PIAG
1-02/2003

PATIENT INFORMATION ADVISORY GROUP

Meeting on Thursday 5 December 2002

MINUTES

1. **Present**

Members: Professor Joan Higgins (Chair), Dr Michael Catchpole, Professor Sir Cyril Chantler, Dr Tricia Cresswell, Mrs Helen Darracott, Professor Andy Haines, Mr Michael Hake, Ms Barbara Meredith, Mrs Shahwar Sadeque, Ms Karen Thomson and Dr Michael Wilks.

In attendance: Dr Patrick Coyle, Professor Martin Severs, Mr Graham Pogson, Mr Phil Walker, Mr Alistair Donaldson, Ms Viki Lowther and Mr Sean Kirwan; Ms Caroline Arbon (for Agenda Item 5); Professor Sandy McCall-Smith and Mr Mark Bale (for Agenda Item 6).

2. **Apologies (Agenda Item 1)**

Apologies were received from: Professor Sir Denis Pereira Gray, Ms Julia Palca and Ms Helen Miller.

3. **Minutes of the last meeting (Agenda Item 2)**

3.1 The minutes of the previous meeting that had taken place on 9 September 2002 (PIAG 4-02/2002) were approved.

4. **Matters arising not covered elsewhere on the agenda (Agenda Item 3)**

4.1 Minute 6.5: The Advisory Group considered a note from Ms Sandra Kiauka [PIAG 4-03/2002], Audit Manager at Diabetes UK, that set out a number of changes made to the way Diabetes UK collected and processed patient information following advice given by the Advisory Group at its previous meeting. The action taken by Diabetes UK was approved by the Advisory Group, and it was agreed that an application to cover UKDIABS would not be necessary provided the progress in implementing the actions described in Ms Kiauka's note was maintained.

5. **NHS Information Authority Consultation on Confidentiality (Agenda Item 4)**

5.1 The Advisory Group considered several consultation documents issued by the NHSIA including, "Caring for Information – Model for the Future" [PIAG 4-04(b)/2002], "Confidentiality – A Code of Practice for NHS Staff" [PIAG 4-04(c)/2002], and a draft script for a public information video [PIAG 4-04(d)/2002].

5.2 It was noted that the deadline for submitting responses to the consultation was 31 January 2003. It was therefore agreed that members should forward comments to the Secretariat by mid-January so that a draft response could be circulated to other members for comment, and a final response could be submitted on the Advisory Group's behalf to meet the deadline.

ACTION: (i) Members to forward comments on the NHSIA consultation documents to the Secretariat by mid-January;
(ii) Secretariat to seek members' comments on draft response, and to submit final response to NHSIA by end of January.

6. **Communications Strategy on Patient Confidentiality (Agenda Item 5)**

6.1 The Advisory Group considered a paper that summarised the proposed aims and objectives of the Department of Health's communication strategy [PIAG 4-05/2002]. Ms Caroline Arbon, of the NHS Information Authority, presented the paper.

6.2 Ms Arbon reported that the NHSIA consultation on confidentiality would be followed by campaigns to increase transparency around the use of patient information, and to inform patients of their confidentiality rights.

6.3 The consultation on confidentiality was well underway: more than 2,000 consultation packs had been issued; the NHSIA had worked closely with patient groups and had organised a conference attended by patient representatives; ethnic minority groups would be consulted throughout January; qualitative research with specific interest groups was being undertaken and would be followed up with an 'omnibus' survey.

6.4 Members commented that it was important to ensure that patients participated in the consultation exercise. This would mean that it would be important to present documents in multi-media format (eg cassette tapes, radio advertisements, etc); and to take account of the advocacy and support needs of patients with learning difficulties. The Advisory Group agreed that it was difficult to engage with patients and members of the public unless they were able to discern a personal

interest in proposals; it was therefore necessary to ensure that materials were phrased so that patients could see proposals were in their interest.

6.5 The Advisory Group agreed that the proposals for a communications strategy were very good, and that the consultation exercise was being carried out in an effective manner. Ms Arbon was invited to address a future meeting of the Advisory Group when the final campaign messages for the communications strategy had been agreed.

ACTION: Ms Arbon to discuss final campaign messages for the confidentiality strategy with the Advisory Group.

7. Use of Genetic Information (Agenda Item 6)

7.1 The Advisory Group considered a presentation by Professor Sandy McCall-Smith, the Vice-Chair of the Human Genetic Commission, about the use of genetic information.

