Minutes of the meeting held on Wednesday 14 March 2007, The Himsworth and Fletcher Rooms, UKCRC, 20 Park Crescent, London, W1B 1AL

Present

Members

Nick Partridge – INVOLVE (Chair)
Dr Alison Austin - Office of Science and Innovation (OSI) / Department of Trade and Industry (DTI)
Jane Austin – NHS Confederation
Professor Colin Blakemore – Medical Research Council (MRC)
Professor Sir Alasdair Breckenridge – Medicines and Healthcare Products Regulatory Agency (MHRA)
Mr Glyn Edwards – BioIndustry Association (BIA)
Dr Russell Hamilton – Department of Health (DH)
Professor Alex Markham – Cancer Research UK (CRUK)
Professor Patrick Maxwell Academy of Medical Sciences (AMS)
Candy Morris – Strategic Health Authorities (SHAs)
Professor Adrian Newland – Academy of Medical Royal Colleges (AOMRC)
Dame Bridget Ogilvie – Association of Medical Research Charities (AMRC)
Professor Bob Stout – NI Health & Personal Social Services
Dr Liam O’Toole – UK Clinical Research Collaboration (UKCRC)
Dr Alison Spaull – Scottish Executive Health Department
Richard Tiner – Association of the British Pharmaceutical Industry (ABPI)
Dr Mark Walport – The Wellcome Trust
Professor John Williams – Welsh Assembly Government
John Wilkinson – The Association of the British Healthcare Industries (ABHI)

Observers/Invited

Professor John Bell – Office for Strategic Coordination of Health Research (OSCHR)
Dr Helen Campbell – Department of Health (DH)
Harry Cayton – Department of Health (DH)
Angela Cooper – Medical Research Council (MRC)
Dr Janet Darbyshire – UK Clinical Research Network (UKCRN)
Professor Ian Diamond – UKCRC Public Health Strategic Planning Group (Chair) and UKCRC R&D Advisory Group to Connecting for Health (Chair)
Sarah Fox – Department of Health R&D (DH)
Catherine Johns – Department of Health R&D (DH)
Professor Sir John Lilleyman – National Patient Safety Agency (NPSA)
Peter Selby – UK Clinical Research Network (UKCRN)
Roger Wilson – UKCRC Public and Patient Involvement Project Group (Chair)
Louise Wood – Department of Health (DH)
UKCRC Secretariat

Dr Sue Bourne       Dr Janet Valentine
Hannah Brown       Philippa Yeeles
Dr Matthew Hallsworth      Dr Andrew Speakman
Dr Ngozi Okwudili-Ince      Sarah Harrop
Samia Majid

Announcements and Apologies

Apologies

Professor Sally Davies – Department of Health
Allan Baxter – Senior Representative from the Pharmaceutical Industry
David Eastwood – UK HEFCE
Sir Michael Rawlins – National Institute for Clinical Excellence (NICE)

Announcements

The Chair welcomed everybody to the eleventh meeting of the UKCRC Board.

1) Minutes of the last UKCRC Board Meeting 12 December 2006 UKCRC/07/01

The minutes were accepted as a correct record of the meeting held on 12 December 2006.

Matters Arising

University Representation on the UKCRC Board

The Board noted that Professor Sir John Tooke as Chair of the UK Health Education Advisory Committee (UKHEAC) and the Chair of the Council of Heads of Medical Schools (CHMS), has agreed to personally represent the UK university sector on the UKCRC Board.

Research Assessment Exercise (RAE)

The Board noted that at the last Board meeting Liam was asked to write to HEFCE regarding its concern about the potential impact of the introduction of a metrics based system on translational and clinical research. A copy of this letter and the HEFCE reply were tabled. The Board thanked HEFCE for their response and recognised the need for further monitoring.

UKCRC General

2) Chief Executive’s Report UKCRC/07/02

Update on Staff Appointments

The Board noted that there have been several new appointments and staff changes since the last UKCRC Board Meeting. The Board welcomed Sarah Harrop who has taken up the post as Science Writer, Samia Majid, who replaced Susannah Keeling as Operations Manager and Katie Gale as the new PA to Liam. Rebecca Hodges will be joining the Secretariat as a new Programme Manager to replace Mags Sara who left last year.
Update on Performance Measures / Metrics

The Board noted that following discussions with individual Partner organisations, the secretariat confirmed that very little reliable historic data exists for baseline activity, in any of the UKCRC areas of work. However the metrics being developed by the Partners in each of these areas should provide this baseline for future measurement of change within the clinical research environment.

