



Department of Health

National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs

Response Form

Question 1: Please tell us which group you belong to? (Required)

This response is on behalf of the Optical Confederation and the Local Optical Committee Support Unit. As the Optical Confederation is a coalition of five separate bodies, please consider this response, combined for your convenience, as six separate responses.

In brief the Optical Confederation represents the community eye health sector, including the 13,000 optometrists, 6,000 dispensing opticians, 7,000 optical businesses and 45,000 ancillary staff in the UK, who provide high quality and accessible eye care services to the whole population. The Optical Confederation also represents manufacturers, distributors and importers. As a Confederation we work with others to improve eye health for the public good.

The Local Optical Committee Support Unit (LOCSU) provides quality, practical support to Local and Regional Optical Committees (LOCs) in England to help them to develop, negotiate and implement local objectives in respect of primary ophthalmic services.

Question 2: If you are a member of an organisation or profession, please tell us if you are responding in a personal or private capacity

N/A

Question 3: If the Department of Health or other organisations were to create further opportunities to engage on data security and the consent/opt-out model, would you be interested in attending? If so where would you find it helpful an event to be held?

Yes No

Event location

We have no preference.

Question 4: The Review proposes ten data security standards relating to Leadership, People, Processes and Technology. Please provide your views about these standards.

Which standard do you wish to comment on?

1 2 3 4 5 6 7 8 9 10

Comments

The ten data security standards appear to have been drafted on the assumption that providers are part of the mainstream NHS and that, if they are not, then they are large scale organisations which are digitally integrated with the NHS. This is not the case for optical sector providers, and as a result, many of the standards would be impractical, inappropriate or overly burdensome for our sector.

Optical practices are independent organisations including large national chains, regional chains, small groups of three or four independent practices and many smaller, independent practices. They provide primary eye care services both for NHS funded patients, under contract to the NHS, and for privately funded patients. Their patients regularly move in and out of NHS entitlement. Registered optometrists, dispensing opticians and optical businesses are subject to regulation by the General Optical Council (GOC), which includes requirements in relation to patient consent for sharing information, and for recording and protecting patient records.

We have the following comments on the specific standards

Standard 3 would place an additional and unfunded cost burden upon an already stretched sector by the way of annual data security training.

Standard 4 would place a large financial burden on our software suppliers which in turn would place an added cost burden on the optical practices, leading to a negative economic impact, without patient benefit.

Standards 6 & 7 could place a requirement for cyber security testing upon practices which, without significant additional funding, would unnecessarily undermine many of the current local initiatives to move care closer to home in contravention of the *Five Year Forward View*. As a minimum, smaller community services should be exempt from any such requirements.

Standard 8: unlike GP IT, optical practices have to self-fund all software upgrades and, whilst we would always encourage our members to follow good governance, we have concerns depending what is considered an unsupported browser and the level of risk applied.

Standard 9: would significantly increase the workload for practices if Cyber Essentials and IGT were both required. Optical practices should only be required to meet one set of standards. For those not eligible for IGT then Cyber Essentials represents a way of demonstrating compliance, for those already IGT compliant it is an unnecessary and unfunded duplication.

Standard 10: Whilst it is admirable to hold IT suppliers to account this will undoubtedly increase costs for practices.

Question 5: If applicable, how far does your organisation already meet the requirements of the ten standards?

Where 0 = Not at all and 10 = Fully compliant

0 1 2 3 4 5 6 7 8 9 10

Please provide examples which might be shared as best practice

As already mentioned, registered optometrists, dispensing opticians and optical businesses are already required to comply with standards set by the GOC and subject to rigorous intervention, including the possibility of suspension or fines for non-compliance. Optical representative and professional bodies, including the Optical Confederation and the College of Optometrists publish

guidance to support members in meeting these duties.

By definition optometrists, dispensing opticians and registered optical businesses will be fully compliant with proposed standards 1 and 2.

Standard 3 is most likely not currently in use in the optical sector, IGT is currently not a requirement of GOS and there is no provision or funding for yearly IG tests for staff.