7.2 He reported that the HGC had been established in 1999. It was an advisory group, but had been given a broad brief. One of the first issues identified as a key concern by the Commission was the use of personal genetic information. Its consideration of this issue had led to the publication of the HGC report, "Inside Information".

7.3 The HGC recognised that it was difficult to set guidance about the use of personal genetic information. Researchers were treading a tightrope between personal rights and wider community interest.

7.4 The Commission supported the establishment of BioBank which would collect genetic information from individuals on a fully consented basis, and would be used to support clinical research. However, concern remained about police access to genetic databases – even though opinion data had shown that there was strong public support for forensic databases.

7.5 Members of the Advisory Group stated that they had already identified concerns about the disclosure of personal data about family members. Although the law did not prevent this from happening, it was recognised that there may be legal consequences. Professor McCall-Smith agreed that wherever possible this data should not be identifiable.

7.6 Professor McCall-Smith also agreed with the Advisory Group that any data containing DNA sequence information could be regarded as identifiable.

7.7 He reported to the Advisory Group that it was important to establish safeguards for members of the public in relation to the use of over the counter genetic tests. The HGC would be reporting to Ministers during Spring 2003 about the commercial use of genetic information.

Professor McCall-Smith added that the HGC would like to work closely with the PIAG in the future – particularly on consent issues.

8. **Applications for Section 60 Support (Agenda Item 7)**

(i) Application for the Ataxia-Telangiectasia Society and Cancer Research UK

8.1 The Advisory Group considered additional information that had been submitted in support of an application that had been considered at the previous meeting [PIAG 4-07(a)/2002].

8.2 The Advisory Group agreed that the applicant had provided evidence that data security was adequate. It was also acknowledged that the research project had been carried out within the boundaries agreed when ethical approval had been granted in 1998 and it would be impractical and insensitive for the research team to recontact the parents of AT patients in order to obtain contact details of wider family members. The application was therefore approved subject to the following conditions:

- That the study was now a closed cohort (ie new patients could not be added to the cohort)
- That the applicant should only hold information about those family members listed in the study's original L/MREC approval
- That the applicant develop a communications strategy for feeding (non-identifiable) information from the study back to AT patients and their families

8.3 The Advisory Group also made it clear that the application had been approved on the basis that it was already underway; it was unlikely that future studies carried out using similar methodology would receive Section 60 support.

ACTIONS: **(i) Secretariat to inform the applicant that the Advisory Group had approved his application for Section 60 support to collect identifiable information for a research study about the risks of cancer in heterozygous carriers of ATM mutations.**
(ii) Details of the application to be entered onto the register of activities carried out with Section 60 support.

(ii) Applications for the All Wales Children's Critical Care Audit and the Paediatric Intensive Care Audit Network (PICANet)

8.4 The Advisory Group considered additional information that had been submitted by the All Wales Children's Critical Care Audit [PIAG 4-07(b)/2002] and the Paediatric Intensive Care Network [PIAG 4-07(c)/2002] in support of applications that had been considered at the previous meeting.

8.5 It was agreed that both applicants had provided evidence that data security would be adequate. They had also provided evidence that they would be taking steps to move away from relying upon Section 60 support by developing procedures for obtaining informed consent.

8.6 The Advisory Group agreed that since the applicants would wish to conduct follow-up exercises in the future, obtaining parental consent to obtain identifiable data about children treated in intensive care units was appropriate. However, the applicants would also need to consider obtaining anonymised information about patients whose parents had refused consent.

8.7 The applications were therefore approved subject to the applicants meeting the following conditions:

- That they should display information about their work in all participating units;
- That they should provide a clear pathway – with milestones – towards using only the NHS number for linkage purposes;
- That they consider the longer term uses of the data they held, taking account of the possible effect of changes to variables such as geographical boundaries, and potential new uses of the data so that these issues were all properly accounted for in advance.

8.8 In addition, the Advisory Group welcomed the feasibility study to be carried out into obtaining consent by PICANet, and asked that both applicants should work closely on this.

ACTIONS: **(i) Secretariat to inform the applicants that the Advisory Group had approved their applications for Section 60 support to collect identifiable information so that paediatric intensive care services could be monitored.**
(ii) Details of the applications to be entered onto the register of activities carried out with Section 60 support.

