

# Minutes

# PIAG

Patient Information Advisory Group

PIAG 5-02/2008

## Meeting held on Wednesday 9<sup>th</sup> September 2008

### Present:

*Members:* Professor Dame Joan Higgins (Chair), Mrs Pauline Brown, Professor Mike Catchpole, Dr Patrick Coyle, Dr Tricia Cresswell, Ms Stephanie Ellis, Ms Ros Levenson, Mr Michael Hake, Professor Roy McClelland, Ms Susan Parroy, Professor Sir Denis Pereira-Gray, Mr Terence Wiseman.

*In attendance:* Ms Natasha Dunkley (Secretariat), Ms Melanie Kingston (Secretariat), Mr Sean Kirwan (Department of Health) and Ms Karen Thomson (Secretariat).

### 1. Welcome and Apologies for absence

1.1 Apologies for absence were received from Dr Fiona Douglas, Ms Barbara Meredith, Dr Peter Rutherford and Dr Mark Taylor.

### 2. Minutes of last meeting

2.1 Minutes of the previous meeting held on 25<sup>th</sup> June April 2008 [PIAG 4-02/2008] were agreed to be an accurate record, subject to minor amendments.

### 3. Secretariat report

The Secretariat report [PIAG 4-03/2008] was received and its contents noted. It was noted that there were still some outstanding actions from the previous meeting.

#### 3.1 GP Extraction Service – Information Centre

The Secretariat met with Consultants working for Tim Straughan (CEO for the Information Centre for Health and Social Care) with respect to issues relating to the proposed new GP Extraction Service and with a view to improving the chances of success for the programme (OGC Gateway process). The key issue the Secretariat had raised was the need for a secure basis in law for the Service either through primary legislation or via Section 251 powers. Other issues raised included:

- The need, if one was not already in place, for a strategy with respect to the establishment of safe havens and honest brokers to minimise duplication and the number of bodies that would have access to confidential patient information.
- That there was no information governance (IG) workstream within the plans as outlined. IG was perceived to be a constraint rather than a

necessary means of providing protection to sensitive personal information. The question of the legal basis for the service had also not been identified in any of the project documentation.

- That both the Project Board and Project Assurance Group should include someone with IG expertise.

The Consultants clarified that it was envisaged that the IG aspects would be dealt with by NHS CFH and that this was the reason it had not been included in the documents.

It was also proposed that the Advisory Group be approached for a representative for the Project Assurance Group. The Secretariat indicated that this request should be made formally but that the Advisory Group may consider direct involvement as compromising their independence and consequently inappropriate.

The link between safe havens and honest brokers with the National Information Governance Board (NIGB) was discussed and it was noted that the NIGB would determine the principles under which they would operate. The Advisory Group also noted that the respective roles of safe havens and honest brokers need to be clearly defined and that this fell within the remit of the Advisory Group.

**ACTION: Secretariat to circulate paper on safe havens and honest brokers to Advisory Group members.**

**[Note from the Secretariat - added 13 February 2009].**

The NHS Information Centre (NHS IC) requested that minute 3.1 be amended to clarify that the Consultants referred to in the first paragraph were independent consultants who carried out a Gateway Review on behalf of the Department of Health and were not employed by the NHS IC or its Chief Executive Tim Straughan. Any views expressed by them should not therefore be construed as being representative of the NHS IC of the GPES project. The NHS IC were also concerned that the minute may give the impression that the NHS IC perceived information governance to be a constraint. This was not the intention of the minute. In relation to the "other issues raised" these refer to the concerns raised by the PIAG Secretariat with the consultants based on the information available at the time in relation to GPES.

### 3.2 Clinical Trials – Disclosure of data re: non-participants

An issue was raised by a researcher in relation to a clinical trial. Local clinical care teams were to identify the cohort of patients and seek their consent to participate; however, the research co-ordinating centre, also wanted to collect data about patients that met the inclusion criteria but for some reason are not invited to participate or who had withheld their consent to participation. The Advisory Group was asked to consider the following

proposal for handling such requests, where anonymised / aggregate data would not suffice:

- 1) Where the patients were being approached for their consent to participate but had refused, that consent should be sought for the more limited participation of permitting their data to be disclosed to the research team for analysis and provide comparative data with respect to the intervention cohort. This may need to adopt a nuanced approach so that if patients were unhappy for detailed data to be disclosed that very limited data to prevent duplication of cases and to collect numbers and limited demographic data could be facilitated.
- 2) Where patients had not been approached for consent because only a sample had been invited to participate that consideration be given to the practicality of consent for the data collection. Only where consent was genuinely not practicable should approval under Section 251 powers be sought.
- 3) Where patients had not been approached for consent because it was felt to be inappropriate to invite them to participate, consideration should be given to both the appropriateness and feasibility of seeking consent for the data collection and where there are grounds for not seeking consent then to pursue Section 251 approval.

