

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

Consultation response from the Academy of Medical Royal Colleges

Introduction

1. The Academy of Medical Royal Colleges is the umbrella body for medical royal colleges and faculties in the UK. It speaks on standards of care and medical education across the UK. By bringing together the expertise of the medical royal colleges and faculties it drives improvement in health and patient care through education, training and quality standards. The Academy provided in-put to National Data Guardian's Review and the review is seen as highly important by our member organisations and, more particularly, to the individual clinicians who comprise their membership across the UK.
2. We therefore welcome the opportunity of the public consultation to comment on the proposals. However we are not addressing all the consultation questions as all are not applicable to a national organisation such as ours.

Consent

3. The Academy welcomes the proposals in the report. We recognise the tensions between the need for patient confidentiality and the benefits to be gained from sharing data as identified by the report. Colleges and the Academy have been clear of the benefits that accrue to patients through sharing data for purposes beyond that of direct clinical care provided appropriate individual safeguards are in place.
4. We believe the proposals in the report provide a sensible and pragmatic balance and, importantly, provide a necessary degree of clarity. We do believe that in the past many clinicians have been not been clear about requirements regarding consent and data sharing and found arrangements confusing. As a result clinicians were sometimes not sharing data in circumstances where it could have been shared. We believe the proposed arrangements provide a clear and simple framework.
5. The Academy does not have strong views on the specific question as to whether the choice about use of personal data should be presented as one or two separate opt-outs. Having a single opt-out has the attraction of simplicity and as such is appealing but the Academy would be content with two separate opt-outs if there is a cogent view from most stakeholders in favour of that.

6. The Academy agrees that all organisations that use health and social care information must respect the opt-out but also supports list of circumstances where the opt-out will not apply.
7. The Academy also supports the use of anonymised information where possible as set out in Section 7.
8. In response to Question 12, the Academy would support the Government considering introducing stronger sanctions in case of deliberate or negligent re-identification. This is important in terms of making clear to both patients/users and to staff the importance of the issue and protecting an individual confidentiality. Of course, care would have to be taken in ensuring this did only penalise deliberate or negligent activities and not cases of inadvertent or technical error.
9. In response to Question 15, the Academy has no specific suggestions as to steps required to move to new consent/opt-out model but would urge that progress is made as swiftly as possible. We believe the delay in resolving this issue has not been helpful and it is in the benefit of patients, clinicians, the service and research that we move to a new, accepted and working system as soon as possible. It is going to be essential for there to be an extensive communications exercise with clear and simply explanatory guidance widely available for patients, users, carers and staff alike.

Data Security

10. The questions around data security have been less of a concern for the Academy and Colleges although we obviously recognise the importance of the issue. We accept that all staff must ensure that personal confidential data is handled, stored and transmitted securely and that staff must understand their responsibilities. Whilst this imposes a personal responsibility on individual members of staff, there is an equal obligation on employing organisations to ensure that staff have the training and that the appropriate systems are in place to enable staff to meet their obligations.

Conclusion

11. The Academy would be happy to contribute to any further discussions particularly in relation to the consent/opt-out model.

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