(iv) <u>Applications for the NHS Wide Clearing Service (NWCS), the Health Episode Statistics (HES), the National Health Authority Information System (NHAIS) and the Patient Episode Database for Wales (PEDW) databases</u>

8.9 The Advisory Group considered applications for support under Section 60 of the Health and Social Care Act 2001 to obtain patient identifiable information without consent for the NHS Wide Clearing Service [PIAG 4-07(d)/2002], the Hospital Episode Statistics (HES) system [PIAG 4-07(e)/2002], the National Health Authority Information System [PIAG 4-07(f)/2002] and the Patient Episode Database for Wales [PIAG 4-07(g)/2002].

8.10 The applications set out a number of NHS activities carried out nationally and locally that required patient identifiable information to be processed. These activities included: commissioning of healthcare

services, public health purposes, provision of Hospital Episode Statistics (HES) data to the Department of Health, GP payments, call/recall for national screening programmes, performance management, management and planning of NHS services, measuring health outcomes, public and Parliamentary accountability.

8.11 The Advisory Group agreed that it was important that these activities should be allowed to continue and that it would be necessary to give them Section 60 support while they developed a mechanism for pseudonymising information. In the longer term, the Advisory Group hoped that information would be pseudonymised by the NHS organisations that had collected it from patients rather than by a "pseudonymisation service" provided by a third party.

8.12 With regard to extractions of data from these databases by third parties for ad hoc activities such as clinical research and audit, the Advisory Group agreed that for NWCS and HES the Security and Confidentiality Advisory Group (SCAG) should oversee the applications process. A Welsh equivalent of SCAG would need to be established to oversee ad hoc access to PEDW.

ACTION: Welsh Assembly to establish body to oversee access to PEDW.

8.13 The Advisory Group also recommended that further thought should be given to establishing controls on NHAIS. It was concerned that the 88 databases that made up NHAIS were not managed on a consistent basis, and believed that there should be some independent oversight of access to data held on NHAIS. Thought should be given to extending the role of SCAG in this area or to establishing a new body for this purpose.

8.14 In addition, the Advisory Group recommended that NHAIS should never hold clinical data about patients. It also asked for a definitive list to be drawn up describing all activities that received data from NHAIS.

ACTION: NHSIA to compile list of all activities/organisations using NHAIS data.

8.15 The PIAG Secretariat was asked to draft new Section 60 regulations covering national databases for consideration at the next meeting.

ACTION: Secretariat to prepare new regulations for consideration by the Advisory Group.

(v) <u>Application from the Office for National Statistics to allow patient records on the NHS Central Register to be flagged to support historic studies</u>

8.16 The Advisory Group considered an application that had been submitted by the Office for National Statistics to cover historic studies that had flagged patient records on the NHS Central Register so that they could

be notified of the date and cause of death of study participants [PIAG 4-07(h)/2002].

8.17 The application set out mechanisms for evaluating the ongoing validity and value to patients and the public of studies that would benefit from the application being approved. The Advisory Group agreed that these were appropriate and that the application should be approved.

8.18 The Advisory Group recommended that in addition ONS should be required to identify categories of activities using NHSCR so that the process of applying for Section 60 support could be streamlined. ONS should also establish a working group with independent representatives to review the use of NHSCR by new studies; approved studies should be reported to PIAG for inclusion on the register of activities carried out with Section 60 support.

ACTIONS: **(i) Secretariat to inform the applicant that the Advisory Group had approved their applications for Section 60 support to flag records on the NHS CR to support historic studies.**
(ii) Details of the application and studies supported by it to be entered onto the register of activities carried out with Section 60 support.
(iii) ONS to establish working Group to review use of NHSCR by new studies and to report approvals to PIAG.

(vi) Application from the Department of Health for support to establish a National Cancer Waiting Times System

8.19 The Advisory Group considered an application from the Department of Health for Section 60 support for a new database for monitoring the waiting times from diagnosis to treatment of cancer patients [PIAG 4-07(i)/2002].

8.20 Mr Walker advised the Group that the Secretariat had met with the applicant to discuss the proposal for a Cancer Waiting Times database. It had been acknowledged that this would be a very large database, managed from the centre, which would be used to measure progress in meeting targets set out in the National Cancer Plan.

8.21 The Advisory Group expressed concern that although patient identifiable information would not be held on the system, patient pathway information could, in some circumstances, be used to identify individuals. However, it recognised that the applicant had done as much as was possible, given the limits to technology currently available, to pseudonymise data and limit the chances of individual patients being identified.

