MINUTES
UK CLINICAL RESEARCH COLLABORATION (UKCRC)
BOARD MEETING 6 October 2016

Minutes of the meeting held on 6 October 2016, Seminar Rooms, Francis Crick Institute, Midland Road, London NW1 1AT

Present

Members

Chris Whitty – Department of Health, England; Chair
Mike Thompson – The Association of the British Pharmaceutical Industry (ABPI)
Stephen Axford – Department for Business, Energy and Industrial Strategy (BEIS)
Catherine Ball - Association of Medical Research Charities (AMRC)
Simon Denegri – INVOLVE
Pamela Kearns – Cancer Research UK (CRUK)
Nicola Perrin – Wellcome Trust
Ricky Verrall – Scottish Government Health Directorates
Naho Yamazaki – Academy of Medical Sciences (AMS)
Sarah Garner – National Clinical Institute for Health and Care Excellence (NICE)
Michael Rawlins - Medicines and Healthcare products Regulatory Agency (MHRA)
Steven Hill – Higher Education Funding Councils (HEFCE)
Tony McEnery– Economic and Social Research Council (ESRC)
David Wynick - The Association of UK University Hospitals (AUKUH)
Kate Ravenscroft – NHS Confederation
Alan Chant – Patient/Public Involvement (PPI) Member
John Savill – Medical Research Council (MRC, Deputy Chair)
Nick Partridge – Independent (Deputy Chair)
Ian Young – Health & Social Care, Northern Ireland (NI)
Louise Wood – Department of Health, England (DH)
Alistair Henderson - Academy of Medical Royal Colleges (AoMRC)
Bernie Hannigan – Public Health England (PH England)

In attendance

Sarah Qureshi – Partnership Manager, UKCRC
Jim Smith – Crick Institute (item 1 only)

Observers

Helen Campbell – Department of Health, England (DH)
David Cox – Department of Health, England (DH)
David Warriner – Academy of Medical Royal Colleges

1. Welcome to the Crick Institute

The Chair welcomed the Board to their first Board meeting at the Crick Institute and introduced Jim Smith, Director of Research. Jim Smith emphasised that the Crick Institute was building a greater network than just the building via its interactions and career structures. It has a UK wide network via group leaders who are at the early stage of their careers. They aim to produce a steady state of 20-25 tenure staff and 70 junior staff with approximately six new leaders a year who will populate the rest of the UK. They also have link labs and placements in industry and academia.
2. **Apologies and Announcements**  

**Apologies**

- Simon Wessely (Academy of Medical Royal Colleges)
- Harpreet Sood (NHS England)
- Steve Bates – BioIndustry Association (BIA)
- Alex Newberry – Health and Care Research, Wales
- Iain Cameron – Universities Representative
- Janet Wisely – Health Research Authority (HRA)
- Tim Cave – Senior Representative from the Pharmaceutical Industry

**Announcements**

The Chair welcomed Public Health England as a Board Member, represented by Professor Bernie Hannigan

3. **Minutes of the thirty-second UKCRC Board Meeting**  

**The Board approved the minutes of the last meeting.**

4. **Matters arising**  

**The Board were informed that the final report on Accelerated Access Review (AAR) is expected to be published shortly and that a representative from Genomics England will be invited to a future Board meeting, as well as John Watson (Deputy Chief Medical Officer) for an update on AntiMicrobial Resistance (AMR). All relevant updates would be circulated.**

All other matters arising were covered in the agenda.

**Discussion**

5. **Academic Trainees**  

**The Chair introduced Dave Jones, National Institute for Health Research (NIHR) Dean for Trainees. The following was highlighted in his presentation:**

- The new ‘Platinum Guide’ is a simplification of existing guidance and is currently undergoing a final review before publication.
- The guide will contain a new document ‘principles and obligations’ setting out responsibilities of funders, trainees and Postgraduate Deans.
- Operational structures have been amended to include think-tanks, operational and working groups.
- Analysis of the first destinations, success rates and gender distribution of Academic Clinical Fellows (ACFs) and Clinical Lecturers (CLs) appears to show that the model is working with ongoing concerns regarding employment rights.
- A tracking project surveying completed ACFs has taken place with positive results. Further work will now look at trainee career progression.
- A review of NIHR training is ongoing.

The UK Shape of Training Steering Group (UKSTSG) was established in response to the Greenaway report and will address academic pathways shortly. It was explained that in Northern Ireland a parallel independent scheme is run which participates in NIHR rounds and that in Scotland the infrastructure is different and therefore does not translate in the same way.
During discussion the following was raised:
- The Academic Leads would be meeting with Dave Jones in the near future.
- Trainees remain ‘in programme’ during these posts and the term ‘out of programme’ is unhelpful.
- The introduction of the new practice of trainees paying back training fees if they leave within four years of NHS training will need to be observed to see if it affects numbers.
- Incentives may be required in certain areas e.g. elderly care.
- Workforce planning is historically poor in the NHS.

