

NIGB Insider

Editorial

I hope you agree that this is a welcome reappearance of the NIGB Insider after its absence for several months. This was due to staff shortages which I am pleased that we have now largely resolved.

You will see from the contents that a considerable amount of work has been done outside the NIGB and ECC meetings and again I would like to thank the members of the NIGB Office for their commitment and sterling efforts.

The number of requests for advice from NHS and social care organisations is increasing. This is not only due to the role of the NIGB becoming better appreciated but also due to the quality of advice that is given. The number of applications to the ECC is also increasing which I hope is reflecting an increased awareness of the role of the ECC and the importance of a legal basis for sharing information.

You will see from the section by Chris Webb, our NHS Lead, that she is leaving us at the end of March and will retire from the NHS a few days after that. Chris joined us when the role of NHS Lead was largely a blank canvas and she has done a tremendous amount of work not only in making local NHS organisations aware of the NIGB and what it does but also in championing the need for training and actually delivering some. Chris will be missed and will be a hard act to follow.

This, of course, is the last one of these that I will write. You will have seen from the note that Harry has sent that Dr Alan Doyle, Director of the NIGB, will take over on 1 March. Establishing the NIGB has been a fascinating, challenging and rewarding secondment which I wouldn't have missed for the world. So, thanks to everyone for their help and support and may the NIGB go from strength to strength!

Ian Johnstone
Head of Office

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Requesting Amendments to Health and Social Care Records – NIGB Guidance

On 14 January 2010, we published the NIGB guidance on 'Requesting Amendments to Health and Social Care Records'. The production of this guidance began when the NIGB office was contacted by patients who were finding it difficult to get changes made to the parts of their healthcare record they disagreed with. The guidance is aimed at patients, and health professionals and explains what should happen in these instances.

A group of NIGB members, medical and legal experts contributed to the development of this guidance. The working group talked to members of the public, GPs, Caldicott Guardians and other staff responsible for health and social care records, all of whom had experience of this issue. The guidance covers:

- the purpose of healthcare and social care records;
- how we believe problems develop in terms of what information records contain;

- what the law says;
- what should happen when you ask to change information in your record; and
- making a complaint.

Working Group members were:

Ian Hayes (Chair)
Dr Gillian Braunold
Dr Nick Clements
Dr John Holden
Rabbi Sylvia Rothschild
Dr Michael Wilks

Contact: Ian Johnstone

NHS Lead - Update

Part of my work programme this year was to develop communication links between the NIGB and the SHA IG Leads groups – 16 in total. To date I have now visited 13 groups and have one more booked in for January and two awaiting dates.

The visits have covered most of England and along the way I have met most of the IG Leads from a variety of NHS organisations and a few from social care.

The impact of these visits has been a lot more enquiries into the NIGB Office on IG issues and grey areas and a significant increase in communication with front line staff which was the aim of this work. I apologise to the NIGB team for this increase in workload! Each visit allowed me to present the work of the Board, the ECC, the CRG and answer questions. In turn I found a lot of very good work being delivered by these groups and one piece of work in

particular stood out as something the Board might be interested in seeing in more detail. It relates to a subject often raised at Board with regard to IG training and how key this is to managing IG risks. One very enterprising SHA Lead had conducted a study across a thousand NHS staff in her patch on IG training. The study looked at what training had been undertaken if any and relevant areas of understanding and behaviour. It reveals some very interesting details which will be presented at the April Board meeting.

I delivered a further awareness session to the Institute of Record and Information Management Conference in November and hopefully have forged a good working relationship between NIGB and IHRIM who have many IG managers as members of this professional body and provide some of their training and

support.

I have also completed the first ECC annual review visit. A new area of work, which combines the skills and knowledge of the ECC team and NIGB team in providing a comprehensive assurance mechanism that those with section 251 approval are meeting the requirements and conditions of their approval.

As I am retiring at the end of March, I would like to take this opportunity to thank all Board members and the NIGB Office team for the support and friendship given to me whilst in post. I would also like to thank the many IG Leads I have met for their enthusiasm and persistence in driving the IG agenda forward. It has been a real pleasure to help develop the role of NIGB NHS Lead and I will watch the NIGB website with great interest in the future.

Contact: Chris Webb

Research Database Working Group

At the NIGB Board meeting in October 2009, the ECC reported an increase in the number of applications it had received from clinicians and academic departments to establish research databases using identifiable patient information. In addition to this it reported an increase in the number of requests to local research committees to give 'secondary permission' to researchers to access data held in such databases.