8.22 Although the Advisory Group was content to approve the application, it expressed concern that its advice on the Cancer Waiting Times database had not been sought earlier so that concerns about

methodological and procedural flaws could have been discussed in more detail. It was agreed that the Chair should write to Sir John Pattison, the Department of Health's Director of Research, Analysis and Information , to request that PIAG should be involved in the design stage of similar developments in the future.

ACTIONS: **(i) Secretariat to inform the applicant that the Advisory Group had approved their applications for Section 60 support to collect identifiable information so that it could be pseudonymised for used on the Cancer Waiting Times database.**
(ii) Details of the applications to be entered onto the register of activities carried out with Section 60 support.
(iii) Chair to write to Sir John Pattison requesting that the Advisory Group's advice be sought at the design stage of similar projects in the future.

(vii) Application from Cancer Research UK to support colorectal cancer screening

8.23 The Advisory Group considered an application from Cancer Research UK for support under Section 60 to link patient identifiable information without consent to cancer registry and NHSCR data to support research into the effectiveness of flexible sigmoidoscopy screening for colorectal cancer [PIAG 4-07(j)/2002].

8.24 The application explained that the research had been underway since 1996 and that it would be impracticable to obtain consent because the study was a randomised control trial with 195,000 patients.

8.25 The Advisory Group approved the application.

ACTIONS: **(i) Secretariat to inform the applicant that the Advisory Group had approved their applications for Section 60 support to link data with cancer registries and the NHS CR.**
(ii) Details of the application to be entered onto the register of activities carried out with Section 60 support.

(viii) Application from UK Transplant to support flagging patient records on the NHS Central Register and other record linkage purposes

8.26 The Advisory Group considered an application from UK transplant for support under Section 60 to maintain a database of donors and patients awaiting, or having received, organ transplants [PIAG 4-07(k)/2002].

8.27 The applicant had argued that implied consent would be a sufficient basis for collecting and holding data for a range of purposes including matching donors and patients, audit, and linkage to NHSCR.

8.28 Although the Advisory Group agreed that UK Transplant would require Section 60 support for its national database, it was concerned that there were no plans to obtain informed consent from patients to process their data. The Advisory Group therefore requested additional information from UK Transplant on its plans for either obtaining informed consent from patients or using pseudonymised data in the future.

ACTION: Secretariat to obtain additional information from the applicant on plans for obtaining informed consent/using pseudonymised data.

(ix) Application from the University of Oxford to support flagging records in a cohort study to quantify the long term health effects of participation in chemical weapons research at Porton Down on the NHS Central Register

8.29 The Advisory Group considered an application from the University of Oxford for support under Section 60 to link identifiable data to the NHSCR and to contact people in order to obtain their consent to be included in a research study to quantify the long term health effects of chemical warfare experimentation at Porton Down [PIAG 4-07(l)/2002].

8.30 The application explained that it would be impracticable to obtain consent from the outset because there was a large cohort involved (40,000 patients) and it was expected that more than 50% of the cohort would be dead. The initial record linkage was therefore required to identify survivors.

8.31 The Advisory Group agreed that the application should be approved subject to the following conditions:

- That the applicant be required to develop an appropriate confidentiality policy to ensure that arrangements were in place to safeguard patient identifiable information;
- That staff who have access to patient identifiable information should have confidentiality clauses in their contracts of employment.

ACTIONS: (i) Secretariat to inform the applicant that the Advisory Group had approved their application subject to the conditions set out above.
(ii) Details of the application to be entered onto the register of activities carried out with Section 60 support.

(x) Application from Professor Alastair Compston to support flagging records of patients diagnosed with MS in the 1980s on the NHS Central Register

8.32 The Advisory Group considered an application from Professor Alastair Compston for support under Section 60 to link identifiable data to the

NHSCR for a research projects on patients diagnosed with MS in the 1980s [PIAG 4-07(m)/2002].

8.33 The Advisory Group agreed that following its approval of the application from ONS to support historic studies flagging NHSCR records, there was no longer any need to approve individual applications seeking approval for work in this area.

ACTION: Secretariat to advise Professor Compston that approval for flagging NHSCR records should be obtained through ONS.

(xi) Application from the National Blood Service for support for a study on the epidemiology of blood transfusion recipients

8.34 The Advisory Group considered an application from the National Blood Service for support under Section 60 to use patient identifiable information without consent for record linkage and audit [PIAG 4-07(n)/2002].

