**Consent / opt-outs [NDG review]**

**14. The case for data sharing still needs to be made to the public, and all health, social care, research and public organisations should share responsibility for making that case.**

**15. There should be a new consent / opt-out model to allow people to opt out of their personal confidential data being used for purposes beyond their direct care. This would apply unless there is a mandatory legal requirement or an overriding public interest.**

**16. HSCIC should take advantage of changing its name to NHS Digital to emphasise to the public that it is part of the NHS ‘family’, while continuing to serve the social care and health system as a whole.**

**17. The Government should consider introducing stronger sanctions to protect anonymised data. This should include criminal penalties for deliberate and negligent re-identification of individuals.**

**18. The forthcoming Information Governance Alliance's guidance on disseminating health and social care data should explicitly refer to the potential legal, financial, and reputational consequences of organisations failing to have regard to the ICO's Anonymisation Code of Practice by re-identifying individuals.**

**19. People should continue to be able to give their explicit consent, for example to be involved in research.**

**20. The Department of Health should look at clarifying the legal framework so that health and social care organisations can access the information they need to validate invoices, only using personal confidential data when that is essential.**

**21. The Health Research Authority should provide the public with an easily digestible explanation of the projects that use personal confidential data and have been approved following advice from the Confidentiality Advisory Group.**

**22. The Health and Social Care Information Centre (HSCIC) should develop a tool to help people understand how sharing their data has benefited other people. This tool should show when personal confidential data collected by HSCIC has been used and for what purposes.**

**23. The Department of Health should conduct a full and comprehensive formal public consultation on the proposed standards and opt-out model. Alongside this consultation, the opt-out questions should be fully tested with the public and professionals.**

**24. There should be ongoing work under the National Information Board looking at the outcomes proposed by this consultation, and how to build greater public trust in data sharing for health and social care.**