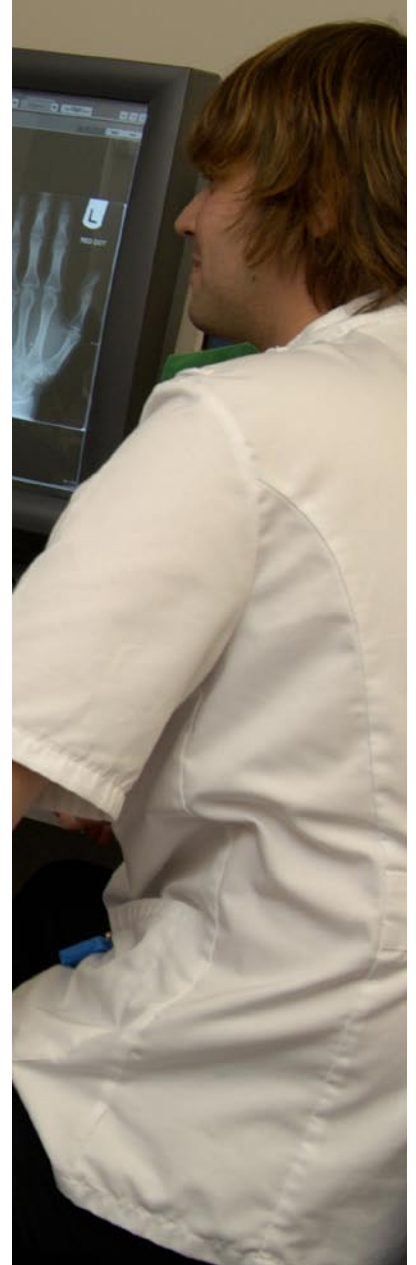


National Information Governance Board for Health and Social Care



Annual Report
2008

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October 2008

Dear Secretary of State,

I am pleased to enclose a copy of our annual report.

The National Information Governance Board for Health and Social Care (NIGB) was set up in October 2007 to support improvements to information governance practice and to monitor information governance trends in both the NHS and adult social care. We meet every two months and report annually to you.

In this report we explain what information governance is, the role and remit of the board, what we have achieved in our first year and information about our board members. We refer frequently to the NHS and also to social care. When we make these references they do, of course, include the independent sector and the third sector where they are delivering services under contract for the NHS or local authority social care teams.

In the last year we have seen significant and welcome attention being given to information governance across government. We have also seen greater recognition of the value of safe, secure and confidential data sharing. In giving its advice the Board seeks to balance the sometimes conflicting interests of individuals and the public good in the effective use of information to improve health and care.

Health has always been particularly active in implementing information governance. The Information Governance Toolkit, a scored evidence based system to measure internal information governance standards, has been in place for some years and is now mandatory across NHS organisations. The NHS Care Record Guarantee for England was introduced in May 2005 and set a precedent for the introduction of Information Charters across all government departments. The NIGB is now the owner of both the Information Governance Toolkit and the NHS Care Record Guarantee for England.

In this context we note and welcome the designation of Caldicott Guardians at the most senior level in the Department of Health, the NHS and NHS Connecting for Health. The confirmation that the Department of Health is the Data Controller for the Summary Care Record was also welcome as we have received letters seeking clarification on this subject from patients and the public.

(cont.)

NIGB

National Information Governance Board for Health and Social Care

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Patients, service users or members of the public, if they have any comments on this report or on our work in general, are welcome to contact us via our postal or our email address, both of which are shown above.

Before the end of this year the NIGB will combine with the Patient Information Advisory Group (PIAG) and become a statutory body. We welcome the members of PIAG who will continue to carry out their important role of supporting research and ensuring that its use of data is legal.

We have used the period before the NIGB becomes a statutory body to prepare for that role. Our work and our approach to it, reflect an ongoing process of development, both as a Board and as individuals.

I would like to express my thanks to all the members of the Board for their positive approach to a new and challenging set of responsibilities and also to our advisors who have supported us in this.

I hope that we will continue to be a constructive contributor to improvements in information governance in health and social care.

Yours sincerely



Harry Cayton
Chair

The National Information Governance Board for Health And Social Care (NIGB)

What is Information Governance?

The term Information Governance is used to describe the structures, policies and practices which are used to ensure the confidentiality and security of the records of patients and service users. Correctly developed and implemented it enables the appropriate and ethical use of information for the benefit of individuals and the public good.

About The National Information Governance Board For Health And Social Care

Why is there a National Information Governance Board for Health and Social Care?

A review of Information Governance in the Department of Health and the wider NHS (available at <http://www.connectingforhealth.nhs.uk/nigb/papers/igreview.pdf>) carried out in 2005 commented on the absence of a single coordinating body which, in the case of disagreements about interpretation of best practice or in the pursuit of advice, could be a single authoritative source of advice or arbitration. The review recommended that a National Information Governance Board covering both Health and Social Care should be established and this recommendation was accepted by Ministers.

What the NIGB is in place to do

Overall the role of the NIGB is to support improvements to information governance practice in health and social care. Its full terms of reference are to:

- Provide leadership and promote consistent standards for information governance across health and social care, to enable ethical, legal and policy issues to be appropriately dealt with;
- Monitor information governance trends and issues through analysis of annual information governance returns from all bodies using or holding NHS or social care information;
- Arbitrate on the interpretation and application of information governance policy and give advice;
- Have oversight of and advise on the confidentiality management and access control frameworks implemented through the National Programme for IT;
- Own and review the NHS Care Record Guarantee for England annually;
- Advise the Secretary of State on any matters of information governance that should be brought to their attention and to produce an annual report to the Secretary of State;
- Deal with other such matters as required by the Secretary of State and other appropriate bodies; and
- Work with appropriate bodies, including those in the home countries, on issues within its remit.

Why include both Health and Adult Social Care?

The boundaries between health and social care are blurring, especially from the perspective of service users, and this means that information often has to be shared between these two services. Patients and service users expect the rules that govern how their information is used and shared to be the same in both health and social care but historically this has not been the case.

Whilst the remit of the NIGB covers all health information it only covers adult social care information. Responsibility for children's social care policy, and consequently the governance of children's social care information, rests with the Department for Children, Schools and Families (DCSF). The NIGB has a good working relationship with the DCSF and they are represented on our Board.

How does the NIGB fulfil its remit?