The Board requested that a future agenda item should be non-clinical trainees.

6. **Leaving the EU: Implications and Opportunities**

The Chair introduced this discussion item by explaining that the result of the referendum on the 23rd June would lead to Britain leaving the EU. Recently the Government had indicated a timetable and now it was time for Partners to assist in making plans for exit. The Government would be seeking advice from Partners who would have to be prepared. Partners would also need to be organised as the Government forms its policy for the Life Sciences Industrial Strategy and in preparation for the Spending Review.

Mike Thompson reported that the ABPI was part of a taskforce that had reported to Ministers. Four main areas were identified, they were:
- Long-term research funding. The government has now underwritten funding for approved Horizon 2020 projects before the UK leaves the European Union and extended the biomedical catalyst.
- Trade goods. There are approximately 0.5 million medical devices on the market. These are regulated via the CE mark (European Conformity) and are used by those with associate status such as Turkey and Australia.
- Regulatory framework. Regulations would be required to be recreated in UK legislation along with a greater understanding of pharmacovigilance databases.
- Attracting and retaining talent. The Government appear to have a clear understanding of this issue as it involves attracting the best people in the world.

Public Health was also found to be an extremely important consideration.

Catherine Ball reported that the main issues for the AMRC were:
- Ensuring participation for collaboration.
- Free movement of staff (including support staff e.g. technicians and qualifications).
- Access to emerging technologies.
- Rare diseases (regarding access to a greater patient population in the EU).

In addition, consideration needed to be taken into account that Northern Ireland is the only UK nation to share a land border with the EU and the sensitive political environment e.g. the potential for a second referendum in Scotland.

During discussion the opportunities afforded by Brexit were found to include:
- The NHS, in particular the records kept on patients e.g. in the US data is lost when patients change medical insurance company.
- The attitude of the British public to health research and the vision that ‘every willing patient is a research patient’.
- Introduction of greater flexibility where there previously was very little e.g. the scope to accelerate and adapt licences.
- Global reputations of UK organisations such as MHRA and NICE and the links between them.
- Collaboration in public health included global disasters and the co-ordination of funders.
• The possibility of sharing inspections with other organisations.

The Board agreed that a co-ordinated approach was required and this could be best achieved via the UKCRC as the most representative group. It was proposed that the UKCRC compose views and ideas that included relevant data and analysis. As a next step a smaller group led by Chair with the deputy Chairs, ABPI, WT and Devolved Nations would agree a template for Partners to complete and collate the responses for the end of calendar year.

**Activities**

7. **Update from Health Departments**

Developments in Scotland included:
- Ricky Varrall’s appointment as the new Head of Chief Scientist Office, Scotland taking over from Mike Stevens.
- Following the Scottish elections in May, re-arrangement in the same administration with a new research cabinet secretary. The key manifesto pledges are being taken forward via Programme for Scotland in particular to support world class research in Scotland’s universities, support innovations centres and three new PhD’s in Motor Neurone Disease and Multiple Sclerosis.
- Following launch of the Scottish government health and Social Care Research Strategy in November last year, a re-focussing on research grant schemes with additional emphasis on translational health research.
- Scottish Genomes Partnership that includes genomic research partnerships on cancers, rare diseases, Scottish cohorts and collaboration with Genomics England for the enrolment of Scottish rare diseases patients in the 100,000 genomes project.
- Scottish Precision Medicines Ecosystem bringing together key assets across Scotland coordinated by Stratified Medicine Scotland Innovation Centre to support development of precision medicine.
- Budget cuts in the region of £2 million this year; therefore challenges for future budgets and the need to re-enforce the benefits of the research base.

Developments in Northern Ireland included:
- The NI Programme for Government 2016-21 is currently in draft form, but will emphasise the importance of research for the benefit of patients and the economy and in its final form is likely to contain a number of positive commitments in relation to research funding and strategy.
- A Life and Health Sciences Strategy is being jointly developed by the Departments of Economy and Health.
- There will be an increased focus on the development of all-Ireland research linkages in relation to healthcare research.
- A review of all research infrastructure and processes will be conducted with a view to maximising the benefits from current investment.

Developments in England included:
- The appointment of new Ministers and restructuring of government departments. As a result a 30% reduction in staff will take place in the Department of Health. The NIHR programme budget will not be affected.
- Biomedical Research Centres competition outcome announced.
- Funding for 19 Clinical Research Facilities for Experimental Medicine – announcement imminent.
- Close of the call for Patient Safety Translational Research Centres.
- New call for MedTech and InVitro Diagnostics Co-operatives.
- Working group on brain tumour research.
• A new research and Innovation team at NHS England, which will continue to address concerns on Excess Treatment Costs.
• The development of further partnerships in mental health research.
• Retirement of a long time member of staff, David Cox. The Board thanked him for his valuable contribution over the years.

