

Foreword *from the Chair, Harry Cayton:*

“The NIGB has always recognised the need to communicate effectively with its stakeholders and users. This becomes even more important at times of significant change such as now and for the forthcoming few years. I therefore take both pride and pleasure in being able to introduce this Newsletter, which sets out the current position on the Government’s proposals with regard to the future of NIGB and the Ethics and Confidentiality Committee. I want to reassure our wider constituency of patients, the public, health and social care professionals and researchers that we remain active and in place (until at least March 2013). Indeed we have plans to develop further advice and guidance to support best practice in Information Governance (IG) in health and social care. Therefore, you will see reports from our working groups, news about changes in the NHS Care Record Guarantee and our plans for a Workshop for IG professionals in social care and health in June 2011.



I want also to record my thanks to all of our Board and Committee members and the staff of NIGB for their continuing commitment to the work in hand even though there are plans to make significant organisational changes in progress.”

NIGB Information Governance Collaborative Workshop

An Information Governance Collaborative Workshop, sponsored by the NIGB, will take place on Monday 6th June 2011 at Friends Meeting House, Euston Road, London.

The aim of the workshop is to set the scene for information governance in health and social care in the context of the new landscape of delivering the Information Revolution. Likely workshop streams will include:

- Common problems from the IG Toolkit v8 submissions, and their solutions;
- The future of regulation and the IGT;
- Privacy Impact Assessments;
- Records Management;
- IG training;
- Pseudonymisation and anonymisation;
- Consent;
- Reuse of public information and FoIA;
- Lessons learned in info sharing from electronic Common Assessment Framework (eCAF) demonstrator sites.

All IG professionals in health and social care will be welcome to this collaborative peer learning event, which will cost £50 + vat for those working in the public sector and third sector.

Keep an eye on the [NIGB website](http://www.nigb.nhs.uk) as booking will open in March, or email nigb@nhs.net

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Outcome of the Government Non-Departmental Public Body Review

It was announced on October 14th 2010 that as result of the Government's Review of Arms Length Bodies, the NIGB will be abolished as a Non-Departmental Public Body. Subject to legislation, the statutory functions of the NIGB are to be transferred to the Care Quality Commission and its advisory role will return to the Department of Health or be given to other bodies.

We anticipate that the transfer of the functions of the NIGB and the ECC will be subject to ongoing discussion with our Departmental sponsor. In the interim the priority will be to continue to deliver the NIGB's statutory functions whilst the transfer arrangements are developed. Consequently, there will be no changes to the requirements or process for applicants for Section 251 support, other than through ongoing development and improvement; and the NIGB Office will continue to operate on a business as usual basis.

Current information from the Department of Health is the intention to abolish the NIGB through statute coming in to force on the 31st March 2013. It is also proposed that there will be a statutory body called the NIGB maintained within CQC for a further two years, and that this could be extended by CQC at their discretion.

The position regarding the future of the NIGB Ethics and Confidentiality Committee is less certain. We understand that the different Department of Health bodies that will in future regulate activities will be responsible for administering Section 251 approvals in their own area of responsibility. Thus, the NHS Commissioning Board will be responsible for approvals relating to NHS Services, the Secretary of State would retain responsibility for social care and public health approvals and the proposed new Research Regulator would be responsible for proposals relating to research.

Information Sharing Workshops



The Board's NHS and Social Care Leads ran Information Sharing Workshops at Stockton University and St James's Hospital, Portsmouth (based on material developed by County Durham and Tees Valley IG Leads Group). They focussed on multi-agency information sharing to achieve improved outcomes for service users and patients and to safeguard both vulnerable adults and children. Both events were a resounding success and highlighted the concerns

professionals experience when making decisions on how, when and if to share information legally and appropriately with other agencies.

Materials are available to assist local IG staff who wish to run their own workshops, and can be found on the NIGB website <http://www.nigb.nhs.uk/advice/workshopmat>

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New Members appointed to the Ethics & Confidentiality Committee

Three new members of the ECC were ratified by the main Board at the December meeting: Dr Colin Harper, Professor Julia Hippisley-Cox and Dr Jane Kaye. Due to a current freeze on advertising, notice of the vacancies was disseminated through a number of routes including the NIGB website. Over 40 applications were submitted.