- **Leadership** - Stakeholder organisations represented at the NIGB (page 20) includes both health and social care organisations and with and through these the NIGB provides leadership and promotes consistent standards for information governance across both health and social care.
- **Giving patients and the public a voice** – Half of the members of the NIGB are members of the public, appointed by the independent Appointments Commission after a public recruitment campaign. The public members ensure that the perspective of patients and the public is taken into account when the board discusses or provides advice or guidance on governance matters.
- **Advice to care professionals** - The NIGB provides advice on the interpretation of policies, guidelines and legislation relating to information governance. There are many policies, procedures, legislation and professional guidelines which relate to the use and sharing of service user information. Whilst the general principles are consistent there can be differences in the detail which can make it difficult for those providing care to be sure that they are acting appropriately. NHS and social care organisations have individuals, called Caldicott Guardians¹, in place to support staff in ensuring that information is handled appropriately and most will also have information governance boards or committees. The NIGB provides a forum where these people can seek guidance on the interpretation of legislation, policies and guidelines in situations where they feel unable to decide on the correct action.
- **Advice to service users and the public** - The NIGB owns and reviews the NHS Care Record Guarantee for England (available at http://www.connectingforhealth.nhs.uk/nigb/crsguarantee/crs_guarantee.pdf).

¹A Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing. The Guardian plays a key role in ensuring that the NHS, Councils with Social Services responsibilities and partner organisations satisfy the highest practicable standards for handling patient identifiable information.

The Guarantee was first published in 2005 and sets out for patients how their information should be used so that their rights are protected and their health and wellbeing promoted. An equivalent guarantee for social care records is being launched and the NIGB will also own this.

Not complying with the Care Record Guarantee could be used as the basis of a complaint and how patients can complain about the use of their information is explained in the Guarantee.

A number of patients and members of the public write to the NIGB seeking advice. Wherever we can, we provide them with advice, but the NIGB is not able to investigate individual patient's complaints.

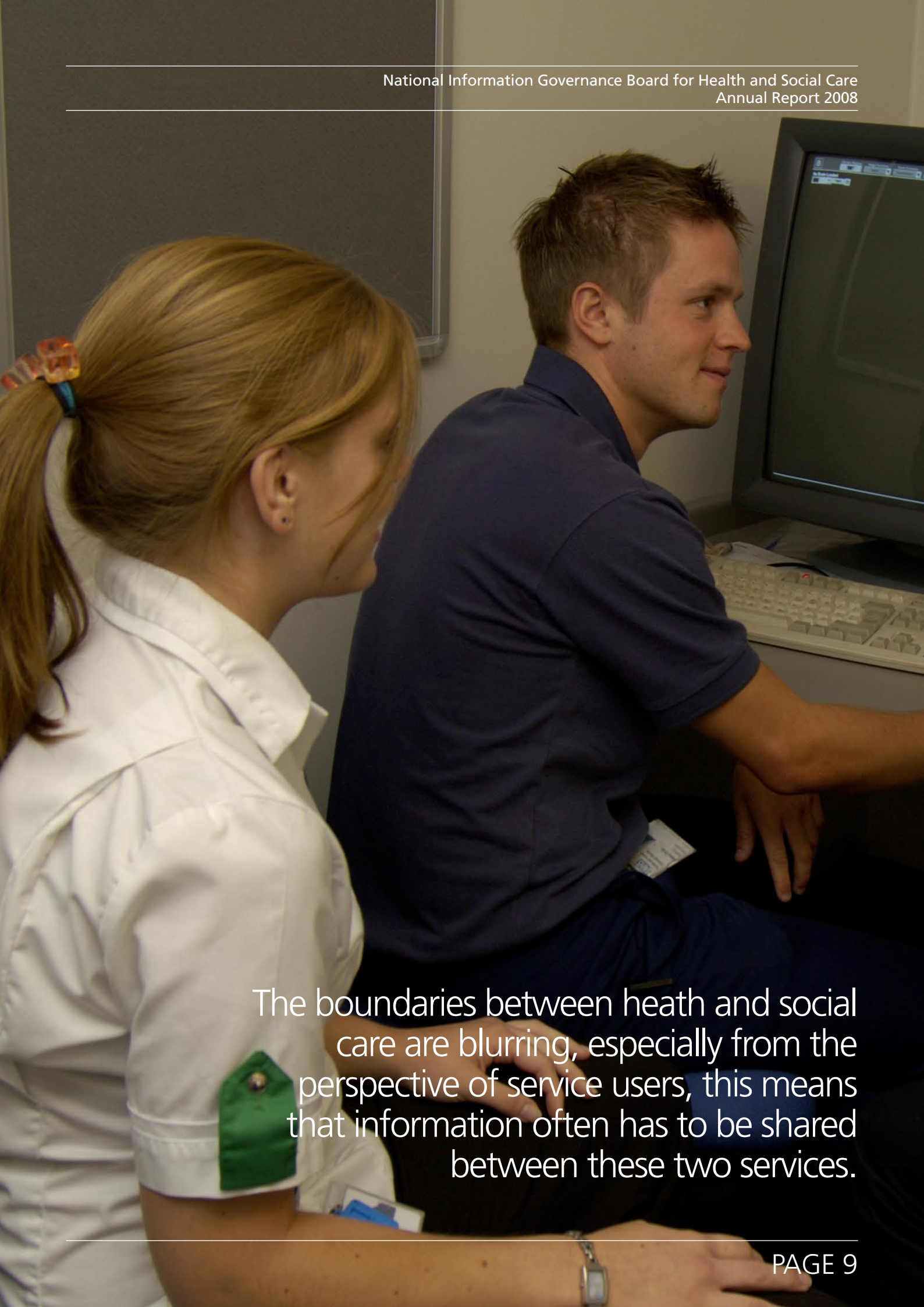
- **Monitoring and oversight**

- NHS organisations are required to assess their information governance performance annually using the Information Governance Toolkit (available at <https://www.igt.connectingforhealth.nhs.uk/>). The NIGB oversees the content of the toolkit and uses the annual returns to monitor information governance trends and issues in the NHS, social care and the independent sector. The NIGB is supporting work to increase the use of the toolkit within social care.

- New IT systems are being implemented in all NHS organisations in England as part of the National Programme for IT. The NIGB maintains an oversight and provides advice on the confidentiality management and access control frameworks which the National Programme for IT uses.

- **Links with other countries** - The devolution of government has led to differences in the way that healthcare and social care are delivered across the UK. The NIGB works closely with similar boards in Wales and Scotland.