The Advisory Group commented that the appropriateness of using Section 251 powers would be considered on a case by case basis. Members also commented that clarity would be required over the scope of what is meant when patients state they do not wish to participate, and that patients should be specifically asked whether they would be content for pseudonymised data to be used as part of the consent process. It was agreed that permitting one's data or tissue to be used for research purposes was still a form of (indirect) participation.

- 4) Where the data to be collected is limited to list cleaning that a more limited form is used for approval and that this can be considered via the Fast track process, where this data is not already available through IRAS. The form should include the data requested and justification for why consent is not feasible, how long the data will need to be held in identifiable form and completion of the security form.

It was noted that this would require further work by the Secretariat and that this should be considered within the context of the overall development of IRAS.

### 3.3 National Research Ethics Service – Research Databases workstream

The Secretariat reported that work had begun with NRES in relation to developing an application process for Research Databases within IRAS. It was noted that as part of this work, the Secretariat has made it clear that long-term retention of identifiable data for research databases must be undertaken on a consent basis. There may however be a role

for Section 251 powers in identifying relevant patients from whom to seek consent and for historical databases. Members agreed that there must be a suitable consent process in place.

The Secretariat reported that a question had arisen during discussions for this project, and the views of the Advisory Group were sought:

In circumstances where a research database holds identifiable patient data with consent and has released pseudonymised data to a researcher, with the database retaining the key to reverse the pseudonymisation; but where the data is otherwise effectively anonymised for the researcher, if a patient subsequently withdraws their consent for inclusion on the database:

- 1) Should the database be obliged to trace the researchers who have received data and instruct them to destroy the data about the individual (providing the research process has not passed the point of no return)?
- 2) Or would it be acceptable that the database destroy the identifiers held in the database and thereby rendering the data held by the researcher effectively anonymised?
- 3) Whether there was a time element to the above, i.e. for data released less than e.g. six months previously, the researcher should be traced, but for data released more than six months ago, then anonymisation was acceptable. If so, whether the Advisory Group had a view on what an appropriate timescale would be?

The Advisory Group noted that this issue was applicable to the UK Biobank study, which the Advisory Group had considered with respect to the initial identification and contacting of relevant participants.

This issue generated considerable discussion and there were a range of views about which best served patients' interests and were reasonable for researchers. Most members felt that option 2 constituted a common-sense approach, and that once effectively anonymised data ceased to be personal data and therefore could be used without further restraint. Some members felt that Option 1 would be more in keeping with Data Protection legislation. Members agreed that Option 3 addressed ethical concerns as well as considering the legal aspects.

Members agreed that overall Option 3 represented a useful framework but with a shorter time period during which information could be withdrawn. Members agreed that each case would need to be reviewed individually, rather than applying a blanket rule to minimise disruption to research and because for some studies the withdrawal of a significant number of cases would lead to data bias. Additionally in some instances considerable distress may be caused to individuals if their data could not be withdrawn, and hence there is need for a balanced judgment in individual circumstances.

3.4 The Redfern Inquiry – Deceased patients’ records

It was noted that the hearing for the Redfern Inquiry case was due to take place later in the week. The outcome of the hearing would be reported to the Advisory Group in due course.

3.5 The Health and Social Care Act 2008

It was noted that the Health and Social Care Act 2008, which would formally establish the National Information Governance Board for Health and Adult Social Care (NIGB) and abolish PIAG, received Royal Assent on 21 July 2008. It was reported that this would not come into effect until an order had been passed by Parliament and consequently that the Advisory Group would continue to function as a statutory body until such time. It was reported that the current Chair of the NIGB wanted to ensure there was continuity of service between the formal winding up of the Advisory Group and the establishment of its replacement Committee. As the Advisory Group’s members had been asked to sit on the new Committee, it was not envisaged that this would present a difficulty.