Colin is currently Manager of the Centre on Human Rights for People with Disabilities, Disability Action, Belfast, and has previously been a lecturer in political philosophy and ethics, and a research

fellow in ethics, human rights and mental health.

Julia is currently Professor of Epidemiology and General Practice at the University of Nottingham. She has an extensive career in research utilising



NHS data sets (Q Research /Q Surveillance) with a large portfolio of publications and has retained her role as a sessional General Practitioner in a deprived area of Nottingham.



Jane is currently Director of the Centre for Health, Law and Emerging Technologies (HeLEX) at the University of Oxford. She participates in a number of international projects aimed at

developing policy, best practice and governance frameworks to facilitate international data sharing.

Biographies of all NIGB and ECC members can be found at

<http://www.nigb.nhs.uk/nigb/members> and <http://www.nigb.nhs.uk/ecc/eccmembers>

Guidance regarding the use of NHS Smartcards

The Board has recommended to health regulators and the Council for Healthcare Regulatory Excellence (CHRE) that smartcards were not to be shared and that doing so without justification should result in disciplinary action of the individual whose smartcard was used.

The NIGB wanted to remind staff of their personal responsibilities not to share smartcards. Where exceptional circumstances forced sharing, for example where there are urgent patient safety considerations, organisations should have an appropriate authorisation procedure and seek remedy for the underlying problems forcing the sharing as a matter of urgency. The guidance can be viewed at the NIGB website, <http://www.nigb.nhs.uk/pubs/smartshare.pdf>

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Research Database Working Group

The Research Database Working Group was established following a report from the ECC to the NIGB highlighting the increased number of section 251 applications to set up and allow third party access to research databases. The Group was created to assess the need for specific guidance on good practice in the area and, in particular, to consider the issues raised by access to such resources by third party researchers. Dr Mark Taylor, ECC member, chaired the group which included NIGB and ECC members and representatives from the National Research Ethics Service (NRES) and the National Cancer Intelligence Network (NCIN). The Working Group met six times and at two of the meetings representatives with relevant expertise were invited to comment on the requirement of guidance in the area, as well as to highlight other pertinent issues relating to research databases that they considered

important. The Group advised in their report to the NIGB that operational and management issues should be addressed by further developing existing guidance for custodians of research databases, it was noted that any guidance issued would need to be consistent with that of the Integrated Research Applications System (IRAS).

The Group recommended that the Board could consult with stakeholders and consider further information governance issues relating to identifiability of data, consent for processing of identifiable data, notification to patients of the research uses of their data and working across jurisdictions within and outside the UK. The Group concluded that high quality guidance would make a positive contribution to facilitate medical research. The report to the NIGB is available on the NIGB website at <http://www.nigb.nhs.uk/pubs/RDreport.pdf>

NIGB Section 251 applications database

Work on the new NIGB applications database is progressing well and is near completion. Non-research applicants will be able to sign up via the NIGB website and fill in their section 251 application via this route. It will link directly with IRAS so applicants will be able to submit their application on the IRAS system and it will be sent straight into our database. We are the first organisation to link up electronically with the IRAS system, and are delighted to be helping to make the application process more streamlined for applicants. All current applicants should have now received communications to notify them of the forthcoming changes, and further communications will be assimilated as development progresses. The annual review process for existing and new applicants will now be automated, reminders will be sent to applicants directly from the system when a review is due. This will mean that the whole process will be easier for both applicants and office staff to monitor. The fast track process will also be managed through the database in a similar way. All existing approvals will have basic information (similar to that contained on our register currently) migrated onto the database.

We are confident that the new database will considerably streamline the approval process and are looking forward to the improvements it will bring to the administration process. If you have any queries contact nigb@nhs.net or tel: 0207 633 7052.

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IG for Screening Working Group

The first meeting of the Information Governance (IG) for Screening Working Group took place in December. The group was established to determine the information governance issues related to screening programmes, and to develop specific guidance and advice to support screening programmes regarding the lawful disclosure of patient information.

The group confirmed the previously proposed aims and scope of the group, identifying key issues from a number of witnesses from extensive screening backgrounds, and the plans for 2011. Meetings and development work will continue by this group and it is envisaged that guidance will be produced by the end of the year.