8.35 The application stated that it would not be practicable to obtain informed consent from patients because of the large size of the study (12,000 blood transfusion recipients) and the wide geographical spread of patients. There was also concern that the study might be biased by including only consenting patients.

8.36 The Advisory Group was concerned that the application did not explain why a range of patient identifiers, including full postcode, was required and asked that the applicant should explain why NHS number was not sufficient for linkage purposes. In addition, it was concerned that the data destruction policy described in the application was inadequate, and that the applicant was not doing enough to meet the fair processing requirements of the Data Protection Act by notifying patients about how their information was used. The Advisory Group therefore agreed that the applicant should be invited to submit additional information on these issues.

ACTION: Secretariat to seek additional information from the NBS to support its application.

(xii) Applications for support for the Trent and West Midlands Neonatal Registries

8.37 The Advisory Group considered 2 applications for support under Section 60 to process patient identifiable information for the Trent and West Midlands Neonatal Registries. Both applications claimed that it was insensitive to seek consent from parents to collect information about their children at a stressful time [PIAG 4-07(o)/2002 and PIAG 4-07(v)/2002].

8.38 Although the applications were broadly similar, it was noted that the Trent Registry appeared to be seeking access to more items of

identifiable data than the West Midlands Registry. The Advisory Group asked that the Trent Registry be asked to justify this difference.

8.39 It was also noted that the West Midlands Register had provided less information about how it intended to move away from relying upon Section 60 support by either obtaining consent or using pseudonymised data. The Advisory Group agreed that it was not necessary for either Registry to have 100% coverage – so suggested that the applicants should be advised to use pseudonymised data for those children whose parents failed to provide consent.

8.40 The Advisory Group was unwilling to approve the applications until the applicants had provided additional information in response to these concerns.

ACTION: Secretariat to obtain additional information from the applicants as follows:

- **Justification for collecting additional identifiable data items (Trent);**
- **That they develop procedures over the next 12 months towards obtaining parental consent to hold data about their children (Trent/West Midlands);**
- **That they develop a means for collecting and working with pseudonymised data for those children whose parents refuse consent (Trent/West Midlands).**

(xiii) Application from Ealing PCT for support for a shared care web-based Chronic Disease Register

8.41 The Advisory Group considered an application by Ealing PCT for support under Section 60 to collect patient identifiable information without consent for a web-based chronic disease register for use by Ealing, Hammersmith and Fulham, and Hounslow PCTs [PIAG 4-07(p)/2002]. The register would be used to support geographical analysis, record linkage, audit and transmitting up to date information to clinical teams.

8.42 The applicant argued that it would be impracticable to obtain consent from patients because of the wide range of sources from which data was obtained (GP practices, outpatient clinics, discharge summaries and lab results), with a core group of 40-60,000 patients involved. However, it was intended that GPs would be provided with information about the register that they could share with patients, that feedback on the information materials would be evaluated and that patients would be given assisted access to data about themselves.

8.43 Although the Advisory Group was generally supportive of the application, it was unable to give approval because it was concerned that the applicant's data destruction policy was inadequate. It therefore requested that additional information be sought on this issue.

ACTION: Secretariat to obtain information about Ealing PCT's data destruction policy.

(xiv) Application from the Institute of Cancer Research for support for a research project into the relationship between mobile phone use and leukaemia

8.44 The Advisory Group considered an application from the Institute for Cancer Research for support under Section 60 to obtain patient contact details in order that their consent could be obtained for a research study to investigate the relationship between leukaemias and mobile phone use [PIAG 4-07(q)/2002].

8.45 The Advisory Group agreed that it would be important for the applicant to confirm that any contact with patients seeking their consent should, in the first instance, come from a clinician with whom they had a direct relationship (eg their GP). In addition, it asked that the applicant be required to provide a system level security policy and more information about their data destruction policy.

ACTION: Secretariat to obtain additional information in support of the application from the Institute for Cancer Research.

(xv) Application from the Office for National Statistics for support to access identifiable data so that anonymisation techniques can be developed

8.46 The Advisory Group considered an application from the Office for National Statistics for support under Section 60 to carry out developmental work using patient identifiable data to assess the risks of individuals being identified from release of "small numbers" data [PIAG 4-07(r)/2002].

8.47 Although the Advisory Group was sympathetic to the application, it agreed that Section 60 could not be used to support work of this kind, as it could not be defined as meeting "medical purposes" as defined by the Health & Social Care Act 2001. Mr Walker agreed to discuss this matter with ONS so that an appropriate means of carrying out the work could be identified.