The Board has agreed a set of principles that it will use to promote a consistent approach to its decision making and the provision of advice and guidance. These are shown in Annexe 1 and are also available on our website at <http://www.connectingforhealth.nhs.uk/nigb/principles/NIGB-principles.pdf>



The boundaries between health and social care are blurring, especially from the perspective of service users, this means that information often has to be shared between these two services.

Chair's Report

As information technology becomes an integral part of everyday life information governance is becoming a 21st century challenge. Whether it be health records, the internet, the threat of terrorism, identity theft or surveillance, the power of information technology to cross boundaries and to empower both citizens and States, creates benefits and risks. Society's development of the ethics of information and communications technology still lags behind the opportunities that technology is creating. The aim of the NIGB is that ethics and values get at least alongside and perhaps ahead of the pace of technological change in the NHS and social care.

Whilst it is inevitable that the use of information technology in record keeping is a key focus for us, we remain acutely aware that millions of paper records still play an integral part in the delivery of health and social care, and bring with them their own inherent information governance challenges.

The loss of the records of 25 million individuals by HM Revenue and Customs attracted widespread media attention and condemnation. We have all benefited from the spotlight that it shone on information governance practices, and the resulting activity to ensure that information governance practices are fit for purpose.

When the loss was announced the NIGB was briefed by the Department of Health and NHS Connecting for Health on the security applied to electronic health records. Whilst no system is perfect it appeared to us to be at least fit for purpose. We take the view that no system can have zero risk of loss of data and that security has to be balanced with the risk of harm to patients due to either the difficulty of accessing records or restrictions in working practices; it is a matter of balancing risks and benefits. We recognise too that it is human error, negligence or dishonesty, and not information management systems, which primarily put confidentiality at risk.

Identifying the quality of information governance around adult social care records was more difficult. This of course is not to say that social care records are held any less securely than health records or that social care put any less effort into assuring its information governance. We simply did not have data to support a view. In contrast to the NHS where there is a Chief Executive and a management structure down to local NHS organisations to support this, there is no equivalent in social care. In local authorities the responsibility stops with their Council and Head of Paid Service, who are often supported by Caldicott Guardians and Information Governance Managers.

Whilst use of the Information Governance Toolkit to assess performance annually is mandatory in the NHS, this is not the case in social care. Uptake in social care so far is not as high as it might be and there are several reasons why this might be the case. As a statutory body the NIGB will have a responsibility to assure itself that both health and social care organisations assess their information governance practices regularly and we will be working with colleagues in social care to identify the best way the Board can obtain assurances for social care.

We were reassured that the Department of Health (DH) established an Information Governance Assurance Programme. The NIGB was an observer, along with the Information Commissioner's Office and the Healthcare Commission, at meetings of the Programme Board. The purpose of the programme was firstly to provide assurances regarding the current processing of person identifiable information, and secondly to produce an Information Governance Assurance Framework applicable to the DH and its Arms Length Bodies (ALBs), the NHS and associated organisations. The framework allows these organisations to continue to assure that sensitive person identifiable information is managed securely and confidentially. The owner of the framework is the Chief Information Officer for Health, and a recommendation from the Assurance Programme is that the NIGB should independently assure the effectiveness of the framework. We have accepted this recommendation and will do this work annually.

Whilst some data losses did come to light in the NHS as in-depth reviews were carried out, all examples of data loss which have come to our attention were the result of human error. We believe the lesson from this is that whilst we can, and should, develop information governance systems and procedures and create a high level of security, nevertheless human error or intent will always create a risk. Data management systems, whether paper or electronic, can assist good practice but not replace it and should ideally be enforced by appropriate training. The NIGB aims to focus on the challenges of addressing these issues in the coming year.

The Cabinet Office also reviewed data handling procedures across government following the loss of data by HM Revenue and Customs and produced a report (available at http://www.cabinetoffice.gov.uk/reports/data_handling.aspx) in July 2008. The report made several recommendations for both central government and public facing organisations such as the NHS, and the NIGB reviewed how the NHS would respond to these recommendations.

One Cabinet Office recommendation requires all government departments to issue an Information Charter, explaining the standards that people can expect when a government organisation requests or holds their personal information and how they can get access to the information held. This is the equivalent of the NHS Care Record Guarantee for England which the NHS has had in place since 2005 when it was created by the Care Record Development Board and launched by Department of Health Ministers. Following the closure of the Care Record Development Board in 2007 the NIGB now owns this Guarantee and has responsibility for reviewing it annually. We uphold the Guarantee by promoting the balance between public and personal good and by ensuring that it remains focused on the interests of patients and the public.

Another major development over the past 12 months was the review of data sharing which was requested by the Prime Minister. This was carried out by the Information Commissioner, Richard Thomas, and Dr Mark Walport, Director of the Wellcome Trust, and reported in July 2008 (available at <http://www.justice.gov.uk/reviews/datasharing-intro.htm>).

The NIGB welcomes the report of the Data Sharing Review and is supportive of its aims. We are particularly pleased to see that one of its recommendations (recommendation 2) that organisations should review their information governance arrangements annually, is closely linked to the remit of the statutory NIGB, which was drafted in 2007.

The report of the Data Sharing Review makes reference to increasing the resources and powers of the Information Commissioner, which we also support. The NIGB, like the Care Record Development Board before it, supported the Information Commissioner in seeking increased penalties, including a prison sentence, for inappropriate use of information. Whilst we are pleased that the penalties have been increased we regret the suspension of the clause to introduce a prison sentence.

The Data Sharing Review also considers data sharing for medical research and contains a strong recommendation that the NHS should educate the public about how their health information might be used in the future. We recognise the benefits that good medical research can bring and agree that it should be easy for patients to participate should they wish to do so. We expect to be consulted by the Department of Health about how it plans to undertake the public education that the Data Sharing Review recommends.

There are tensions in the current system of access to information for research but there are also several initiatives underway aimed to address these. The Department of Health has established a Research Capability Programme to support the ambition to make the UK the preferred place to carry out medical research. The Programme will provide a common information infrastructure of a range of technical resources and data sets, under strict protocols of information governance, to aid the research community to conduct research of the highest methodological standard. NHS Connecting for Health continues to move forward with its Secondary Uses Service, and the Information Centre for Health and Social Care is working with both organisations on the implementation of Honest Brokers² and Safe Havens³. The NIGB is maintaining an oversight of these pieces of work.

During the year we sought clarification from the Department of Health over who their Caldicott Guardian was and we were pleased to see that they have confirmed that it is a senior clinician in the Department who reports directly to the Chief Medical Officer.