3.6 Avon Longitudinal Study for Parents and Children (ALSPAC) 4-05(i)/2007

It was noted that this study had requested an extension to obtain historical address in addition to postcode for geographical analysis purposes. This was because of changes in postcode boundaries over time. As the data was already highly identifiable and consent had been obtained historically, this was felt to be a modest and justifiable extension. It was therefore approved by Chair’s action subject to a number of conditions.

3.7 Dr Foster Unit at Imperial College

A proposal from the Dr Foster Unit at Imperial was considered by the Advisory Group at the last meeting, with respect to mental health data. Although members had generally felt supportive, there was agreement that Professor McClelland’s view should be obtained, given that this was his area of expertise, as members did not feel comfortable approving this without his input. It was agreed that the Chair, Professor Roy McClelland and the Secretariat should meet with Dr Paul Aylin to discuss this issue. This meeting took place in July 2008. Professor McClelland had felt that what had been proposed, which would allow the Unit to collect information about organic mental health conditions such as dementias but not inorganic conditions was reasonable. He agreed that organic conditions had been reasonably defined. The application has been given final approval therefore by Chair’s action.

**4. Chair’s report**

The Chair reported on the Research Capability Programme and notified Members that a public consultation would be carried out shortly that would look at public attitudes to use

of confidential patient data for research. The Advisory Group agreed to respond to the consultation.

The Chair also led a discussion on the importance of retaining the Advisory Group's corporate memory via the PIAG webpages. It was noted that the Advisory Group is under a statutory obligation to publish a list of all approved applications and this should remain during and after the transition period to the NIGB, at least for a reasonable period of time.

**ACTION: Action: Chair to work with NIGB to ensure continuity of PIAG web pages over the long term and the Secretariat to ensure the website remains operational during the transition period.**

## **5. Database Monitoring Sub Group Report**

DMsG had not met since the previous Advisory Group meeting. The next DMsG meeting was scheduled for 12 September 2008 and a report would be provided at the October Advisory Group meeting.

## **6. Applications previously considered**

### 6.1 Clinical features in metastatic cancer [PIAG 1-05(f)/2008]

This purpose of this study was to identify key features of metastatic cancer with a view to assisting GPs to identify cases and relapse earlier to allow quicker access to secondary treatments. Section 251 support was sought for the identification of deceased patients with metastatic cancer. This study had originally been considered in February but had been referred as the application had not been clear in a number of respects, the applicant had not completed the query sheet properly and the Advisory Group concluded that insufficient detail had been provided for them to reach a decision.

Further clarification had subsequently been provided and the Advisory Group re-considered this application. The study included both cases with metastatic cancer and two control cohorts, one with non-metastatic cancer and the other healthy patients matched for age and gender.

The Advisory Group agreed to support the application because of the complexities involved in determining the cases and because of the limited access in order to extract and anonymise the data.

The approval did not include approval for access to the records of the living controls, as this was not included within the application and there was insufficient information provided for the Advisory Group to consider this aspect. Members advised therefore that GP Practice staff should be asked to identify the living controls and seek patient consent on behalf of the researcher. The Advisory Group agreed that, as the process of identifying

controls was much simpler than for the cases, this should be practicable. If, however, the applicant finds difficulties with this, then the Advisory Group would be willing to consider a new application for this aspect of the study.

The Advisory Group additionally commented that whilst the Data Protection Act only applies to the living, this does not take account of the common law duty of Confidentiality, and which is embraced by the first Data Protection principle that data is processed fairly and lawfully. It is the Advisory Group's understanding that the common law duty almost certainly extends beyond death (c.f. *Bluck v Information Commissioner and Epsom and St Helier University NHS Trust*, 2007 WL 4266111). As data protection principles align with Caldicott principles, they are applicable as a means of protecting patient confidentiality.

With respect to the Honorary Contract arrangements, it has been widely accepted within Research Governance that Honorary Contracts are not adequate in terms of providing protection for patient confidentiality, as they are not legally enforceable. It is necessary that the duty of Confidentiality is included within a researcher's substantive contract of employment and that this would be enforced through disciplinary procedures.

