available to users of the new system, but not to run the two systems in parallel.

16.) The College of Optometrists Guidelines detail the considerations to bear in mind with practical advice for providers transferring from paper to electronic records.

Effective integration of Health and Social Care Services

17.) Throughout the NHS reforms, we have been calling for the introduction of secure cost-effective electronic links between primary care and secondary care. This would allow practitioners securely to transmit information about patients to support the delivery of patient care.

18.) As a sector, we currently refer approximately one million patients a year to their GP or hospital eye service. Historically, such referrals have been done in paper format. This builds in an unnecessary delay in the system and also constrains the quality of those referrals, for example, it is too expensive to include images of the back of the eye in a paper referral, while it would cost nothing to attach these to an

email. Should additional information be required by the recipient practitioner this can be requested quickly and electronically from the original referrer.

19.) To facilitate service integration, we would be most grateful if the recommendations in the Caldicott Review could be explicitly framed so as to expedite and facilitate electronic referrals for our patients. This would have a manifest benefit to patients, as the referral can be dealt with much more quickly and effectively. Improved referrals would also reduce the cost burden of eye care to the NHS, thereby helping to eliminate unnecessary referral appointments as well as duplicated tests.

20.) We would be more than happy to work with all parties to ensure that such electronic referrals are secure. We can also confirm that we are happy for our response to be made public.

Key Questions

Q1*: What needs to be done to improve the effectiveness of information sharing by clinicians, social workers and other Health and Care Services Staff to improve the care of individuals and maintain public trust in the care consultation process and its confidentiality? E.g improving the consistency of multiple professional standards requirements and guidance documents.*

As stated above, we would like to see facilitation of secure, but not overly complex, electronic referral between community optical practice, GPs and the hospital sector. We would also wish to see consistency between the relevant standards. In our experience, this has not occurred in the past, for example, the IG Toolkit for Eye Care[5] was simply cut and pasted from the toolkit for GPs and dentists and issued by *NHS Connecting for Health* without consultation. This not only created a great degree of confusion, but also the toolkit was simply not tailored to our requirements and therefore could not be implemented in its current form, with the result that it currently creates a barrier to integration. We would welcome a recommendation that, when putting in place such standards, professional and industry representative bodies must be consulted. The benefit we see of doing so is to avoid the unintended consequence of duplicatory and disproportionate IG requirements on optical practices.

We would greatly welcome recommendations leading to sensible, proportionate and principles-based IG requirements that are not only secure, but can also be aligned with profession-specific circumstances.

Q2) *What needs to be done to ensure that individual staff have the confidence and ability to share information appropriately in the best interests of patients and service users?*

As a sector, we would be more than willing to produce profession-specific guidance for staff and practitioners, to clarify how and when they could share patient data

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[5] The IG Toolkit for Eye Care Services is available here:
https://www.igt.connectingforhealth.nhs.uk/RequirementsList.aspx?tk=411635745643196&lnv=2&cb=05e25ffb-de7f-4cbc-9a28-0e3dd0096fdc&sViewOrgType=20&sDesc=Eye%20Care%20Service

appropriately in the best interests of patients. We would look to complement this with Continuing Education and Training (CET) and in undergraduate or Pre-Registration training.

Q6) *What are the key steps necessary to enable a unified information governance framework for services, analysis and research communities within the health and care system in England that best balances their requirements with those of individual's control of their personal information?*

From our perspective and as stated above, the key steps are:
- ensuring a principles based approach that allows IG standards to be implemented effectively and quickly
- careful design and consideration of their impact and proportionality to the risks involved
- consultation on the design of IG standards with those governed and with patient groups to ensure appropriate balance.

About us:

The College of Optometrists is the Professional, Scientific and Examining Body for Optometry in the UK, working for the public benefit. Supporting its 13,000 members in all aspects of professional development, the College provides Pre-Registration training and assessment, continuous professional development opportunities, and advice and guidance on professional conduct and standards, enabling our Members to serve their patients well and contribute to the wellbeing of local communities.

The Optical Confederation represents the 12,000 optometrists, the 6,000 dispensing opticians and 7,000 optical businesses in the UK who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of the five optical representative bodies: the Association of British Dispensing Opticians (ABDO); the Association of Contact Lens Manufacturers (ACLM); the Association of Optometrists (AOP); the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.

Submitted by Ben Cook
On behalf of the College of Optometrists and the Optical Confederation