²*An Honest Broker is an organisation who has the responsibility to implement systems of access to patient information, for research or other secondary uses, and to ensure such information is either anonymised or pseudonymised.*

³*A Safe Haven is a designated physical or electronic area that provides the most appropriate level of security for the use of the most sensitive and confidential information.*

Members of the public have written to us asking for help in establishing who the Data Controller for the Summary Care Record is. The Summary Care Record is being implemented by NHS Connecting for Health as part of the National Programme for IT in the NHS. The Data Controller is the person who decides how information is processed and it is a requirement under the Data Protection Act that organisations processing personal data do identify a Data Controller. The situation around the Summary Care Record is complicated and we welcome the confirmation that the Department of Health is Data Controller for the Summary Care Record and hope that they will further refine this by indicating a named contact.

We were pleased to see that the draft *NHS Constitution* issued for consultation by the Department of Health contains a commitment to confidentiality and also to patients' access to their medical records. However, we were very concerned to see that the Handbook on the Draft Constitution contains a proposal to allow health professionals or research professionals to use care records, without the informed consent of the patient, to identify patients who are suitable to participate in approved clinical trials. We believe that this is a breach of good practice in confidentiality and consent and have questioned if there is a sound legal basis for it. We have informed the team running the consultation process of our concerns and requested that this proposal should be removed. We have also written to the Secretary of State for Health. In both cases we have emphasised our acceptance of the importance of good clinical and epidemiological research in improving healthcare delivery and outcomes for the population as a whole and also the benefits that participation in clinical trials and research may bring to the individuals involved personally. We have also been clear that we appreciate the challenges and issues that the current system of inviting patients to participate in research brings. We believe strongly that this proposal should not be included in the Constitution but are equally strongly committed to working to find a legal solution to improving patients' timely access to research.

Later in this report you will find a summary of the work that we have carried out since we were established in 2007. We have worked to promote trust and public confidence and to increase transparency about how people's information is recorded, held and used. Our decisions and advice are based on the NHS Care Record Guarantee for England, which is a fundamental statement of the principles involved in using patient information. A Social Care Record Guarantee is also being launched. A set of principles which we drew up to provide governance around our advice and decision making is at Annexe 1.

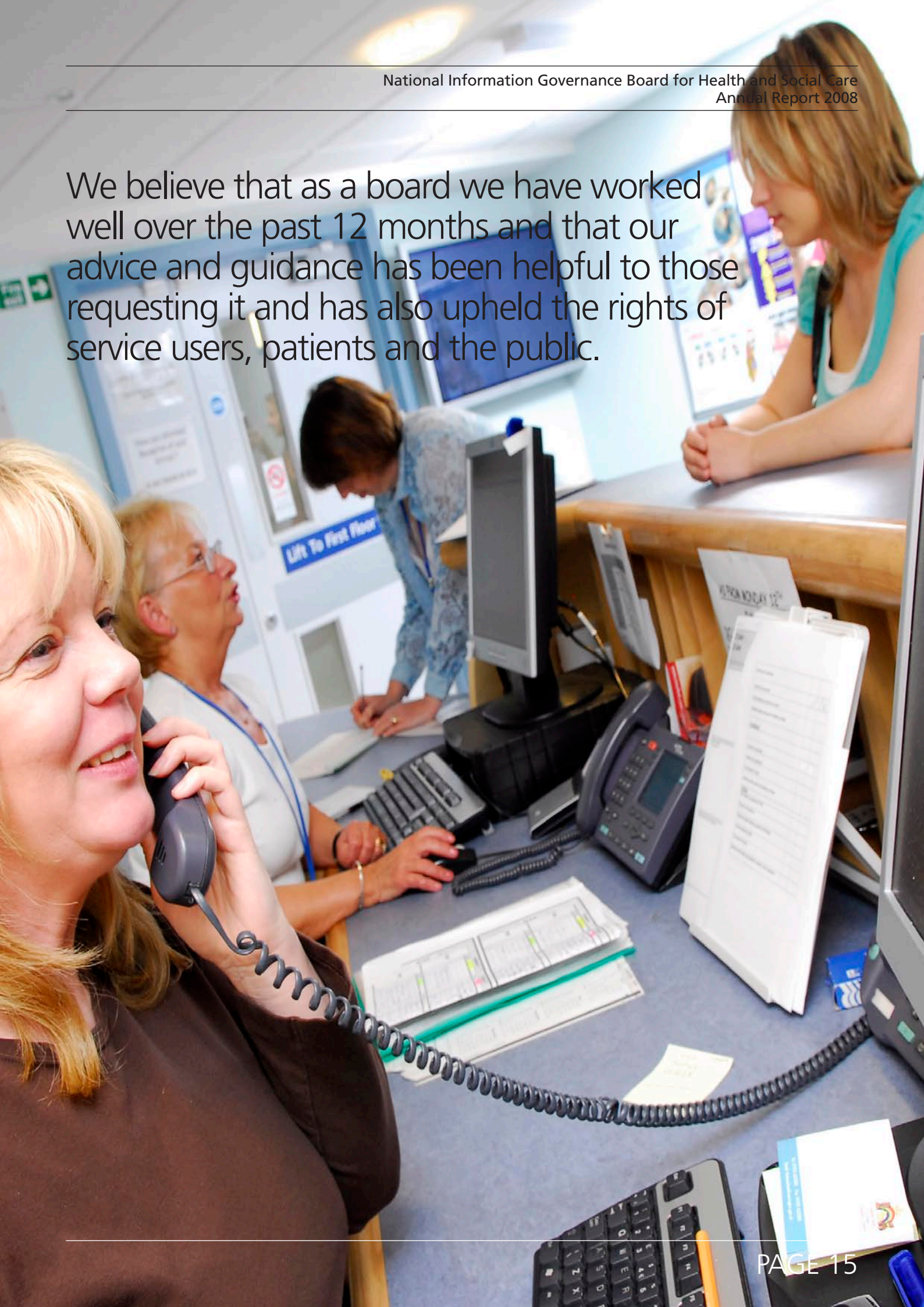
Also to assist our decision making and advice we held a half day workshop to allow our public members to meet with organisations representing patients and service users. They gave us an insight into the practical benefits of sharing information and the problems caused when information is either shared inappropriately or not at all. This was a very successful exercise and we intend to repeat it at least annually.

We believe that as a board we have worked well over the past 12 months and that our advice and guidance has been helpful to those requesting it and has also upheld the rights of service users, patients and the public.