3) Implications of the Cooksey Report for the UKCRC Oral

The Board was reminded that as the Cooksey report was published just prior to the December Board meeting, the Board had decided to delay discussion of the review until the March 2007 meeting. The Board considered the key recommendations of the review and welcomed the report. The importance of ensuring appropriate patient and public involvement in the implementation of the constituent parts of the report was highlighted.

John Bell, interim chair of the OSCHR Board, updated the Board on progress with the Office of Strategic Co-ordination of Health Research (OSCHR). A key aim of OSCHR is to ensure the alignment of MRC and NIHR strategies, and the focus of activities over the past 6 weeks has been on harmonising the CSR bids from OSI and DH in order to deliver the Cooksey reforms. OSCHR has a UK-wide remit with the aim of developing strategies that facilitate effective cross working with the devolved administrations. Early engagement with industry is also important in order for systems and structures to be put in place that will enable the commercial sector to benefit from the opportunities offered by this joint strategy for publicly funded health research.

Three new boards in the areas of e-Health, translational medicine and public health will be established under the strategic direction OSCHR. These boards will have strategic oversight of funding and a monitoring role in their area but will not have a direct research funding function. In areas of overlapping activity, lead organisations will take responsibility for managing tasks such as administering funds and peer-review processes on behalf of both organisations. It was noted that OSCHR would adopt the approach of collaborative working that has been successfully developed and used by the UKCRC.

Russell Hamilton reported that DH and NIHR were positive about the proposed changes to be implemented and looked forward to working closely with OSCHR. John Williams welcomed the steps being taken by OSCHR and emphasised that Wales was fully support of this process. Colin Blakemore reported that the MRC also welcomed the approach and hoped that new institutional arrangements could be introduced with minimum bureaucracy.

The Board agreed that good progress had been made in a short period of time and that clear communication about these new arrangements with the research community was essential. The Board thanked John Bell for his presentation and asked him to update the Board on a regular basis on OSCHR’s progress.

The Board turned to the implications of Liam O’Toole’s interim part time secondment to OSCHR on the UKCRC’s operations. The Chief Executive’s report detailed the steps that had been taken to maintain momentum across UKCRC activities and to ensure effective delivery of the UKCRC Workplan: Janet Valentine in her capacity as Deputy to the Chief Executive had taken on responsibility for some of Liam’s workload; Matthew Hallsworth’s role had been refocused on promoting UKCRC to external stakeholders; the new members of the UKCRC Secretariat would support the changed responsibilities in the team; and there would be greater emphasis on using the expertise of the Partners to lead specific pieces of work.
The Board agreed that these measures were appropriate to ensure continuity of operations and ability to deliver UKCRC objectives.

The Board considered the potential impact of OSCHR on the UKCRC’s role and workplan. Members agreed that there could be implications for the UKCRC Workplan but it was still too early to identify. They noted that OSCHR could build on the culture of collaborative working developed in the UKCRC, and closer working between the Public Funders could have a positive effect on the UKCRC agenda.

4) **UKCRC Workplan – Discussion Paper on Developing Incentives for Research within the NHS**

Members noted that the Board approved the UKCRC Workplan for 07/08 at the December meeting but had requested that issues within the Building Incentives for Research in the NHS Workstream should be the subject of further in depth discussions.

Turning to the discussion paper, the Board were reminded that the Research for Patient Benefit Working Party had made many recommendations for incentivising research within the NHS and these cut across all the UKCRC Workstreams. However, given the importance of this area the UKCRC Board had agreed that it should also stand as an individual Workstream. The focus of workstream activity had been based around developing individual and institutional incentives including working with the Healthcare Commission (HC) to explore the possibility of adopting research within their developmental standards. Although the HC ultimately decided not to include R&D metrics in their final list of standards, they have subsequently met with the DH and work is still ongoing to explore ways of utilising existing research metrics to inform performance assessment.

Members considered whether there would be any added value in the UKCRC undertaking additional joint work in the context of ongoing work by individual Partners and within other UKCRC Workstreams. The Board agreed the following:

- Building incentives for research in the NHS continues to remain an important area for the UKCRC Partners
- Many of the issues in this area can only be taken forward by the four health departments
- At this stage there appears to be no specific role for the UKCRC beyond monitoring the situation
- Incentives should stay as a standing item on the Board agenda for the health departments to report any progress in this area

5) **UKCRC Financial Report to the Board**

The UKCRC Financial report was presented by Russell Hamilton on behalf of the UKCRC Budget Committee. The Board was reminded that the remit of the Budget Committee was to oversee the UKCRC’s internal financial management including the budget, on behalf of the Board. The financial reports submitted to the Board are summaries of more detailed financial reports prepared by the UKCRC Secretariat that have been scrutinised in depth by the UKCRC Budget Committee.