The ECC proposed that the NIGB should provide guidance on both the legal basis for research databases and on good practice governing 'secondary permissions' and access to data. To achieve this, the ECC suggested that the NIGB should establish a working group to assess the nature and scope of this problem and to make recommendations on practice. This small working group had now been established.

The members are:

Mark Taylor (Chair)
Tricia Cresswell
Carol Dezateux
Nadeem Khan
Michael Chapman (NCIN)
David Neal (NRES)

The group will meet for the first time in January. It will report to the NIGB during the Summer.

Contact: Zoë Lawrence

Collaborative Working

On 1 October 2009, the NIGB gained transitional delegated powers under s33 of the HFEA Act 2008 to advise on applications made for access to patient identifiable data held on the HFEA register. Once the regulations come into force, which is expected to be in April 2010, this will be a permanent arrangement.

A Memorandum of Understanding (MOU) which

sets out the operational arrangements between the HFEA and the NIGB to administer applications for HFEA data has been agreed.

The NIGB Office is also in the process of establishing a similar arrangement with the National Research Ethics Service (NRES). Research applications for s251 support also need a

favourable opinion from a research ethics committee. There are a number of areas of overlap between these two processes. An MOU between the NIGB and NRES will help us manage these interfaces and improve the process for applicants.

Contact: Zoë Lawrence

IG Toolkit Working Group

In the Board meeting of 17th June 2009 members agreed to establish a working group to contribute to the development of the next version of the IG Toolkit. The IG Toolkit working group met on the 19th November 2009 for the first time and discussed with the DH IG Toolkit team the functionalities and requirements of the Toolkit. The working group will meet again in January 2010. It will make suggestions for the next version of the Toolkit and consider whether the NIGB should use the Toolkit to monitor

information governance practices. The members of the working group are:

Stephen Hinde (chair)
Gareth Beatty
Tony Calland
Wayne Cleghorn
Nadeem Khan
Hilary Newiss
Sally Taber
Michael Wilks

Contact: Rick Borges

The Ethics and Confidentiality Committee (ECC)

Due to the increasing number of applications, (up from 60 in 2008 to 90 in 2009), the ECC are trialling a change of format to its meetings. In February, standard applications will be discussed on one day, and those applications of particular national significance or that are complex will be discussed on a separate day. Applicants will also be invited to attend this meeting in order to discuss the application and answer any queries. It is hoped that this will help balance the workload and enable the ECC to have all the information necessary to make a decision.

Approved studies are required to submit an annual review setting out how conditions of approval are being met. The Office is moving towards a more proactive approach where, if an annual review raises key issues, a meeting will take place with the applicants which will often involve an on-site visit to discuss issues in depth including any information governance concerns. The purpose of these visits are to provide support to applicants and to work with them to resolve any issues. A visit to Biobank took place in December.

Finally, the Office is in the process of updating the website to include more user-friendly guidance on section 251. This includes frequently asked questions (FAQs) which have already been published and topic-specific guidance on related issues to section 251, such as the use of tissue, and effective service user involvement. Future plans are to develop guidance on completing section 251 forms and the overall process and what applicants can expect from the Office.

Contact: Natasha Dunkley

Database Monitoring sub-Group

Since the last NIGB Insider, DMsG has continued to hold meetings every 2 months. There have been some minor changes to the process, however, the majority of the work continues as normal. The main change has been that the formal response letter to the applicant is now from the NIGB Office. These were previously sent from the Information Centre. This change is intended to improve accountability and provide a better audit trail.

The interim terms of reference for the DMsG have been approved. We have also developed HES and ONS registers of approved applications.

These have all been published on the NIGB website.

Recently, we have seen an increase in the number of queries relating to the Demographic Batch Service (DBS) which has replaced the NHS Strategic Tracing Service (NSTS). The NSTS is no longer accepting applications for access and extracts. There has been some confusion as to the status of previously approved SCAG/DMsG applications and whether approval can be carried forward. The discussions are ongoing, however for fully consented studies we have agreed that the previous approval will stand

and a new application is not necessary. Other studies continue to be assessed on a case by case basis.

As there is quite a gap between the November meeting and the first meeting of 2010, we have dealt with more queries and extensions out of committee in order to reduce potential delays for applicants. The next DMsG meeting will take place on 23 February

Contact : Mel Kingston

Information Governance Lead - Update

Since the last Insider, I have provided advice to a number of organisations including:

- the Human Fertilisation and Embryology Authority (HFEA) on interaction between the disclosure for research provisions of the Human Fertilisation and Embryology Act 2008 and section 251;
- The Information Centre on the GP Extraction Service and on the Information Governance Framework;
- The Centre for Maternal and Child health Enquiries on information governance issues related to how they undertake enquiries, following organisational changes, and including the continuing need for support under section 251;
- The Office for National

Statistics on information governance issues related to their processing of health data and the provision of NHS data to researchers;

- The Care Quality Commission on their guidance in relation to disclosure of information for infection control purposes.