Standard 4 poses particular problems, given the often small size of staff teams in optical practices, many staff members have multi-function roles.

Standards 5-9 will be complied with by optical practices proportionate to the size and nature of their business, and the level of risk. These Standards are likely to be particularly difficult to meet for many smaller optical practices (see detailed response to question 6).

Standard 10 is of direct relevance to the optical sector – the NHS can ensure compliance through its contractual relationship with optical practices.

Question 6: By reference to each of the proposed standards, please can you identify any specific or general barriers to implementation of the proposed standards?

Which standard do you wish to comment on?

1 2 3 4 5 6 7 8 9 10

As already mentioned, the main barrier to compliance with some aspects of these standards is that although they are applicable they are not appropriate to independent healthcare providers, particularly smaller organisations, which are already regulated by the GOC and many of which would not be able to meet the level of IT infrastructure, or staff resources envisaged in the standards. Where compliance is appropriate and required this should be managed through contracts between the contractor and the NHS rather to save costs on both sides rather than via a separate channel.

As we stated in our response to the previous consultation on the role of the National Data Guardian, we would hope that the aim of the National Data Guardian would be to support, streamline and consolidate existing processes by working in partnership with and where appropriate through existing sectoral bodies that already provide advice and guidance. We would be very concerned if this were to result in an additional layer of bureaucracy in our sector and which may prove detrimental to patient access to care.

3. Unlike many other health service providers, optical practices are not as a matter of course subject to the IGT to deliver sight testing services (GOS mandatory and additional services). IGT is not a requirement of GOS. However, it is a requirement of the NHS standard contract for those practices which offer community services through LOC companies or directly. It is also a requirement if, for example, an optical practice has chosen to use an nhs.net email address. Where applicable, therefore, practices are compliant with this standard.

4. We would expect all practices to ensure that personal confidential data is held securely and only accessible to staff who need access. However, optical practices use of a range of different practice management software systems which will not necessarily be able to monitor who accesses patient records. Other means of security are used in such circumstances. Given the multirole nature of practice staff it is often necessary for all staff to access all, or nearly all, of a patient record.

5-9. As already mentioned, these standards have clearly been developed and are suited to

traditional state funded NHS institutions or large-scale providers with substantial IT infrastructure, staffing structures and connectivity to the wider NHS. A number of optical practices still use paper records or have only limited IT connectivity.

Question 7: Please describe any particular challenges that organisations which provide social care or other services might face in implementing the ten standards.

As stated above, these standards have been designed with traditional NHS institutions and larger providers in mind, i.e. those who have substantial IT infrastructure and support. As a result, many of the standards are impractical, inappropriate and overly burdensome to independent providers, all of whom in NHS terms are small and therefore would be inappropriate and unacceptable in our sector.

The underlying risk of these proposals is not data management but that the prohibitive costs of an unnecessary implementation may serve to reduce access and choice for patients within the healthcare environment. In less affluent areas choice could simply cease to exist as many practices could become uneconomic, if this scale of financial burden is forced upon them.

Question 8: Is there an appropriate focus on data security, including at senior levels, within your organisation?

Yes No

Please provide comments to support your answer and/or suggest areas for improvement

The optical sector is committed to high levels of information governance but, unfortunately, unlike the rest of the NHS, we have never received any IT investment and, despite the best attempts of the sector, still operate largely in technological isolation. We would cite the example of the recent removal of fax machines from hospitals which, whilst in principle is understandable given both the age of the technology and the inherent governance risks, without a readily available and suitable alternative the benefits of removal (minor) are far outweighed by the risk to patients in our sector of emergency and urgent (life or sight threatening) referrals not being received.

Question 9: What support from the Department of Health, the Health & Social Care Information Centre, or NHS England would you find helpful in implementing the ten standards?

It would be helpful if the Department of Health, NHS Digital and NHS England could provide clear guidance to commissioners on how these standards should be applied to the independent contractor professions. This guidance should make it clear that the key standards for contracted services are 1, 2 and 10. We would be very happy to work with the Department and NHS England on this.