ACTION: Mr Walker to discuss with ONS how its developmental work might be carried out.

(xvi) Application from the South West Public Health Observatory for support to develop a surveillance system for sexually transmitted infections

8.48 The Advisory Group considered an application from the University of Bristol and the South West Public Health Observatory for support under Section 60 to obtain patient identifiable information without consent to establish a system for routine surveillance of sexually transmitted diseases [PIAG 4-07(s)/2002].

8.49 Dr Catchpole advised the Advisory Group that he chaired a working group established by the Department of Health to examine the issues

involved in establishing a dataset for sexually transmitted disease. Although that group had not yet completed its work, it had agreed that named data should never be collected.

8.50 The Advisory Committee agreed that it could not approve the application. Instead, it advised the applicant to consider how work could be carried forward using pseudonymised or anonymised data.

ACTION: Secretariat to advise the applicant that it should seek to use pseudonymised/anonymised data.

(xvii) Application from Dr Steffan Davies for support to conduct a follow-up study on a cohort of patients treated between 1983-89 at Arnold Lodge Regional Secure Unit

8.51 The Advisory Group considered an application from Dr Steffan Davies for support under Section 60 to carry out a follow-up study on a cohort of first admission patients to Arnold Lodge Regional Secure Unit between 1983 and 1999 to establish long term outcome [PIAG 4-07(t)/2002].

8.52 The application explained that it would be impracticable to obtain informed consent because it would be difficult to recontact patients in the cohort group because many of them would be dispersed throughout the prison system; all of the patients had suffered from a mental disorder and it was possible that some may be unable to consent; and many of the patients had carried out serious offences and may not wish to be reminded of their past. In addition, past attempts to obtain consent for similar work had led to loss to follow up of 39% - rendering the study meaningless.

8.53 The Advisory Group identified a number of issues that needed further clarification before it could consider approving the application, as follows:

- An explanation of the balance between the health and crime aspects of the study – specifically, what was the principal focus – health or crime reduction;
- Advice on the legality of the study – ie on what basis would the applicant be obtaining information from the Home Office Offender's index, the Police National Computer and the Home Office Mental Health Unit;
- How the data obtained by the applicant would be anonymised (the application stated that data would be extracted and then anonymised – how would the data be extracted?);
- How the applicant intended to ensure data security, and how would the security of back-up data be ensured?

ACTION: Secretariat to obtain additional information from the applicant.

(xviii) Application from the National Confidential Enquiry into Perioperative Deaths for support for research it carries out

8.54 The Advisory Group considered an application from the National Confidential Enquiry into Perioperative Deaths for support under Section 60 to collect patient identifiable information for research about clinical practice in anaesthesia, surgery and other invasive procedures [PIAG 4-07(u)/2002].

8.55 The application stated that it would be impracticable to obtain informed consent from patients because many of them would have died. It also reassured the Advisory Group that identifiable data was required only for linkage purposes, and that NCEPOD staff reviewed anonymised data only.

8.56 However, the Advisory Group was concerned about the effectiveness of NCEPOD's data destruction policy and asked that additional information be submitted before the application was approved.

ACTION: Secretariat to obtain additional information about NCEPOD's data destruction policy.

(xix) Application from University of Bristol for support to access HES and South West Public Health Laboratory Safe Haven data for audit purposes

8.57 The Advisory Group considered two applications from the University of Bristol for support under Section 60 to collect patient identifiable information for research into regional trends and patterns in hospital admissions [PIAG 4-07(w)/2002].

8.58 The application explained that it was impracticable to obtain patient consent because patients were not readily identifiable from the data set being used, every hospital admission was involved – and scale of hospital admissions was huge, and pseudonymisation was the preferred option as 100% coverage was required.

8.59 The Advisory Group accepted that pseudonymisation was the way forward for work of this type. However, it understood that robust NHS numbering, and techniques for mapping postcodes and possibly DoB into less identifiable aggregations was a prerequisite. The Advisory Group was content that the applicant had developed a solution that was a considerable way towards pseudonymisation and that work was in hand to take advantage of technology as it developed to allow a full solution. In addition, the applicant had put in place a number of safeguards that ensured patient information was well protected.

8.60 The Advisory Group therefore agreed to approve the applications.

ACTIONS: (i) Secretariat to inform the applicant that the Advisory Group had approved their applications.