We look forward to the challenges the next 12 months will bring, establishing ourselves as the statutory body for information governance in health and social care and using our statutory powers to promote improvements in information governance. As a statutory body we are joined by colleagues from the Patient Information Advisory Group (PIAG) who have agreed to join the committee of the NIGB which will administer our responsibilities under section 251 of the NHS Act 2006, the Ethics and Confidentiality Committee. These responsibilities relate to the use of identifiable patient information in specific circumstances without the consent of the patient, and they will pass to the NIGB on 1 January 2009.

The closure of PIAG is neither a reflection on its chair and members or the way it carried out its responsibilities. The original intention was that PIAG should migrate to become the NIGB, but government solicitors advised that the most effective way to establish the Board was to set up a new body and then transfer PIAG functions to the new body and this advice was accepted. We are grateful to the Chair and members of PIAG for their support.

We believe that as a board we have worked well over the past 12 months and that our advice and guidance has been helpful to those requesting it and has also upheld the rights of service users, patients and the public.



Our work in 2007/08

The NIGB first met on 24th October 2007 and meets every 2 months. At the six meetings we have held before this report went to press we have:

Provided advice and guidance on:

- Children's Summary Care Records;
- Access by locum staff to systems delivered as part of the National Programme for IT in the NHS; and
- The criteria and characteristics of "Honest Brokers"⁴ and "Safe Havens"⁵.

Approved:

- The Social Care Record Guarantee;
- Changes in the Information Governance Toolkit to reflect data handling guidance from the Cabinet Office; and
- The proposed NHS response to the final report of the Cabinet Office Data Handling Review.

Supported:

- The recommendations of an independent review of the Secondary Uses Service; and
- The development of guidelines for patients having access to their electronic care records following a presentation from General Practitioners Dr Amir Hannan and Dr Brian Fisher.

⁴An Honest Broker is an organisation who has the responsibility to implement systems of access to patient information, for research or other secondary uses, and to ensure such information is either anonymised or pseudonymised.

⁵A Safe Haven is a designated physical or electronic area that provides the most appropriate level of security for the use of the most sensitive and confidential information.

Considered:

- Information Governance issues around children and their transition to adulthood;
- The security of NHS data in light of the HM Revenue and Customs data loss;
- The resolution of disputes over the content of clinical records; and
- The NHS Connecting for Health statement of compliance and the results of the 2007-2008 Information Governance Toolkit.

Outside meetings we have:

- Provided evidence to the Data Sharing Review by Richard Thomas, the Information Commissioner, and Dr Mark Walport, the Director of the Wellcome Trust. The NIGB Chair attended a workshop to help refine the findings of the review;
- Provided evidence to the General Medical Council on the review of their guidelines on confidentiality;
- Provided evidence to the General Medical Council consultation on consent for Research;
- Participated in the British Computer Society seminar "Building Trust in eGovernment";
- Participated in the Programme Board of the Department of Health/NHS Information Governance Assurance Programme which was established in light of the data losses at HM Revenue and Customs;
- Dealt with enquiries and requests for advice from both health and social care organisations and from patients, service users and the public;
- Participated in the exploratory workshops to confirm the direction of a review of Informatics carried out by the Department of Health;
- Provided evidence to the Violent Patient Indicator Consultation by the Counter Fraud and Security Management Service of the NHS Business Services Authority;
- Provided evidence to the consultation by the Ministry of Justice into the Information Commissioner's inspection powers and funding arrangements under the Data Protection Act;
- Reviewed the Royal College of Physicians clinicians guide to record standards; and
- Participated in the consultation on the draft NHS Constitution.

The NIGB Members

The NIGB was established to give assurance to service users and the public that their information is being shared and used appropriately. To emphasise this commitment to the public, half of the members of the NIGB who attend board meetings are members of the public who have responded to a public recruitment campaign and been appointed by the Appointments Commission. The remaining members represent organisations which are stakeholders in information governance and have been invited to be represented on the board.

Chair



Harry Cayton

Harry Cayton OBE was appointed chief executive of the Council for Healthcare Regulatory Excellence (CHRE) in August 2007. He was formerly National Director for Patients & the Public at the Department of Health. From 1992 to 2003 he was chief executive of the Alzheimer's Society and from 1981-1992 Director of the National Deaf Children's Society. Harry was chair of the Care Record Development Board from 2004 until it closed in summer 2007 and also chaired a Ministerial Taskforce on the Summary Care Record in 2006. Harry is an advisor to both Macmillan Cancer Support and The Health Foundation and is a trustee of both Comic Relief and the Friends of Alzheimer's Disease International.

Public Members



Edward Briffa

Edward Briffa is Head of Learning at BMJ Publishing and has a background in online medical education, online broadcasting and TV production. This included working for the BBC for many years, as a science editor, award winning TV producer and he also led the launch of BBC Online and Interactive services.



Rodney Brooke

Sir Rodney Brooke CBE DL was Chair of the General Social Care Council until 31st October 2008. Rodney is a solicitor, a trustee of the Dolphin Square Charitable Foundation, the RNID, the Internet Watch Foundation and the Tavistock Institute. He has been Chief Executive of West Yorkshire County Council, Westminster and the Association of Metropolitan Authorities and Chair of the Bradford Health Authority.



Della Cannings

Della M Cannings QPM FRSA BSc MloD, was born in Exeter, Devon and is a graduate in Mathematical Studies from the University of Bath. Ms Cannings was Chief Constable of North Yorkshire Police 2002 – 2007. She currently undertakes consultancy work and is a trained assessor, and is also a keen gardener, traveller and photographer.



Wayne Cleghorn

Wayne Cleghorn, L.LM, is a Senior Legal Officer with South Gloucestershire Council. He specialises in data protection, information law and aspects of intellectual property law. He also has a professional interest in public law and human rights. He began his career as a barrister but more recently became a qualified solicitor and his experience includes public and private sector legal services.



Ian Hayes

Ian Hayes is 50 years old and lives in rural Somerset. He was born with Haemophilia and was infected with HIV and Hepatitis more than 20 years ago as a result of treatment failure. Ian was a senior NHS finance manager until 1996. He now has a range of interests centering on patient empowerment, self-management and patient safety. He is a trustee of the Terrence Higgins Trust.



Penny Hill

Penny Hill is the Information Strategy Manager for Social Care in Warwickshire, overseeing a range of Information Services that support work with both adults and children. She has a wealth of experience in Information Governance and Information Management for Social Care, including work on Information Sharing. Prior to her joining the NIGB she was a member of the Care Record Development Board.