Additionally, in July a letter was sent jointly from Harry Cayton and Joan Higgins in response to a letter from the Department of Health asking for views on the state of readiness of the NHS to have regard to the NHS Constitution. The response welcomed the pledges to safeguard patient confidentiality and to access patient records. It highlighted the need for systems to be able to

record consent and for good quality information to be provided to patients about how their information is used by the NHS and other organisations. It also called attention to the need for adequate staff capacity and training to ensure the information governance agenda could be met effectively.

I have also written a section for the website on when s251 may be applicable to research data and tissue banks and on the interaction between section 251 and the Human Tissue Act 2004. Additionally, I am in the process of completing a section providing advice on consent for disclosure for research and when section 251 may be applicable.

Contact: Karen Thomson

Social Care Lead - Update

It has been a busy few months since the last edition of Insider, with the NIGB Office seeing an increase in enquiries from social care organisations in both adult and children's services following the launch of the Social Care Record Guarantee in October. I have produced some Frequently Asked Questions for the website, providing advice and guidance for organisations on various methods of implementation and compliance. Copies of the Guarantee have also now been sent to a number of voluntary organisations to enable them to raise awareness of the commitments contained in the Guarantee to their clients.

I am hoping to attend the Strategic Improving Information Programme Board as an observer. This will enable me to update the NIGB on the progress of the Social Care Record Guarantee and future plans to further embed the standards within the culture of social care and associated stakeholder organisations.

Following Chris Webb's SHA Group visits, and in an attempt to promote and inform social care organisations of the work and impact of the NIGB, I shall be working on building up a list of social care contacts around the country and facilitating links to the

SHA Information Governance Groups where this is appropriate. My first visit is in January to the Social Care Information Management Group for London, sponsored by the Association of Directors of Adult Social Care and Association of Directors of Children's Services.

Finally, we have been working on material for an information sharing workshop. Chris Webb and I will be presenting the workshop at Stockton University on January 20th to both social care and health students. An update on these events will be provided in the next edition of Insider.

Contact: Jan Boucher

Update on Legislation

The Crime and Security Bill

This Bill includes the measures setting time limits for the destruction of DNA and other samples in a range of circumstances. The maximum limit is six years although shorter periods are likely to be more common. If convicted of an offence, however, the 'clock' will restart. These limits do not apply where a person has been arrested under the Terrorism Act 2000, for which there would be a requirement to review retention every two years. The Bill also includes provision for a National Database Strategy Board to oversee the operation of the database, and governance rules and reporting requirements for the Board must be published.

The Children, Schools and Families Bill

This Bill includes provisions relaxing the restrictions on publication and reporting of family court proceedings provided publication is authorised and conditions are met. It includes adoption and parental order proceedings. The Courts have discretion to permit or restrict publication and to impose its own conditions as well as those set out in the legislation. In general, identifying information will be excluded for restricted adoption or restricted parental order information and sensitive personal information, unless permitted by the Court or with the appropriate consents. Publication would need to be in the public interest and the Court would need to take account of any risk posed to the safety or welfare of the individuals concerned. However, the Courts cannot prohibit or restrict the publication of information arbitrarily but must be able to justify their decisions. Wrongful publication would constitute Contempt of court; but there are also a number of defences. The Bill also includes provisions requiring disclosure of relevant information to Local Safeguarding Children Boards in England and Wales.

The Health and Social Care (Independent Living) Bill

This Bill requires NHS bodies and local authorities to create and maintain a register of people with disabilities, including their known requirements and details of their carers. The register should also include those who may have independent living support in future. People have the right not to be included in the register and this decision should not prejudice their right to assessment or support.

The Bill also makes provision for any provider delivering services under the Health and Social Care Act 2008 and registered under Section 10 to be regarded as a public authority for the purposes of Human Rights Act 1998.

Articles of Interest

Paul Ohm, Broken Promises of Privacy: Responding to the surprising failure of anonymisation. University of Colorado Law Legal Studies Research Paper No. 09-12. American Social Science Research Network 2010
http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1450006

Emma Cave, Adolescent consent and confidentiality in the UK, European Journal of Health Law, 2009, Vol 16(4), 309-331

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