

Introduction

1. The Academy of Medical Sciences welcomes the opportunity to contribute to the Department of Health's consultation on proposals to strengthen the NHS constitution. The Academy promotes advances in medical science and campaigns to ensure these are translated into healthcare benefits for society. Our elected Fellowship includes the UK's foremost experts drawn from a broad and diverse range of research areas. We are also an integral part of the UK's strong biomedical research community, working closely with funders, medical research charities, the NHS and the private sector.
2. Information about patients collected by the NHS to support individual care plays an important role in the delivery and improvement of health care services. Patient information is also an invaluable asset to the UK research community. The NHS offers a unique resource of pooled data which, if used appropriately, can increase understanding of disease development, progression and spread in a way that is impossible at the individual or small community level. The data can also be used to detect outbreaks of infectious diseases, monitor the safety and efficacy of drugs and medical devices, and to study the safety and effectiveness of interventions and treatments
3. Access to patient records also enables researchers to identify suitable individuals to take part in research, such as clinical trials that test how well new treatments or diagnostic screening programmes work. This support for participant recruitment helps to create a facilitative environment in the UK for public, charitable and commercial collaboration in clinical trials and other studies that benefits society by improving our understanding of health and disease, and also promote economic growth.
4. Despite the significant value and public support for utilising public data in a research setting¹, current access systems are complex and often confusing adding considerable barriers to data sharing. The Academy's 2011 report, *A new pathway for the regulation and governance of health research*², highlighted the lack of clarity about the NHS' commitments around the use of patient data and the rights of patients.

Do the proposed changes to the NHS constitution make clear how the NHS will safeguard and use patient data?

5. Patient data must remain safe and secure but in a way that does not unnecessarily restrict effective data sharing for research. Privacy and trust are essential to maintain public support for the research use of data. People need to

¹ Wellcome Trust (2009). *Monitor Wave 1* <http://www.wellcome.ac.uk/About-us/Publications/Reports/Public-engagement/WTX058859.htm>

² Academy of Medical Sciences (2011). *A new pathway for the regulation and governance of health research*. <http://www.acmedsci.ac.uk/p47prid88.html>

see how and why their data will be used and shared, and to understand the safeguards that are in place to protect their personal information.

6. The Academy welcomes the proposed changes to the Constitution that will offer patients a fuller explanation of their rights on the use of their data under existing law. We also welcome the inclusion of following NHS pledges with regard to research:
 - to anonymise the data collected during the course of treatment and use it to support research and improve care for others;
 - where identifiable data has to be used, to give patients the chance to object wherever possible; and
 - to inform patients of research studies in which they may be eligible to participate.
7. It will be helpful if additional supporting information can be provided alongside the Constitution outlining why patients are being asked to share their data in this way and the benefits of research for improving healthcare. The supporting information should also explain the safeguards that are in place to protect confidentiality and processes to be followed if patients wish to request that their confidential data are not used except in their own care and treatment.
8. We also consider that the second bullet point above could be amended to emphasise a more positive approach: *where identifiable data has to be used, to inform patients and gain their consent wherever possible.*

Do you have any further comments about our proposals for strengthening the NHS Constitution?

9. Revision of the Constitution is an important opportunity to facilitate the sharing of patient data and to increase the understanding of patients, families and their carers of this process. For the amendments to effectively address current barriers to the use of patient data for research, both awareness and tractability of the NHS Constitution must increase. The changes can therefore be seen as one of a series of necessary subsequent steps for the full implementation of the revised Constitution.
10. Greater awareness of the Constitution and provision of supporting information, such as the booklet produced by the UK Clinical Research Collaboration, *Your Health Record Saves Lives*³, will be necessary to clarify and make transparent the process by which patient data will be used for research and to ensure the system is sustaining of public confidence.

For further information, please contact Dr Naho Yamazaki (naho.yamazaki@acmedsci.ac.uk; (0)20 3176 2168)

Academy of Medical Sciences

41 Portland Place
London, W1B 1QH
+44(0)20 3176 2150
info@acmedsci.ac.uk
www.acmedsci.ac.uk
Registered Charity No. 1070618
Registered Company No. 35202

³ National Institute for Health Research (2011) .Your Health Record Saves Lives.
<http://www.ukcrc.org/publications/informationbooklets/>