**ACTION:      Secretariat to advise the applicant of the Advisory Group's decision**

6.2      Extension to CEMACH [PIAG 4-08(c)/2003]      Obesity in pregnancy audit.

This Confidential Enquiry, to carry out a national audit of care on pregnant obese women, was developed in order to determine the adherence to consensus standards of care. Section 251 support was requested as aspects of the audit would involve researchers, external to the clinical care team, reviewing the cohort's medical records and the potential of anxiety caused to participants through seeking consent.

Members were unable to approve this application on the basis that the study was significantly different from the original CEMACH application in relation to child and maternal mortality. The Advisory Group agreed that this could not be considered to be an extension of its current work programme.

Additionally, the Advisory Group agreed that the first phase of this study, with prospective case notification, could be achieved with fully anonymised data (with age and a unique identifier), as the risk of duplication of cases was not significant. With respect to the second phase of the study, the Advisory Group agreed that consent was practicable and therefore that this route should be taken rather than seeking support under S251, which is only to be used as a last resort where anonymised data will not suffice and consent is genuinely not practicable.

The Advisory Group did not accept the arguments made about clinician time or the distress that might be caused to patients. Use of patient information without consent can also cause distress and in this instance the potential distress caused did not warrant breaching confidentiality. Members of the Advisory Group suggested that if CEMACH

anticipated that there would be a high refusal rate then a larger number of cases should be randomised.

Members also expressed concern that some of this data may have already been collected and therefore asked the Secretariat to seek assurance that any data already collected, relating to the first phase of data collection, would be anonymised immediately. If any data has been collected in relation to the second phase of this study, members advised that this should be destroyed and re-collected once a legitimate basis for holding this data through consent or S251 approval had been obtained. Members advised that if difficulties arose during the course of the second phase which could not be addressed in other ways the Advisory Group would consider a new application.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

## **7. Fast track applications**

The summary of fast track applications [PIAG 4-05 (FT)/2008] was received. The Advisory Group noted that the following fast track applications had been approved since the last meeting.

### 7.1 A Surveillance study of the incidence, associated factors and short term outcome of conversion disorder in children in the UK and Ireland [PIAG/BPSU 4-05(FT1)/2008].

This application, for a British Paediatric Surveillance Unit surveillance study, was to determine the frequency, pattern and short-term outcomes of Conversion Disorder. It was noted that this study followed the standard BPSU methodology and was only minimally identifiable. It was noted that the approval only pertained to data generated within trusts in England and Wales. It was approved by Chair's action.

## **8. New applications for Section 60 support.**

### 8.1 Avon, Gloucester and Wiltshire Cardiac Registry [PIAG 4-06(b)/2008]

This application, for the development of a Cardiac Registry utilising and linking data from MINAP and other sources, was to describe longitudinal changes in treatment practices and outcomes. Section 251 approval was requested as the proposal was for the database to obtain retrospective data without consent and retain it long-term. The Advisory Group did not approve the application. Members expressed concern that the reason consent could not be sought was due to a lack of funding. This was not, by itself, a valid reason to justify why consent could not be obtained, particularly as the proposal was to retain identifiable data long-term.

The Advisory Group's position is that long-term retention of identifiable data should only occur with consent, other than in exceptional circumstances. Members proposed that other options should be explored either to obtain consent prospectively, or to seek assistance from the Information Centre for Health and Social Care to obtain linked pseudonymised data. Members also expressed concern about the limited extent and nature of user involvement. If the applicant were to re-submit in future, the application would need to provide more detail in terms of engaging with patient groups; the outcomes of engagement activities and how their input had been integrated into the work of the Registry.

The Advisory Group agreed that the specific purpose behind the establishment of the Cardiac Registry was not sufficiently defined and that a resubmitted application would similarly require further detail on this aspect. Members noted that approval would not be sought from research ethics committees (REC) for each individual piece of research but rather that generic ethical approval would be sought. The Advisory Group indicated that that this would only be applicable where anonymised data would be used other than by Registry staff and that use of identifiable data would need both further PIAG and REC approval.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

#### 8.2 National Endocarditis Register [PIAG 4-06(c)/2008]

This application related to the establishment of a national registry for endocarditis following recommendations from NICE. Support under section 251 was sought on the basis that consent would be impractical due to the potentially large number of deceased patients or near to death patients, who would be unable to give consent.