(ii) Details of the applications to be entered onto the register of activities carried out with Section 60 support.

(xx) Application from Northumberland Care Trust for support to research the extent of injecting drug misuse in Northumberland

8.61 The Advisory Group considered an application from Northumberland Care Trust for support under Section 60 to collect patient identifiable information to support the development of drug misuse services [PIAG 4-07(x)/2002]. It was proposed that data would be linked between a number of local agencies including police, probation, local authorities, and NHS organisations.

8.62 The application stated that it would be impracticable to obtain patient consent because many of them were very mobile and had infrequent contact with the agencies concerned, and it was anticipated that many would be unlikely to agree.

8.63 The Advisory Group was content that the applicant had sought the minimum amount of identifiable data appropriate to carry out their work. In addition, the applicant was committed to destroying all identifiable data at the end of the study and had set out adequate plans for implementing this objective.

8.64 The Advisory Group approved the application, subject to the applicant supplying evidence that organisations contributing data to the study had satisfied the fair processing requirements of the Data Protection Act.

ACTIONS: (i) Secretariat to inform the applicant that the Advisory Group had approved their application, subject to the conditions set out above.
(ii) Details of the application to be entered onto the register of activities carried out with Section 60 support.

(xxi) Application from the Yorkshire Specialist Register of Cancer in Children and Young Adults to collect additional data about patients on the register

8.65 The Advisory Group considered an application from the Yorkshire Specialist Register of Cancer in Children and Young Adults to collect place of birth data from the ONS for patients on the register to support geographical studies of children who develop cancer [PIAG 4-07(y)/2002].

8.66 It was noted that Cancer Registries had already received Section 60 support to collect patient information. The Advisory Group was not convinced that Section 60 support was necessary for the work outlined in this application, since the applicant was seeking access to data that was publicly available. However, it was accepted that ONS had concerns about processing patient identifiable data without consent.

8.67 Since the work necessary to meet the applicant's requirements was very similar to that already approved under Section 60 for flagging records on the NHSCR (see above), the Advisory Group was content to approve the application.

ACTIONS: (i) Secretariat to inform the applicant that the Advisory Group had approved their application.
(ii) Details of the application to be entered onto the register of activities carried out with Section 60 support.

(xxii) Application from the Dr Foster Unit for access to HES data to support research to identify and publish measures of quality of delivery of healthcare

8.68 The Advisory Group considered an application from Dr Foster for support under Section 60 to obtain patient identifiable information from the HES system for use in research to identify and publish measures of quality of delivery of healthcare by provider/area [PIAG 4-07(z)/2002].

8.69 The application explained that it would be impracticable to obtain patient consent because HES data did not include patient contact details, and because the volume of data (10 million records a year) would make the costs prohibitive.

8.70 It was also noted that it was likely that Dr Foster would wish to carry out similar work in Wales using data obtained from PEDW.

8.71 The Advisory Group was content to approve the application. It also authorised the Secretariat to approve the use of data from PEDW provided Dr Foster gave written confirmation that it would process data in accordance with the commitments it had made in its application.

ACTIONS: (i) Secretariat to inform the applicant that the Advisory Group had approved their application, subject to the conditions set out above.
(ii) Details of the application to be entered onto the register of activities carried out with Section 60 support.

9. Date of future meetings (Agenda Item 8)

9.1 Future meetings of the Advisory Group were confirmed as follows:

- Tuesday 25 March 2003
- Tuesday 10 June 2003
- Monday 15 September 2003
- Tuesday 9 December 2003

10. **Any other business (Agenda Item 9)**

10.1 The Advisory Group discussed the volume of applications that had been considered at the meeting and agreed that new arrangements should be established for future meetings to ensure that its work remained manageable.

10.2 It was agreed that over the course of the year the Advisory Group had developed a number of principles that should be taken into account when applications for Section 60 support were being considered, and that it would therefore be possible for the PIAG Secretariat to carry out an initial analysis of new applications and to recommend to the Advisory Group whether or not they should be approved.

10.3 It was proposed that an appropriate check on the Secretariat would be required to ensure that each new application was viewed by at least two members of the Advisory Group, and that all members should be provided with a summary of the application. Applications that were likely to be regarded as controversial should continue to be seen by all members.

10.4 The Advisory Group approved these arrangements and asked that they be trialled at the next meeting.

ACTION: Secretariat to implement new arrangements for considering applications for Section 60 support.