Nadeem Khan

Dr Nadeem Khan is the programme lead for retinal screening services at Sutton and Merton PCT and a consultant with the National Screening Committee (NSC). He has previously worked in the acute sector, academia and led collaborative projects with neuropathology centres as part of Brain Net Europe. Nadeem also lectures in neurosciences at London University and has main research interests in adult-onset dementias. He is a member of the NSC Project Advisory Group (diabetic retinopathy) and a charity trustee.



Hilary Newiss

Hilary Newiss qualified as a solicitor and was a Partner in Denton Hall until 1999 specialising in intellectual property, including confidential information and data protection. She is a former member of the Human Genetics Commission, the Royal Society Working Party Report on Intellectual Property (“Open Science”), the Intellectual Property Advisory Committee and the Ethics and Governance Council of Biobank UK. She is currently inter alia Member of the Governing Body of the Roslin Institute.



Sylvia Rothschild

Rabbi Sylvia Rothschild took a degree in psychology at Manchester University and worked for a mental health charity in a therapeutic community, and for a London Borough in adult psychiatric care. She was ordained as a Rabbi in 1987 by the Leo Baeck College and has worked as a community Rabbi ever since. Rabbi Rothschild has continued her interest in medical and community ethics, sitting on a Research Ethics Committee and a local standards committee. She was Chair of the Assembly of Rabbis, and has edited and contributed to books and periodicals on subjects ranging from theology to prayer to ethical matters.



Michael Wilks

Dr Michael Wilks is a Senior Forensic Medical Examiner with the Metropolitan Police. He worked as a GP in London between 1977 and 1992. He chaired the BMA’s Medical Ethics Committee from 1997 to 2006, and its Representative Body from 2004 to 2007. He is currently President of the Standing Committee of European Doctors (CPME). He is Chairman of the Trustees of the Rehabilitation of Addicted Prisoners Trust (RAPt), a leading provider of addiction treatment in UK prisons.

Members representing Organisations

Members representing organisations either attend Board meetings or are corresponding members and provide written input to the Board having reviewed the papers.



Allied Health Professions Federation - Gareth Beatty

Gareth Beatty qualified as a Podiatrist in 1984 and has worked for the NHS ever since, in a range of posts from domestic porter and nursing auxiliary to his current role as the Clinical Transformation, Benefits and Information Governance Lead at Richmond and Twickenham PCT. His first professional post was at Guy’s Hospital before moving to Richmond and Twickenham. He has been the accredited staff-side representative for The Society of Chiropodists & Podiatrists, and is the chair for the Partnership Forum for Industrial Relations.



The NHS Confederation - Frances Blunden

Frances Blunden is senior policy manager at the NHS Confederation working on informatics, regulation, quality, safety, and patient and public engagement. Frances has extensive experience of research, policy and campaigning on key consumer and health issues across a range of Government and the voluntary sector organisations as well as a lay member of the Council for Professions Supplementary to Medicine. Prior to this she was principal policy adviser at Which? and was also the first Chief Executive of POPAN (now called Witness against abuse by health and care workers).



The British Medical Association - Tony Calland

Dr Tony Calland is a general practitioner working on the Welsh border for the past 34 years. He has been a non executive director of Gwent Health Authority and also Chairman of three major BMA committees including currently the Medical Ethics committee and the Welsh Council. He was part of the BMA GP team which negotiated the new GP contract in 2003. He has an interest in information governance and is involved in these matters in England and in Wales



The Medical Protection Society - Nick Clements (Corresponding)

Dr Nick Clements has worked in the NHS for 10 years, first as a GP and then as a full time medical adviser to the Benefits Agency. Nick joined the Medical Protection Society as a Medicolegal Adviser in 1996, providing medicolegal advice and representation to the doctors from the Leeds office of MPS. He completed an LLB in 1998 and was granted Fellowship of the Faculty of Forensic and Legal Medicine of the Royal College of Physicians in 2008. Nick currently works as the Head of Medical Services (Leeds).



The Academy of Medical Sciences - Carol Dezateux

Professor Carol Dezateux is a paediatrician and currently clinical professor of paediatric epidemiology and Director of the Medical Research Council (MRC) Centre of Epidemiology for Child Health at the UCL Institute of Child Health, London. She is an honorary consultant at Great Ormond Street Hospital for Sick Children NHS Trust and co-director of the UK Newborn Screening Programme Centre. In 2006 she was elected Fellow of the Academy of Medical Sciences.



Strategic Health Authority Chief Information Officers Council - Graham Folmer (Corresponding)

Graham started his career in IM&T at the Queen's Medical Centre in Nottingham working for Trent RHA. He has a degree in Computer Studies and an MBA from Warwick University. He worked in the private sector for eight years before returning to the NHS. He was Director of Information and Performance Management at Addenbrookes Hospital, then Director of Programme and Service Delivery at the NHS Information Authority. Graham is now Chief Information Officer at East of England Strategic Health Authority (SHA), previously having this role for Norfolk, Suffolk and Cambridgeshire SHA.



The Royal College of Nursing - Liz Fradd

Elizabeth is an independent health service adviser. Until April 2004 she was the Nurse Director and lead Director for the Review and Inspection programme in the Commission for Health Improvement (CHI). Prior to this appointment she was Assistant Chief Nurse in the Department of Health. Her current portfolio of work includes commissioned independent reviews, the delivery of innovative development programmes and the mentoring of senior personnel.



Patient Information Advisory Group - Joan Higgins (Ex-officio member)

Professor Dame Joan Higgins has held the positions of Professor Emerita of Health Policy, University of Manchester and Professor of Social Policy at the University of Southampton. She has chaired the national Patient Information Advisory Group since it began. Joan has been a non executive director in the NHS for over 20 years and was Chair of the Christie NHS Trust from 2002 until 2007. Joan was appointed as Chair of the NHS Litigation Authority (NHSLA) in January 2007.



The UK Council of Caldicott Guardians - Stephen Hinde

Stephen is the Group Information Protection Manager & Caldicott Guardian for the BUPA Group. Stephen is Chairman of the UK Council of Caldicott Guardians, Chairman of the Data Protection Panel of the Association of British Insurers, Chairman of the Confidentiality Working Group of the Independent Healthcare Advisory Service, and Chairman of the Private Medical Insurance Companies Confidentiality Forum. He is ex-officio a member of the Financial Crime Committee of the Association of British Insurers. Stephen also represents Caldicott Guardians on the Scottish Information Governance Managed Knowledge Network Steering Group.