Guidance for researchers identifying and contacting research participants

New advice is available on the website, www.nigb.nhs.uk/advice/identifying, to support researchers identifying appropriate research participants whose consent can be sought to participate in a study, and thus without the need for support under section 251. The advice includes clarification of the circumstances where section 251 support would be needed, and what conditions would be typically required for the ECC to give its support with section 251. A number of frequently asked questions and a summary of the legal framework surrounding the use of personal identifiable data is also available.

Review of Clinical Audit Guidance

The NIGB are reviewing current guidance surrounding clinical audit and when support under Section 251 of the NHS Act 2006 would be required for this purpose. The guidance was issued in 2004. A consultative workshop took place in early January with a number of stakeholders, to consider the current guidelines and to identify current issues facing audit. Further workshops are planned shortly. If you are interested in contributing to this work please get in touch via email to nigb@nhs.net. When completed the guidance will be published on the website.

NIGB Responses to Consultations

The NIGB regularly take part in health and social care consultations and calls for evidence. Recent responses include:

- The Department of Health Liberating the NHS White Paper, consultations on [Greater Choice and Control](#) and [An Information Revolution](#);
- The Information Commissioner's Office [Data sharing code of practice consultation](#);
- NHS Constitution [Whistleblowing consultation](#).

All NIGB responses and submissions are published on the [NIGB website](#).

The NIGB Annual Report 2010 is available to download from the website at www.nigb.nhs.uk/pubs/annualreport2010.pdf

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New NIGB Website launched

The NIGB recently launched our new website. The new site has been designed to be easy to navigate through, informative and helpful. It contains up to date information on the work of the Board, including responses to consultations, information governance advice for patients, service users, members of the public and researchers. Visit the new site at:

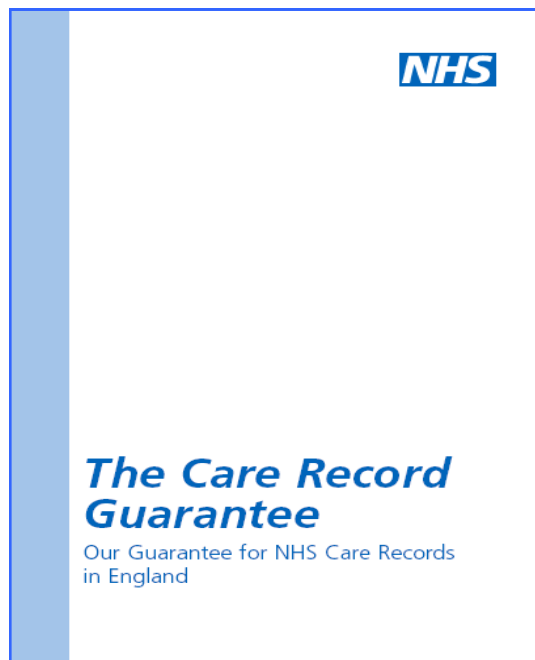
www.nigb.nhs.uk

New NHS Care Record Guarantee Published

Version 5 of the NHS Care Record Guarantee has been published following a review. A number of changes have been made since the previous version:

- Addition of the NHS commitment to privacy and confidentiality as set out in the NHS Constitution for England 2010;
- Removal of reference to the national care record service to reflect the move away from a central to a locally managed model;
- Addition of local organisations responsibility for ensuring confidentiality and privacy and how to find out more about local arrangements for adhering to the CRG;
- Inclusion of the Governments intention to give patients control of their health records over time (Equity and Excellence: Liberating the NHS 2010);
- Further reference to the role research plays in the NHS;
- Clarification of the rights in law that provide protection of privacy and confidentiality;
- Addition of wording to reflect that all organisations providing care on behalf of the NHS are subject to the same strict policies and controls and the mechanisms by which this is done;
- Further clarification of the arrangements that are in place for ensuring appropriate access controls for clinical records;
- Further clarification of the audit functionality that is available in newer electronic record systems;

- Description of what action may be taken if an individual is found to have inappropriately accessed a patient's record;
- Reference to the NIGB and not the ECC committee for Section 251 approvals.



The new version of the NHS Care Record Guarantee can be downloaded from: <http://www.nigb.nhs.uk/nhscrg5>

Printed copies can be ordered from: <http://www.orderline.dh.gov.uk> search for product code 4713

Look out for the next issue of the NIGB Newsletter this summer

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