FINAL MINUTES
UK CLINICAL RESEARCH COLLABORATION
BOARD MEETING 8 October 2015

Minutes of the meeting held on 8 October 2014, Rooms 1&2, 13th Floor, MRC,
One Kemble Street, London WC2B 4TS

Present

Members

Russell Hamilton – Department of Health, England; Acting Chair
Jacintha Sivarajah – The Association of the British Pharmaceutical Industry (ABPI)
Helen Bodmer – Department for Business, Innovation and Skills (BIS)
Aisling Burnard - Association of Medical Research Charities (AMRC)
Sarah Buckland – INVOLVE
Alison Cook – Cancer Research UK (CRUK)
John Williams – Wellcome Trust
Mike Stevens – Scottish Government Health Directorates
Steve Bates – BioIndustry Association (BIA)
Michael Bowdery – Health and Care Research, Wales
John Hughes - Patient/Public Member
John Williams – Academy of Medical Sciences (AMS)
Nick Crabb – National Clinical Institute for Health and Care Excellence (NICE)
Martyn Ward - Medicines and Healthcare products Regulatory Agency (MHRA)
Graeme Rosenberg – Higher Education Funding Councils (HEFC)
Iain Cameron – Universities Representative
Joy Todd – Economic and Social Research Council (ESRC)
Janet Wisely – Health Research Authority (HRA)
Simon Wesseley – Academy of Medical Royal Colleges (AoMRC)
David Wynick - The Association of UK University Hospitals (AUKUH)
Harpreet Sood – NHS England
Phil McCarvill – NHS Confederation
Alan Chant – Patient/Public Member
Tim Cave – Senior Representative from the Pharmaceutical Industry
Tony Peatfield – Medical Research Council (MRC)
David Cox – Department of Health, England (DH)

In attendance

Mark Caulfield – Genomics England
Tamsin Berry – Office of Life Sciences (OLS)
Jim Carter - Medical Research Council (MRC)
Sarah Qureshi – Partnership Manager, UKCRC

Observers

Helen Campbell – Department of Health, England (DH)
Apologies and Announcements

Apologies

- Sally Davies – Department of Health, England (UKCRC, Chair)
- Nick Partridge – Independent (Deputy Chair)
- Janice Bailie – Health & Social Care R&D, Northern Ireland

Announcements

The Board noted that as the UKCRC Chair; Sally Davies was travelling; John Savill (Deputy Chair) was attending another meeting and Nick Partridge (Deputy Chair) was on annual leave, Russell Hamilton was asked to step in and Chair today’s meeting.

1. Minutes of the thirtieth UKCRC Board Meeting

The Board approved the minutes of the last meeting.

2. Matters arising

The Board were informed that an update on AntiMicrobial Resistance (AMR) would be provided at the next meeting and that the new Dean for Trainees, Dave Jones had been invited to a future meeting to report on academic trainees.

All other matters arising were covered in the agenda.

Discussion

3. Genomics England

Mark Caulfield was invited to update the Board on progress on the project since his last presentation in October 2014. He was pleased to report that the project was making a difference already and highlighted progress in the following:

- Northern Ireland & Scotland are now participants in the project.
- Partnerships were working particularly well with 2500 clinicians and scientists involved in Genomics England Clinical Interpretation Partnerships (GeCIP).
- GeCIPs were self-regulating and in cancer, the GeCIPs had enabled the expansion of the number of domains.
- 97.6% of the whole genome had now been sequenced.
- The HRA had granted unique ethical approval for the whole genome sequence.
- A Genomics Expert Network for Enterprises (GENE) Consortium has been established by industry. Twelve companies are working together on 5000 whole genome sequences and to shape the data centre and programme.
- The establishment of eleven Genomic Medical Centres with the NHS allowed even greater participation by patients.
- Patients are able to report outcomes using crowd sourcing Apps.
- The creation of GeCIPs allowed a new approach to working, involving two way dialogue.
- International programmes such as the International Cancer Genome Consortium are increasing.
In discussion the following was raised:

- The greatest advocates of the project were patients, who volunteered not to expect treatment but enrolled to make a difference for a loved one. Making stratified health care in cancer a real possibility.
- As a sign of success of the project companies are choosing to relocate to the UK for ease of access to the project e.g. the testing of cancer cells directly.
- The maintenance of patient and public trust in the project remained paramount.
- The main challenge is not the sequencing but the number of different IT systems that need to be aligned.
- Continued dialogue with the NHS would be highly beneficial to the project.
- The partners involved in the project were UKCRC members. They are closely committed to the project often finding solutions without direct financial gain.

The Board welcomed progress made and asked to be continued to be kept updated on developments.

4. Patient Data and Research

The Acting Chair informed the Board that Tim Kelsey the National Director for Patients and Information, NHS England had contacted the UKCRC Chair this morning to state that as he was stepping down from this position in the near future he had decided to attend an internal NHS England meeting instead. Unfortunately, in the short time available an alternative could not be secured.

The Board expressed their deep disappointment and requested that under the circumstances he be asked to provide a written progress report to the Board and that his successor be invited to update the Board on this most important topic at a future date.

5. Accelerated Access Review (AAR)

Tamsin Berry presented an overview and next steps of the Accelerated Access Review. The review aims to accelerate access to innovative drugs, devices and diagnostics for NHS patients. She highlighted:

- The reasons for the review; Good for patients, NHS, research organisations, charities, business and the UK.
- The independence of review; Sir Hugh Taylor is the Chair and will make recommendations to relevant ministers.
- Set up of the review; it consists of an external advisory group, stakeholder reference group, workstream champions, review team and wider stakeholders.
- The approach of review is to create end to end pathways via four workstreams.
- Each workstream focuses on a set of key questions centred upon sharing (patient and NHS needs), building (on existing regulatory flexibilities), affordability (health and care system) and barriers (reducing and removing).
- Engagement to the review has been very positive, including the public, private and wider community.
- The timeline has had to be revised; the interim report is to be published later this month with the final report in April 2016.

In discussion the following was raised:

- Lessons from the success of the 100,000 Genome Project could be implemented via case studies.
• Partners very much supported the review and were looking forward to receiving the report.
• The strong science and research base in UK created the environment for such a review.
• The main implementation of the review would be in the NHS, it was hoped that this would be addressed in the report.
• Academic Health Science Networks have an important role to play in the process and early dialogue with them should be sort.

The Board requested to be kept up to date with developments.

Reports from Subgroups and Fora

6. Health Research Analysis Forum

Jim Carter reported that the third Health Research Analysis Report (2014) was published online in August. He highlighted that coverage had increased to 64 Funders, 17,000 awards and £3 billion spend. The report demonstrated:

- Increase in health research spending over ten years and a decrease in the growth rate (6.4%).
- Change in the type of research funded from less basic (decrease in underpinning/aetiology from 69% to 50%) to more translational (increase in prevention, detection and treatment development).

During discussion the following was raised:
- Individual funders may wish to investigate the reasons behind the decrease in rate the growth in their fields.
- The gaps identified from the Review of UK Health Research Funding (2006) by David Cooksey were being addressed.
- Charities are looking to demonstrate the impact of research, this data underpins this work.
- The need for each funder to re-assess their objective of undertaking this analysis e.g. to watch trends, to inform strategy etc.
- The work of the forum and production of the report was efficiently done.

The Board looked forward to receiving the proposal from the group for the fourth report.

Activities

7. Update from NHS England

Harpreet Sood reported that the NHS England Research Plan 2015-16 has now been developed with DH. It focuses on three main commitments. The first centres upon influencing the direction of research. This would be achieved through a needs panel, applied healthcare, greater coordination and a national programme of patient recruitment through partnerships with organisations such as Apple and National Voices. The second commitment centred on the creating the right NHS environment that fosters research and involved GP uptake of Clinical Practice Research Datalink (CPRD), excess treatment costs and genomic medicine centres. The final commitment involved translating research into practice and involves a regional central hub, self-assessment for commissioning groups, evaluation of the five year forward plan and decision making master classes.
Regarding Excess Treatment Costs, a task and finish group has been established. NHS England is now working closely with DH and guidance along with a costing template is being released shortly.