Department for Children, Schools and Families - Colin Hurd

Colin has responsibility for the information, systems and technology strategy for the education, skills, children's services system. He is senior sponsor for the system-wide Information Standards Board and Chief Information Officers' Council. Previously Colin specialised in national IT-enabled policy initiatives, notably transforming educational technology in English schools and developing an information management strategy. He has extensive experience of leading and managing the delivery of vocational and educational initiatives across the South East of England, and of working with delivery partners.



Ministry of Defence - Lionel Jarvis (Corresponding)

Surgeon Rear Admiral Lionel Jarvis is Assistant Chief of the Defence Staff (Health). He qualified in Medicine in 1977, thereafter joining the Royal Navy. He trained as a Radiologist, was accredited Consultant in 1990, appointed to RNH Haslar and promoted to Surgeon Commander. He was appointed Defence Consultant Adviser in Radiology 1995–2002 and was promoted to Surgeon Captain in 1999. He also served as an Executive Director of Portsmouth Hospitals NHS Trust. He was promoted to Surgeon Commodore in 2005, and was Director of Medical Policy in the Defence Medical Service Department in MOD. He was appointed Honorary Surgeon to Her Majesty the Queen in 2006.



The Association of Directors of Adult Social Services - David Johnstone

David Johnstone is Executive Director of Adult & Community Services in Devon and is a member of the Executive Council of the Association of Directors of Adult Social Services. He is extensively involved in the development of electronic care records in health and social care, as a board member of the National Programme for IT and co-chairperson of the Electronic Social Care Record Implementation Board. He has been recently appointed to the NHS Clinical Advisory Team.



The Local Government Association - Anne McDonald

Anne McDonald is the Programme Director for Community Well-being at the Local Government Association (LGA). The Community Well-being programme covers local authority activity to improve the well-being of adults, not only health and social care, but the wider determinants of health and well being. Facilitation of local partnerships between councils and the NHS is an important strand of the programme. Anne joined the LGA in 2007 from the Department of Health where she was programme head in the Social Care Directorate.



The General Medical Council - Jane O'Brien (Corresponding)

Jane joined the GMC in 1990, becoming head of the Standards & Ethics team in 1995, and Assistant Director in the Standards & Fitness to Practise Directorate in 2006. Jane is responsible for the development of GMC policy and guidance on standards of professional conduct and medical ethics and she has worked on a number of publications for the GMC. Other key areas of focus include professional standards on consent, confidentiality and withholding and withdrawing life-prolonging treatment.



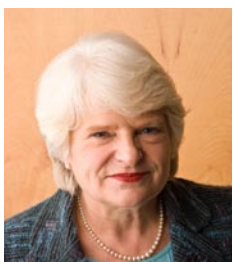
The Royal College of Midwives – Jeanne Roberts (Corresponding)

Jeanne qualified as a nurse in 1990 and as a midwife in 1993. Jeanne worked at University College London Hospitals where she was talent spotted by the Royal College of Midwives. She was seconded to the RCM in 2001 as a part time trade union officer/professional advisor while still working at UCLH. In early 2008, Jeanne joined the RCM full time as a team manager for the North of England.



The Medical Defence Union - Hugh Stewart (Corresponding)

Dr Hugh Stewart MBChB MRCGP LLB MPhil MFFLM DipLP is Head of Case Decisions at the MDU (Medical Defence Union). He previously worked as a principal General Practitioner, lecturer in Law and Medico-Legal Advisor.



The Independent Healthcare Advisory Services - Sally Taber

Sally Taber has worked in the independent sector for 20 years. She has been the Director of Nursing at the Independent London Bridge Hospital, and an advisor to the Royal College of Nursing. She originally qualified as a Registered General Nurse in London and is also a qualified midwife. After a period working abroad, she specialised in renal nursing and pioneered the role of transplant co-ordinator in the renal field. She became the Secretary of the European Dialysis and Transplant Nurses Association and is currently the Director of Independent Healthcare Advisory Services Ltd (IHAS).



The Information Standards Board for Health and Social Care (ISB) - Joan Trowell (Corresponding)

Dr Joan Trowell qualified in medicine in 1964, later becoming an academic physician and an honorary consultant physician. Her professional roles have included; Chair of the GMC Fitness to Practise Committee, Chairman of Trustees for the Royal Medical Benevolent Fund and Deputy Chairman of the Medical Council on Alcohol. Dr Trowell is currently the GMC representative on the ISB and she is particularly involved with information governance issues, in particular involving patients' consent to information sharing and role based access to personal medical data held in IT systems.



The Academy of Medical Royal Colleges - Jim Wardrope

Mr. Jim Wardrope FRCS, FCEM is an Emergency Medicine consultant at Sheffield Teaching Hospitals and is President of the College of Emergency Medicine. Previously he was editor of the Emergency Medicine Journal and Medical Director to South Yorkshire Ambulance Service. His main clinical interest is musculo-skeletal medicine. Main research interest is operational research in emergency care systems.

NHS Employers - Steven Weeks (Corresponding)

Steven Weeks is Policy Manager for NHS Employers covering workforce issues. NHS Employers represents trusts in England on workforce issues and helps employers to ensure the NHS is a place where people want to work. NHS Employers is part of the NHS Confederation. Steven has been employed by NHS Employers since 2005 and prior to this worked for the healthcare union UNISON and the Audit Commission healthcare unit.

Foundation Trust Network - Chris Fokke (Corresponding)

Chris is Director of Clinical Practice & Nursing at the Royal National Hospital for Rheumatic Diseases, Bath.

Annexe 1

Principles of the National Information Governance Board in decision making and the preparation of advice and guidance

1. Principles

- 1.1 The purpose of this Annexe is to set out the principles that the National Information Governance Board will use to promote a consistent approach to decision making and the provision of advice and guidance. The following principles provide a framework:
- a. People have personal interests and responsibilities as patients, users of services, service providers and also as citizens.
 - b. Within health and social care services:
 - The interests of patients and service users come first;
 - Informed consent and personal autonomy should underpin the provision of health and social care; and
 - The right information should be available to the right people at the right time to provide individual care whilst preserving confidentiality.
 - c. It is in people's interests to have:
 - Appropriate and accessible care, which promotes health, social welfare and public safety;
 - A sound research base on which to build and improve effective services; and
 - Well managed and cost effective services.
 - d. Professionals work within a legal framework and professional guidance.
- 1.2 These principles will sometimes be in tension with each other. In seeking to resolve those tensions it should be noted that:
- a. Allowing service users appropriate control over and access to their own information, and its use, is central to the role of the NIGB;
 - b. Trust and public confidence in health and social care services should be earned and not assumed;
 - c. Patients and service users have a right to confidentiality;
 - d. People's information should be stored and shared in a secure manner;
 - e. Those providing care must comply with legislation and their professional guidelines;
 - f. An appropriate balance between individual and public interests must be maintained. In accordance with the Human Rights Act 1998, public interests should only prevail over individual interests when it is necessary that they should do so in order to achieve a legitimate aim in a proportionate manner;
 - g. Where decisions are made concerning the balance of individual and professional or public interests, those making those decisions should be accountable and, except where personal details are involved, the basis for such judgements should be made public.