The Board noted the expenditure for quarter 4 and the projected budget of 2006/07. At the December 2006 meeting it was agreed that the balance of remaining funds at the end of the 2006/07 year should be carried forward to the 2007/08 financial year. The carry over allows the delivery of the 2007/08 Workplan without the need to increase the level of Partner
contributions for 2007/08. The proposed budget for 2007/08 was approved by Board without prejudice for future financial years.

The Board agreed to have an early discussion of the 2008/09 Workplan and Budget and longer term role of the UKCRC at the September 2007 Board meeting.

**UKCRC Activities:**

**NHS IT Systems**

6) NHS IT Systems – Update Paper UKCRC/07/05

The Board received a report from Ian Diamond, Chair of the UKCRC R&D Advisory Group to Connecting for Health in which he outlined the progress made towards meeting the group’s terms of reference. He acknowledged the support of Sally Davies and Richard Jeavons, as sponsors and that of the CfH team led by Jeremy Thorp in supporting the research simulations commissioned by the Advisory Group.

The research simulations were commissioned and conducted within four months with a draft report presented to the sponsors, Advisory Group and the UKCRC Board in March 2007. Wider engagement with stakeholders took place in February 2007 and the initial findings of the simulations appeared to be in tune with the broader academic and public health community requirements. A major finding from the simulations was that the Secondary Uses Service (SUS) as currently proposed, is unlikely on its own, to provide the necessary data to meet the needs of researchers of the public health community. The report made recommendations on how the NHS care record SUS could be improved to meet the needs of researchers, and also called for an initiative to promote the federation of existing databases.

In the light of this the UKCRC R&D Advisory Group had discussed next steps and proposed a two-pronged approach:

- Continue to work with CfH to implement the recommendations from the simulations and in parallel-
- Develop a UK-wide strategy to establish federated databases infrastructure.

The Board welcomes the report and in discussion highlighted the following issues: The need to engage with both the public and clinical professionals in sharing the vision for enabling access to patient records for research; the plans for Mark Walport, as a member of the Advisory Group, to begin a dialogue with the RCGP to capitalise on the important role of the GP community as leaders in the adoption of IT.

In summary the Board agreed that a letter should be sent to the Advisory Group sponsors to confirm that the Board had discussed and endorsed both the report of the simulations and the next steps proposed by the Advisory Group, in addition, they agreed that the report would be enhanced by highlighting the importance of improving data quality and standards.

7) Update on the National Information Governance Board Oral

The Board welcomed Harry Cayton, Chair of the Care Records Development Board (CRDB) who informed them that a report from the CRDB Secondary Uses working group would also be published in April 2007. The report would cover the necessary governance arrangements for secondary uses data. He highlighted the level of ‘cross working’ that has taken place
between the two groups and the opportunities for taking forward the powerful recommendations emerging from these complementary activities.

He then gave an outline of the Information Governance Review, the subsequent report in September 2006 and the current plans for development of the National Information Governance Board (NIGB). In particular he reminded the Board that the review had been commissioned to address the: lack of coherence, clarity and consistency in the way information is governed within and between various bodies involved in the development, delivery and monitoring of NHS care and services. Amongst the seven recommendations in the report was one to reduce the number of bodies with responsibility for information governance from the current nine to just one. In line with this he reported that the activities of the CRDB would be absorbed into the NIGB in June 2007.

The timeline for full implementation of the NIGB would be September 2007 and membership would be 50 percent institutionally nominated representatives and 50 percent from public appointment. The Board heard that the Chair of the NIGB would be appointed by the Secretary of State and that Lord Warner had announced that Harry Cayton would assume the role in the first instance. Letters would be sent to stakeholder bodies regarding membership of the NIGB in April 2007.

The Board then discussed the relationship of the NIGB to the Patient Information Advisory Group (PIAG) which currently has two roles: approving access to personal data which is identifiable (without consent) and also an advisory role to the Secretary of State. They noted that the NIGB was expected to assume the role of providing advice to the Secretary of State and that only once NIGB obtained statutory status would PIAG be dissolved.