Members expressed particular interest in the increase of patient recruitment via the establishment of new partnerships. More information was requested, especially as many members could be at the forefront of such plans.

The Board requested that this useful agenda item remain for future meetings.

Reports from Subgroups and Fora

8. Experimental Medicine Funders Group Oral

Tony Peatfield reported that this group last met in April and were due to meet again at the end of the month. The main highlights of the last meeting were:

- The MRC and NIHR Office for Clinical Research Infrastructure (NOCRI) are scoping the future of the Resource Finder (web platform enabling visibility of infrastructural resources for experimental medicine). Stakeholders include the Precision Medicine catapult.
- The MRC are scoping the opportunity to invest in biobanking as part of the capital roadmap. A business case will need to be considered by BIS in the context of the Comprehensive Spending Review (CSR).

The Board noted progress in this area.

Collaboration

9. Office for Strategic Co-ordination of Health Research (OSCHR) Oral

The Acting Chair reported that George Freeman MP (Minister for Life Sciences) attended the beginning of the last OSCHR Board meeting on 1st July to discuss AAR and access to data. Focussing on a particular clinical area e.g. cancer for AAR and further improvements on access to data were discussed with him.

Other topics discussed during the rest of the meeting included:

- Research Funders working together to support the science ecosystem, specifically health research for the Comprehensive Spending Review (CSR).
- Areas of research activity in the life sciences where the UK could have substantial opportunities and advantages; including:
  - Genetically altered cells as therapies
  - Imaging
  - Informatics application of human biology
  - Manufacturing science
  - Diseases of the developing world
  - Dementia
  - The integration of physics, engineering and chemistry with the life sciences
  - Training

Sally Davies (Chief Medical Officer) requested greater emphasis on AMR and vaccines.
- John Bell (OSCHR, Chair) meeting with Paul Nurse to discuss effective working for the Nurse Review of Research Councils.
- A future topic of discussion on ‘EU and Health Research’ to consider the impact if the UK were to leave the EU.
- Scoping work on Food & Nutrition Science and Health Research drawing together all of the research funder’s activity in human health and food and nutrition science.
The Board noted progress in this area.

10. Comprehensive Spending Review (CSR) Oral

The Acting Chair reminded members that the CSR would be published on the 25th November. Russell Hamilton and Helen Bodmer updated Board members on the current position. Departmental submissions have now been made and bilateral discussions are underway between Departments and the Treasury. The supporting statements and other contributions made by partners on the Board have been very helpful in making the positive case for sustained or increased investment.

11. Dementia UKCRC/15/07

The Board noted this paper for information.

12. Patients and Public in Research UKCRC/15/08

The Board noted this paper for information.

UKCRC General

13. UKCRC Partnership Manager’s Report UKCRC/15/09

The Board noted this paper for information.

14. CTU Network – adhoc call for registration UKCRC/15/10

The Board noted this paper for information.

Activities

15. Update from Health Departments Oral

Developments in Scotland included:
  • NHS Research Scotland annual conference on 28th October. The Scottish Government’s Health and Social Care Research strategy is to be launched at this time.
  • Launch of the fifth round of NRS career research fellowships now taking place, this year focused on building NMAHP capacity.
  • Scottish Government Spending Review decisions will follow the English CSR announcement in November.