Whilst acknowledging the importance of work in this area, the Advisory Group was unable to approve the application. Members advised that there appeared to be significant opportunities within the patient clinical pathway by which to gain consent for the majority of living patients, and this should be explored further. Evidence should be provided to demonstrate whether consent would lead to data bias, and further detail given on considering whether pseudonymisation would be feasible on a rolling basis or via the Secondary Uses Service.

Members highlighted that the user involvement leaflet should be simplified, with technical terms removed and translated into clearer text. Additionally, further patient involvement should be sought in order to develop any re-submission. Members suggested using current NICE guidance on user engagement to inform this aspect.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

#### 8.3 Diabetes morbidity in clinical non attenders [PIAG 4-06(d)/2008]

The purpose of this study was to identify the prevalence of complications amongst patients with Type 2 diabetes, who did not attend clinic appointments, and the reasons for

non-attendance. The aim was to identify potential changes that might be made to how services were delivered to improve attendance and health outcomes. Section 251 support was sought as the contact details of the cohort was intended to be accessed by a researcher who did not work within the clinical care team. The Advisory Group approved the application as it was likely this would result in benefit to individual patients, participating in the study and because the researcher would be a clinician and therefore under a professional as well as contractual obligation of confidentiality. The Advisory Group considered this application to have been well-developed and sensitively thought-out, given the nature of this cohort as 'hard to reach'.

This approval was subject to the following condition:

- Amendment of the patient information leaflet to explain the purpose of the study more accurately and indicating what the barriers to accessing services might be, as this would assist patients in deciding whether to participate. It was proposed that the letter should reiterate that the patient would not be placed under pressure to participate when contacted by the researcher.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

#### 8.4 UK Transplant Potential Donor Audit [PIAG 4-06(e)/2008]

The purpose of the audit was to identify the demographic characteristics of those who did not wish to donate organs in order to enable effective targeting of resources. Section 251 support was requested as the audit required access to the full postcode of deceased patients. The study was previously using a partial postcode and wished to extend to full postcode use so that analysis could be undertaken internally using a commercial marketing tool and which required full postcode.

The Advisory Group approved the application as the current shortage in organ donation meant that this study could identify opportunities and establish current blockages to those currently not choosing organ donation. The view was that the section 251 support could be granted on the basis of assisting with the effective management of health services and by serving the wider public interest.

Members approved the study subject to the following conditions:

- 1) To clarify whether it would be feasible for the data not to be processed off-shore and if necessary, to obtain further assurance relating to the off-shore processing arrangements.
- 2) Confirmation of definitive retention and disposal arrangements.
- 3) Identification of an appropriate patient group to provide views upon the study, and engagement with this group within 12 months.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

8.5 NCASP sudden arrhythmia death audit [PIAG 4-06(f)/2008]

This audit of victims of sudden arrhythmia death syndrome (SADS) had been commissioned under the NCASP umbrella. Section 251 approval was requested for access to deceased patient's data.

The Advisory Group was, in principle, willing to approve this audit, as although index patients were deceased, SADS in younger persons is often indicative of inherited cardiac disease, and therefore there would be potential health benefits for relatives. Before final approval could be given, however, the Advisory Group requires either a joint application from HQIP and the Information Centre or from HQIP for the NCASP programme.

Approval was additionally subject to confirmation of the following:

- 1) Clarification to be provided on who will contact the families and how they would be approached.
- 2) Provision of an appropriate patient information leaflet, to be submitted to the Secretariat for review.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

8.6 NCASP pulmonary hypertension audit [PIAG 4-06(g)/2008]

This audit, part of the NCASP commissioned work programme, was to assess the quality of care, activity levels, access rates and patient outcomes on pulmonary hypertension at a national level. Support under section 251 was requested as the audit required access to identifiable information on adult patients diagnosed with pulmonary hypertension, prior to pseudonymisation.

The Advisory Group did not approve the application. Members noted that the project was at an early stage of development and that user involvement and consent was an area under discussion. It was the view of the Advisory Group that user involvement is a fundamental aspect to any application for approval under section 251. Further engagement with patients and their representatives, and detail about how patient views had been incorporated into the audit would be required in the event that consent from the cohort could not be obtained. Similarly an application for the NCASP programme from HQIP would also be a pre-requisite.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

8.7 Elderly care home residents [PIAG 4-06(h)/2008]

This descriptive study, to identify where elderly care home residents die and the factors that influence hospitalisation at end of life, was to inform the development of services and interventions aimed at improving choices and end of life care.