It is very important that we have very clear oversight of where the responsibility and risk will sit. It would be very helpful if NHS Digital and the DH would provide both funding and exemplar materials that have been designed with full consultation with the profession.

Question 10: Do you agree with the approaches to objective assurance that we have outlined in paragraphs 2.8 and 2.9 of this document?

Yes No

Please comment on your answer

No - this in effect means external audit of IG compliance, which has the potential to make community optical services uneconomic. The added cost burden could devastate a vital area of practice at a crucial time for both the optical sector and the wider NHS.

We suggest that there should be clear exemptions based upon risk and scale. If this is not possible the government's wider aims to move care closer to home may be severely undermined.

Question 11: Do you have any comments or points of clarification about any of the eight elements of the model described above?

Which standard do you wish to comment on?

1 2 3 4 5 6 7 8

Please provide details

In April 2016, the GOC's new Standards of Practice, including guidance on seeking consent to share patient information and the right to opt out, came into effect. The GOC is currently consulting on supplementary guidance on this subject. As previously stated, we would hope that the National Data Guardian would work with such existing processes in partnership with or through existing sectoral bodies rather than creating an additional layer of bureaucracy which does not improve the handling of patient data or benefit the patient.

Whilst we fully agree with the principle that patients should only have to state their information sharing preferences once (element 5), the lack of IT integration between the optical sector and the wider health and social care system means that at present this is not possible.

There is a significant risk that unless the process is very clearly explained to patients they will opt out, reducing the quality of information that is reported to commissioners and practices.

As an example in Birmingham, when the diabetic screening provider changed, patients were asked for approval to share their data for screening purposes. Many opted out meaning that practices could not see the patient details and only an NHS number, making care more difficult and increased risk of assigning the wrong screening images to the wrong patient.

When the change was explained fully to patients the vast majority opted back in, however this process took a significant amount of unfunded optical practice time and in the interim compromised patient care.

Question 12: Do you support the recommendation that the Government should introduce stronger sanctions, including criminal penalties in the case of deliberate re-identification, to protect an individual's anonymised data?

We support the principle, but urge extreme caution in the implementation. There needs to be a clear distinction between a malicious attempt to re-identify patients for inappropriate reasons and the re-identification for understandable, if mistaken reasons. There should be a very clear distinction between a breach of IG and a criminal penalty. History has shown that without very clear ground rules, an overzealous application of a rule can have devastating implications for professionals and patients alike.

Question 13: If you are working within health or social care, what support might your organisation require to implement this model, if applicable?

The model depends upon full electronic integration of primary care providers with other parts of the NHS. This does not yet exist for the optical sector, and until it does then the objectives of a paper free NHS, seamless referrals and patients needing to provide information (including consent) only once cannot be met. NHS England needs to work with the optical sector and provide support to enable proper connectivity.

In short the optical sector requires some investment from NHS England to achieve this objective.

Question 14: If you are a patient or service user, where would you look for advice before making a choice?

N/A

Question 15: What are your views about what needs to be done to move from the current opt-out system to a new consent/opt-out model?

Yes No

Please comment on your answer

The proposed change to the consent model could further hinder the exchange of information from the hospital sector to primary care. If this change results in a lower level of feedback to optical practices, then not only does patient care suffer, but also there is an increased cost to the NHS from unnecessary repeat referrals.

Question 16: Do you think any of the proposals set out in this consultation document could have equality impacts for affected persons who share a protected characteristic, as described above?

Yes, it is feasible that in more deprived areas there will be a poorer understanding of the process leading to a higher than expected level of "opt outs" , this could lead to areas with high levels of minorities being further disadvantaged from accessing care

Question 17: Do you have any views on the proposals in relation to the Secretary of State for

Health's duty in relation to reducing health inequalities? If so, please tell us about them.

If these changes reduce the sharing of data by virtue of making the sector non compliant or by being uneconomic for contractors, then there is a significant risk of increased health inequalities in deprived areas.

We would seek to challenge any proposals that disadvantage practices, particularly those located in areas of deprivation. Should the sector lose practices in these areas it is unlikely that they would be replaced, owing to the economic challenges of running a practice in these areas.

Send your responses to:

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