The Board noted progress in these areas.

8. Update from NHS England Oral

The Chair informed the Board that due to apologies there would be no update from NHS England. As the research and innovation team at NHS England was being re-organised the Chair agreed to write to them to encourage them to attend future meetings.

9. Update from Health Research Authority Oral

Louise Wood reported that Jonathan Montgomery, Chair of the HRA sent their apologies. This was due to Janet Wisely being unwell. In the interim Teresa Allen would be leading the organisation. The surge in amendments is being addressed and is being kept under review.

The Board noted progress in these areas.

10. Open session of new research initiatives (Others) Oral

Partners were invited to give an update on research initiatives that they are involved in.

John Savill (MRC) reported the:
• Appointment of a Director for the UK Dementia Research Institute.
• Launch of the search for a Director to lead the new UK Institute for Health and Biomedical Informatics Research.

Naho Yamazaki (AMS) reported the:
• Launch of the Health of the Public in 2040 report. The report explores how the UK’s public health research environment needs to adapt to meet the complex health challenges the population will face by 2040.

Alistair Henderson (AoMRC) reported that:
• The Academy was keen to engage further with Partners in initiatives, both as individual colleges and as the Academy as a whole.
• Guidance would be issued on 50 clinical interventions of limited value with alternatives. Allowing clinicians to choose wisely as to whether the procedure is really necessary.

The Board noted progress in these areas.

Collaboration

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

John Savill reported that the last OSCHR Board meeting was on 21st June 2016. Items discussed included:

• A discussion on venture capital for new companies with Neil Woodford.
• The Precision Medicine Catapult.
• Initial progress made by the Health Informatics sub-board.
• Allocation and co-ordination of the first two years of the Global Challenges Research Fund.

The Board noted progress in these areas.

12. **Higher Education and Research Bill**  

John Savill reported that the Bill was making its passage through parliament. The Bill represented the reorganisation of Higher Education and the Research Councils in the UK and was due to come into force by April 2018. The first step was the appointment of a Chief Executive for the newly created UK Research and Innovation (UKRI). As part of these changes Research Councils will lose their Royal Charters.

It was noted that this a profound reorganisation, throughout these changes the organisations involved sought to provide quality work, as usual.

The Board noted progress in this area.

13. **Patient Data and Research**  

Nicola Perrin reported that the third Caldicott report was published in July. The report supports greater transparency and opt-outs for patients that wish for their data to only be used by those caring for them. Care.data has been abandoned; the concept however remains. The Wellcome Trust has therefore established an independent group, supported by the MRC, DH, PH England, ESRC, AMS, Farr Institute and patient groups. Its priorities are:

• Producing practical deliverables, consisting of tools and resources such as a bank of case studies.
• Developing better stakeholder engagement and media (especially as the vocabulary is confusing).
• Providing a think-tank to provide leadership on issues such as wearable apps, do/don'ts etc.

Following discussion the following points were raised:

• Following the finding that more extensive dialogue with the public was required taking the time to do it right this time.
• The Royal College of GPs is fully engaged.
• The AMRC are compiling a booklet conveying the importance of data.
• Global centres of excellence may be the best way forward.

It was emphasised that is not a re-badging of care.data and that it was important to note the change in narrative which was; data for direct care. Instead the emphasis was now on; improving your health, that of your family and then research.

The Board noted progress in this area.

14. **Clinical Data Sharing**  

Nicola Perrin reported that the Wellcome Trust was taking part in joint meetings with the International Clinical Medical Journals (ICMJ) to discuss common issues such as the practice of journals, resources required and de-identification. The next meeting will be next month. Funders were encouraged to assist in finding mechanisms with a push-pull approach.

The Board noted progress in this area.
UKCRC General

15. **UKCRC Partnership Manager’s Report**  UKCRC/16/06

Sarah Qureshi referred to the paper and reported that there were no significant variances to report in the current financial year (2016-2017).

The Board noted the current financial position of the UKCRC.

16. **Pregnancy Research Review**  UKCRC/16/07

The Chair referred the Board to the paper and the request for the UKCRC to set a specialist subgroup in this area. It was highlighted that NICE had also recently made recommendations that identified gaps in this area and that a global forum was taking place next month looking at policy.

The Board agreed a subgroup should be formed. Partners were asked to send their recommendations for the Chair and members including secretariat of the group to Sarah Qureshi.

Other

17. **Any Other Business**  Oral

**Patients First Conference**

Catherine Ball informed the Board that the Patients First conference will be taking place at the Royal College of Physicians on 28th November. This is a new conference from the AMRC and ABPI which brings together everyone involved in delivering better outcomes for patients and placing patients at the heart of the discussion. Partners were invited to attend and publicise.

**Board meetings in 2017 were confirmed as 11th May and 12th October from 2pm-5pm.**