2. Compliance

- 2.1 Information Governance in the NHS and social care must ensure compliance with legal requirements and NHS standards as provided within the NHS Confidentiality Code of Practice. This encompasses, in particular:
- a. The Data Protection Act 1998, including the requirements for personal data to be accurate and up to date, 'kept secure, adequate, relevant and not excessive' and only used for the purpose for which it is collected in accordance with the fair processing code;
 - b. The Human Rights Act 1998, especially article 8 of the European Convention on Human Rights (respect for private and family life);
 - c. The Common Law in relation to confidentiality;
 - d. The NHS Care Record Guarantee for England; and
 - e. The Caldicott Principles (justify the purpose, use on a need-to-know basis, use minimum necessary patient identifiable information).

3. Objectives

- 3.1 The promotion of health and well-being, and the prevention of harm, are essential components of effective health and social care services.
- 3.2 In accordance with these principles, the National Information Governance Board should have the following objectives for the decisions it takes and the advice and guidance that it provides. That they:
- a. Are practicable and clearly expressed;
 - b. Benefit everyone fairly;
 - c. Promote trust and public confidence;
 - d. Increase transparency about how people's information is recorded, held and used;
 - e. Support choice and control for patients and service users;
 - f. Improve people's knowledge and understanding of the way in which their information is used within health and social care; and
 - g. Not only support the care provided to people but also the efficient delivery of health and social care services, including governance, public health, health promotion, epidemiology, education and research.

Annexe 2

The NIGB as a statutory body

During the period covered by this report the NIGB had no statutory powers, but the Health and Social Care Bill which received Royal Assent in July 2008 established it as a statutory advisory body reporting to the Secretary of State for Health.

When it was established in October 2007 the "interim" NIGB took over the functions of the Care Record Development Board, which then closed. On becoming a statutory body the NIGB will also take over the functions of the existing statutory body, the Patient Information Advisory Group (PIAG), which will then close. The majority of the members of PIAG have agreed to become members of the Ethics and Confidentiality Committee of the NIGB which will carry out the functions of the NIGB under section 251 of the NHS Act 2006.

The closure of PIAG is neither a reflection of its chair and members or the way it carried out its responsibilities. The original intention was that PIAG should "migrate" to become the NIGB, but government solicitors advised that the most effective way to establish the Board was to set up a new body and then transfer PIAG functions to the new body and this advice was accepted.

Becoming a statutory body does not change the key role of the NIGB in supporting improvements in information governance practice, but the legislation does give it powers to assist it in this.

In summary the statutory powers of the NIGB are:

- All information obtained or created as part of the delivery of NHS funded healthcare or adult social care services delivered by local authorities, including services provided under contract to the NHS and local authorities, comes under the remit of the NIGB. This is irrespective of whether the information identifies patients or is anonymised.
- The Board has the power to issue advice to any individual or organisation using this information irrespective of whether advice has been requested. NHS bodies and local authorities have a statutory responsibility to 'give regard' to advice from the NIGB and to respond if the NIGB seeks clarification on how its advice has been used.
- The Board also has a responsibility to assure itself that organisations have regularly reviewed their information governance practices and if they have determined that these are fit for purpose.

Full details of the NIGB legislation in the Health and Social Act 2008 are available at http://www.opsi.gov.uk/acts/acts2008/ukpga_20080014_en_13. The NIGB details are in clauses 157 – 158.

Annexe 3

How the NIGB is Governed

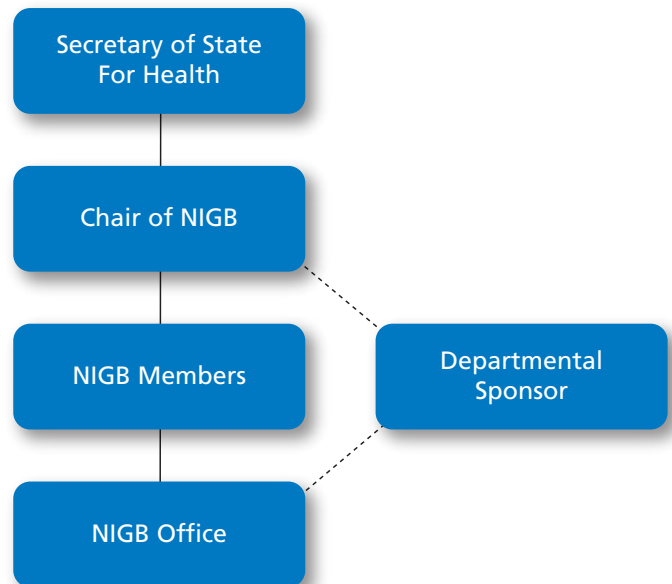
As a statutory body, the NIGB has an advisory role and reports to the Secretary of State for Health.

Both the Chair and the public members are appointed by the Appointments Commission on behalf of the Secretary of State for Health following a public recruitment campaign. The Chair is responsible for ensuring that the board operates in line with its terms of reference and for the advice that the Board gives. The Chair is appointed for a period of four years and public members are appointed for varying periods between two and four years.

The list of stakeholder organisations (page 20) invited to be represented on the board is agreed with Ministers.

Whilst the public are not admitted to NIGB meetings the board operates in a very open way. Within five working days of a board meeting a brief summary of the meeting is put on to the web site and when the minutes have been approved, normally at the next meeting, the minutes and the papers are put onto the web site. The board also holds an annual public meeting.

The day to day business of the NIGB is carried out by the NIGB Office which is also responsible for links between the NIGB and its Departmental Sponsor at the Department of Health. All Arms Length Bodies (ALBs) of the DH have a Departmental Sponsor, whose role it is to help maintain a good working relationship with the Department, ensuring the Board is aware of the departmental objectives and priorities.



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