Section 251 approval was requested as the study required access to patient information in order to identify a suitable cohort, and to carry out retrospective case note reviews on

these deceased patients. The Advisory Group approved the application taking into consideration the balance of the public interest and the wider implications of the study on this vulnerable sector of the population.

This approval was subject to the following:

- 1) There was a risk that third party data could be included within GP records and this would need to be identified and excluded. It was also noted that the scope of approval applied solely to the health information contained within the social care record and not the whole record.
- 2) Consideration should be given to obtaining details directly from CSCI as they receive notification of resident deaths.
- 3) Local consultation should be undertaken e.g. with Age Concern, due to the sensitive nature of the research, particularly for relatives.
- 4) Clarification as to whether there are plans to exclude information relating to Homes outside the geographic nature of the study.
- 5) Identifiers to be removed as soon as possible and clarification as to whether the full postcode would be required. Greater clarity to be provided over data destruction.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

#### 8.8 Thermal injuries in children [PIAG 4-06(i)/2008]

This prospective observational study, to identify a cohort suffering from possible thermal injury, was designed for the purpose of developing a triage tool to assist in the diagnosis of possible abuse. Section 251 support was requested as it was considered inappropriate to obtain consent due to the potential of abuse suffered by participants.

The Advisory Group approved the study as consent was clearly inappropriate in this instance and because of the strong public interest and the potential benefit to child victims and families. This approval was subject to the following:

- 1) The Advisory Group's remit does not extend to Ireland under devolved administration and applies only to data obtained from health service bodies in England and Wales.
- 2) As the Age range of the cohort is from 0 – 16, consideration must be given to whether the older children are competent to provide consent themselves, in line with the Fraser test ("Gillick competence").
- 3) Consideration of the appropriate legal frameworks around reporting of injuries relating to children.
- 4) The study should operate under a local Safeguarding Children's Board who could act as a steering group, (to be completed within 12 months).

- 5) Active seeking of opinions from those within the childcare field, (to be completed within 12 months).
- 6) Under guidance issued by the Cabinet Office and Department of Health, and in line with previous PIAG requirements, laptops and other portable devices holding personal data are to be encrypted to the required standard prior to any data being held on them.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

8.9 Fatigue in breast cancer survivors [PIAG 4-06(j)/2008]

This longitudinal observational study was to identify the characteristics and immune cases of fatigued women treated for breast cancer in order to explore the relationship between these factors. Section 251 support was requested as the study needed access to patient data to identify a suitable cohort from whom to seek consent and who would be attending for a clinic appointment shortly and this would reduce the number of visits that would need to be made if patients agreed to participate in the study.

The Advisory Group approved the application, as there was a clear exit strategy from S251 approval, through consent and because the research team, although external to the clinical care team were within the same Trust. This approval was subject to the following conditions:

- 1) Clarification as to whether the first point of contact would be a nurse with clinical responsibility for the patient.
- 2) Any further studies with this cohort should obtain consent prospectively, on the basis that a mechanism for the clinical care team to contact patients would have been established, thus negating any future requirement for section 251 support.

**ACTION: Secretariat to advise the applicant of the Advisory Group's decision**

8.10 Decline in cervical screening coverage [PIAG 4-06k]

This study, to investigate the organisational factors, which may be associated with a decline in cervical screening, was developed to understand the reasons why women choose not to attend for screening and their characteristics.

Section 251 support was requested to extract relevant data from a screening programme database without consent. S251 approval was needed because of the large numbers of records involved.

The Advisory Group approved the application on the grounds that the identifiable information was reasonably pseudonymised and therefore that the need for support under Section 251 support was borderline.

**9. Other Business: Register of Members' Interests**

The Secretariat reported that a request for the register of members' interests had been received and had been disclosed. Members were asked to complete a new declaration of interests form so that the register could be updated. Members were asked for their views on whether the register of members interests should be published on the website. Members agreed that transparency was important and therefore that the register should be published once updated. It was agreed that for subsequent meetings Members would highlight whether there was a conflict of interest which would be noted at the start of the minutes.

**Action: Secretariat to publish the updated Register of Members' Interests.**

**10. Future meetings for 2008**

October - Monday 20th 2008

December - Monday 8th 2008

All meetings to take place at the Kings Fund, 11-13 Cavendish Sq, London.