Developments in Wales included:
  • Successful launch event for Health and Care Research Wales on 14 May 2015, a new external brand that has a similar relationship to Welsh Government R&D as NIHR to DH.
  • After restructuring, new infrastructure is now in place (and developing well) with the exception of our School for Social Care Research, which is due to be launched early next year. Changes include five new Health and Care Research Wales Centres – in population health, cancer, primary care, mental health and ageing and dementia – and three new Units in diabetes, kidney disease and brain research.
  • National population study, HealthWise Wales, currently being piloted and due to be formally launched on 1 Feb 2015.
  • Full engagement in cross-country compatibility discussions to ensure that the new HRA systems feel as seamless as possible for researchers.
Developments in England included:

• NIHR themed call for research on obesity launched on 16th September with a focus on prevention of type 2 diabetes and increasing levels of physical activity.
• NIHR workshop on the public health research funding landscape on the 21st September and involved the MRC.
• NIHR and Royal College of Psychiatrists are organising a meeting on 2nd November to help identify the key research questions in mental health research.
• AMRC-NIHR workshop on ‘Getting the most out of clinical research’ focussing on the four stages of research (right question; right design; done right; told right). Key outcome was an agreement that NOCRI and AMRC working together to help signpost charities and researchers to the right individuals to support development of effective collaborative partnerships.
• UK Clinical Trials Gateway has been developing over the summer with a new look and significantly improved stability. A ‘widget’ has been developed that will allow direct link from a website without the need to develop further codes.

The position of Chief Scientific Advisor and First Deputy Chief Medical Officer Department of Health has recently been advertised following Sally Davies’s decision to step back from the day to day leadership role for research and development. This is a senior strategic post and will have a planned transition.

The Board noted progress in these areas.

16. Update from Health Research Authority  Oral

Janet Wisely reported that the roll out of the new HRA approval process is proceeding successfully. The roll out is phased by study type and the last cohort (4) is due to take place at the end of March 2016. The original timetable for roll out has had to be amended because of changes required to the Integrated Research Application System (IRAS). Regional Ethics Committees are the last component and opinion rates remain high. It has been found that the quality of the application makes a difference for the time taken to process; the better quality the application the quicker the process.

Martyn Ward reported that implementation of the EU Clinical Trials Regulation in the UK was dependent on the EU portal. The earliest that this would now be available was at the end of 2017. Partners should await developments with the EU portal before details of implementation.

The Board noted progress in these areas.

17. Open session of new research initiatives (Charity Partners)  Oral

Charity Partners (AMRC & Wellcome Trust) were invited to given an update on research initiatives that they are involved in.

Nicola Perrin reported that the strategic framework of the Wellcome Trust is due to be published in late October, this coincides with the appointment of a new Chair (Dame Eliza Manningham-Buller), it will set out the priorities for the organisation and moves forward from previous strategies. Recent initiatives include:

• ‘Our planet, our health’: £75 million investment in a new initiative to investigate the connections between environment and health over the next five years. This includes a call for ambitious, transdisciplinary programmes to address the challenges associated with the global food system and / or urbanisation.
• Developing Excellence in Leadership, Training and Science Initiative (DELTAS). This is in collaboration with the Department for International Development (DFID), seven
leading African researchers are being awarded funding to establish cutting-edge research and training programmes across the continent.

- Funding for the establishment of the Accelerating Excellence in Science in Africa (AESA) platform. This includes DFID and the Gates Foundation and aims to coordinate research across the continent.
- Collaboration with the AMS to produce a report regarding antiviral drugs in epidemics.

Aisling Burnand reported that the AMRC would be publishing their strategy for the next 3-5 years in the near future. Other relevant initiatives include:
- New infographic demonstrating investment, innovation and impact of research (circulated).
- Follow-up to the joint ‘Getting the most out of clinical research’ workshop with NIHR, involving a number of chief executives of health charities meeting with the Chief Executive of NHS England (Simon Stevens) in the near future.
- Annual conference will take place on 26th November.

The Board noted progress in these areas.

Other

18. Any Other Business

The Acting Chair reported that a green paper on higher education will be published later this year. The paper will consult on changes required to remain competitive in the world economy.

He also reminded the board that the Nurse review of research councils is due to be published shortly.

Next meeting is on 12th May 2016 from 2pm-5pm. Rooms 1&2, 13th Floor, MRC, One Kemble Street, London WC2B 4TS.