8) Research Coordination – Update Paper  UKCRC/07/06

a) UK Health Research Analysis

In the update paper it was reported that good progress had been made on the analysis of the research portfolios of smaller medical charities in partnership with the AMRC.

b) Public Health

Ian Diamond reported progress on the £20 million joint initiative to fund three to five UKCRC Centres of Excellence in Public Health Research in the UK. The establishment of the Centres was the major outcome from the evidence based review carried out by the UKCRC Public Health Research Strategic Planning Group (SPG). The aim of the centres is to strengthen public health research in the UK by building academic capacity, boosting infrastructure and encouraging partnerships between leading experts from a range of disciplines, practitioners, policy markers and wider stakeholders.

The Centres competition was launched in January at a well attended open meeting with the research community and the funders. The competition is in two stages with final funding decisions expected in December 2007. The process is being administered by ESRC with

1 Information governance in the Department of Health and the NHS – Harry Cayton, National Director for Patients and the Public and Chair, CRDB
www.connectingforhealth.nhs.uk/crdb
assistance from the National Prevention Research Initiative (NPRI) Secretariat. The funding partners for the initiative are BHF, CRUK, DH, ESRC, MRC, R&D NI HPSS, WORD and Wellcome Trust. The Department of Transport has also expressed an interest in contributing to the initiative.

Other evidence gathered from the SPG process highlighted the need for greater use of existing datasets. This issue will be taken forward as part of the second call of the NPRI, which is due to be announced imminently.

The Board recognised the success of the UKCRC SPG model in bringing funders together to develop a coherent strategy to funding specific areas and noted that this approach will be adopted by OSCHR.

c) Microbiology and Infectious Diseases

The Board heard an oral report of progress by Sir John Lilleyman who chaired the Microbiology and Infectious Diseases Research Strategic Planning Group (SPG). Sir John reported the following:

The major funders of UK health research had come together to form this planning group in February 2006.

- The work of the group involved several evidence based reviews of the area – including a targeted consultation of professional bodies
- The priority issues identified included translational research, collaborative working and issues of career development
- A proposal for a resulting joint initiative had now reached the stage of outline agreement with indicative support of £16 million.
- The proposal would involve the establishment of 3 to 5 research Consortia – targeted at building research infrastructure and capacity and modelled on the Public Health Research Centres of Excellence
- It was judged that some areas in this field were unlikely to be able to support the maximum number of Consortia immediately – hence an additional element to the initiative was a proposal for “strategy development grants” designed to develop promising approaches to research prior to full consortium funding.
- The proposed initiative would be developed further and agreed by prospective funders over the next few months and the planning group would not meet again
- A report of the group’s activities would be brought to a future meeting of the Board

During the subsequent discussion the working arrangements and strategic direction of the proposed initiative were considered briefly. Members of the Board noted that the initiative was timely because microbiology and infection was an important strategic area for the NHS and the UK as a whole. It was also noted that the SPG partnership model was now a well practised approach which could be successfully applied to different areas of health research.

The Board congratulated the group on its work and commended its outcomes. Sir John Lilleyman and the members of the group were thanked for their efforts.

9) Workforce and Careers

a) Development and Implementation of Clinical Academic Career Pathways in Scotland
The Board welcomed the paper providing background information and a summary of the development and implementation of clinical academic career pathways in Scotland.

In particular the Board acknowledged the progress that continues to be made in Scotland in relation to the research careers of nurses, midwives and allied health professionals (NMAHP). Scotland has been active in promoting research careers for NMAHPs since 1994 through a strategic process of development and investment. In 2003 a scoping exercise was carried out focussing on nursing and midwifery research capacity and capability in the academic sector. In 2006 this exercise was repeated and it provided evidence of a notable increase in research capacity, capability and activity in the academic departments of nursing and midwifery. The Board recognised that the knowledge and experience gained in Scotland would provide a valuable source of information and support to the work of the UKCRC Subcommittee for Nurses in Clinical Research (Workforce).

b) Workforce and Careers – Update Paper

Members of the Board noted that good progress continues to be made on the delivery of the integrated academic training programmes for doctors and dentists. The second round of selection to academic programmes is underway and the Board noted the information provided regarding appointments made in the first round of appointments to Academic Clinical Fellowships and Clinical Lectureships.

The Board were reminded that the draft report of the UKCRC Subcommittee for Nurses in Clinical Research (Workforce) will be out for public consultation until 30th March 2007.

10) Regulatory and Governance

a) Regulatory and Governance – Update Paper UKCRC/07/08

The UKCRC Board noted the update on work to streamline the regulatory and governance environment and agreed that lots of progress is being made in this Activity and in particular noted that:

The Regulatory and Governance Advice Service, which is aimed at ensuring consistent, authoritative advice, will start UK-wide roll out from April 2007. The Board noted that many people and organisations have contributed to this but that the MRC Regulatory Support Unit and the UKCRN Coordinating Centre have played a central role in ensuring the timely delivery

b) Lilleyman Committee – Update Oral

Professor Sir John Lilleyman reminded the Board that this Working Group had been convened last May to streamline the information requirements for permissions, approvals and reporting. Key regulators, Health Departments and funding bodies were all represented on the Group, which quickly reached an agreement to streamline information requirements through the development of a common study information form.

The Central Office of Research Ethics Committees (COREC) and the NHS R&D Forum have led work to develop this common form, which utilises the filter functionality developed by COREC for the ethics form. The first phase of development has seen the alignment of information requirements for ethics and NHS R&D permission and subsequent phases will
bring in additional organisational approvals. The Board welcomed the news that the product of this work will become tangible in September 2007 when the common study information form is launched and noted that the Group had set aside work on streamlining information requirements for study reporting as the issue was found to be highly complex and with less gain in terms of bureaucracy busting.

The Board noted that this Working Group will not need to meet until such time as the work is completed or additional negotiations are needed. The Board congratulated Sir John on the progress of this significant piece of work.

11) Building up the Infrastructure in the NHS

a) UKCRN – Update Paper UKCRC/07/09

The Board were updated on progress of establishing Clinical Research Networks across the UK. The Board were asked to note the huge amount of work ongoing within UKCRN and two particular areas of activity were highlighted:

- The Clinical Trials Unit registration process will commence imminently and funders were reminded to encourage the Clinical Trials Units they are involved in funding, to take part in the registration process.
- The UKCRN Coordinating Centre have been working to develop a series of performance measures for their activity and as they are now at the point where they need to begin to set specific targets they asked the Board to approve the proposed performance measures.

In discussion the Board highlighted the importance of capturing metrics of patient and public involvement from the outset and they were reassured that this is part of the plan.

The Board approved the proposed performance measures.

b) Experimental Medicine – Update Paper UKCRC/07/10

The Board noted progress in this area.

12) Public Awareness and Patient and Public Involvement Activity – Update Paper UKCRC/07/11

The Board noted progress being made and was briefly updated on the status of current projects.

Public Awareness:

Work continues with the team developing the Centre of the Cell website (led by Professor Fran Balkwill) to provide a signpost to information resources on Clinical Trials to support the ‘Science in Action’ and ‘How Science Works’ aspects of the National Curriculum for science. The Centre of the Cell website is designed as a national resource providing information for teachers and students about health and disease, cell biology and medical research, built around key stages 2, 3 and 4 of the National Curriculum. The development of a UKCRC module on clinical trials fits well with, and compliments the content already developed for the site.

A potentially much larger piece of work focused on public awareness around the use of personal health information for research is now being planned. The starting point for this work is two recent studies commissioned by the MRC and the Wellcome Trust. The two studies used different approaches to exploring public attitudes to the use of personal data for
research but the findings complement each other and together provide a more comprehensive picture of public perceptions and attitudes in this area. The plan is to launch the two reports together towards the end of April. The findings from the two studies will be used as a basis for coordinated public awareness activity around the value of personal health information to medical research. It is planned that this work will be led by the MRC and the Wellcome Trust under the umbrella of the UKCRC Public Awareness Group.

Patient and Public Involvement:
The pilot People in Research website (www.peopleinresearch.org) is now active. The project team is currently receiving feedback on the site from a panel of members of the public. There were originally fifteen organisations in the central database and more are requesting to join. The UKCRC has advertised for patients/members of the public to join some of its advisory groups. Requests for 220 application packs were made and 52 full applications have been received. Interviews will take place over two days at the end of March. The process and impact of involvement will be evaluate before rolling out more widely to other UKCRC advisory groups.

The Board noted the suggestion made to raise this item higher up the agenda at a future meeting and accepted the offer made by Roger Wilson to make a presentation at the June or September Board Meeting providing more detailed information on progress with patient and public involvement in both the UKCRN and UKCRC.

13) Any Other Business

No issues were raised.

Next meeting: 14.00 –17.00 7 June 2007, UKCRC, Himsworth and Fletcher Rooms, 20 Park Crescent, London, W1B 1AL