MINUTES

UK CLINICAL RESEARCH COLLABORATION (UKCRC)
BOARD MEETING 11 May 2017

Minutes of the meeting held on 11 May 2017, Jenner Room, Wellcome Trust, Gibbs Building, 215 Euston Road, London NW1 2BE

Present

Members

Chris Whitty – Department of Health, England; Chair
Mike Thompson – The Association of the British Pharmaceutical Industry (ABPI)
Helen Bodmer – Department for Business, Energy and Industrial Strategy (BEIS)
Aisling Burnand - Association of Medical Research Charities (AMRC)
Simon Denegri – INVOLVE
Pamela Kears – Cancer Research UK (CRUK)
Nicola Perrin – Wellcome Trust
Ricky Verrall – Scottish Government Health Directorates
Naho Yamazaki – Academy of Medical Sciences (AMS)
Carole Longson – National Clinical Institute for Health and Care Excellence (NICE)
Michael Rawlins - Medicines and Healthcare products Regulatory Agency (MHRA)
Ed Hughes – Higher Education Funding Councils (HEFCE)
Tony McEnery– Economic and Social Research Council (ESRC)
Jonathan Weber - The Association of UK University Hospitals (AUKUH)
Phil McCarvill – NHS Confederation
Alan Chant – Patient/Public Involvement (PPI) Member
David Lomas – Medical Research Council (MRC)
Ian Young – Health & Social Care, Northern Ireland (NI)
Mike Batley – Department of Health, England (DH)
Neena Modi - Academy of Medical Royal Colleges (AoMRC)
Bernie Hannigan – Public Health England (PH England)
Lindsey Hughes – NHS England
Steve Bates – BioIndustry Association (BIA)
Michael Bowdery – Health and Care Research, Wales
Cyrus Cooper – Universities Representative
Tim Cave – Senior Representative from the Pharmaceutical Industry
Phil Brown – Association of British Healthcare Industries (ABHI)
Teresa Allen – Health Research Authority

In attendance

Sarah Qureshi – Partnership Manager, UKCRC
Nathan Moore – Office for Strategic Co-ordination of Health Research (OSCHR)
Hannah Brown – Office of Life Sciences (OLS, items 1-5 only)

Observers

Helen Campbell – Department of Health, England (DH)

1. Welcome and Apologies Oral

The Chair welcomed the Board to the meeting.
Apologies

Nick Partridge – Independent (Deputy Chair)

2. Minutes of the thirty-third UKCRC Board Meeting UKCRC/17/01

The Board approved the minutes of the last meeting.

3. Matters arising Oral

The Board were informed that final Accelerated Access Review report was released last year, at the next Board meeting in October the Head of Vaccines (Alex Mclauglin) at DH has been invited for an discussion item as well as the Deputy Chief Medical Officer (CMO) to give an update on Antimicrobial Resistance (AMR). A discussion item on non-clinical trainees is being organised for a future meeting along with an update on Genomics England. All relevant updates would be circulated.

All other matters arising were covered in the agenda.

Discussion

4. Life Sciences Industrial Strategy Oral

The Chair introduced Hannah Brown from the Office of Life Sciences. She presented the draft of the UK Life Sciences Industrial Strategy being developed. The following was highlighted in her presentation:

- The vision of the UK Life Sciences Strategy is to make the UK the home of clinical research and medical innovation.
- This would be achieved through 4 pillars: Science, Growth, NHS and Digital with two themes running across these pillars: Skills and Regulation.
- Sixteen draft recommendations have been put together.
- Draft success metrics have also been created (the majority of which will be measured after the strategy has been in place for more than five years).
- Potential Grand Challenges are being developed.
- Sector Deals will be proposed.

During discussion the following was raised:

- Relevant Ministers across all parties are supportive of the strategy.
- The strategy takes a strong lead from industry.
- The strategy contained the long cycles of investment required.
- This strategy will provide stability during the disruption of leaving the EU.
- Innovation is the way forward for the NHS particularly as demand on the NHS is ever increasing.
- The strategy could be seen as the development of industrial policy, driving more investment in universities and faster growth for companies.
- The strategy will need to feed into regional strengths and be in synergy with regional strategies in place.
- Industry involvement in preventive health and health promotion was missing.

The Board asked to be kept up to date with developments.
5. **Leaving the EU: Opportunities and Implications**

The Chair introduced this discussion. Following the last Board meeting, the UKCRC had produced a short brief and the Prime Minister had decided to hold a General Election. With a new government in place it would be several months before it could articulate the UK position. It was the duty of Partners to ensure that the health sector was one of the best prepared sectors on Leaving the EU. A useful discussion focussed on the importance of industry and academic engagement followed.

The Board requested that this topic remain on the agenda.

6. **Patient Involvement and Engagement**

The Chair invited Simon Denegri (INVOLVE), Aisling Burnand (AMRC) & Nicola Perrin (WT) to update the Board on Patient Involvement and Engagement in Health Research. During their presentation the following was highlighted:

- The inaugural Patients First joint conference (AMRC & ABPI) took place last year, was well attended and received very positive feedback (including social media).
- The 'Delving into Digital' Conference showcasing the potential of the medical charity sector in digital health was well received with very positive feedback (including social media).
- Understanding Patient Data has three main work streams: developing tools and resources, supporting conversations and analysis and horizon scanning.
- The UK is ranked 1st in adding value to research via patient involvement.
- A revamp of UK Clinical Trials Gateway website has taken place.
- International networks are now being developed.

During discussion the following was raised:

- Compliance can be detrimental to patient involvement and engagement.
- A communications strategy is required regarding the use of clinical data to convince the public.
- As an example, parents of paediatric patients trust doctors, but not the government or industry regarding the use of data. They also insist that the data must be used. Therefore greater dialogue with profession, family and industry was required.
- The nutrition industry was not around the table.
- The NHS is better at collecting data than analysing it.
- Data privacy groups are well organised and vocal.
- Real obstacles and opposition still exist regarding patient involvement in clinical research in organisations such as the BMA.

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

**Activities**

7. **Update from Health Departments**

Developments in Scotland included:

- Publication of Health and Social Care Delivery Plan. This focuses on transformation of health and social care services driven by four programmes of activity: health and social care integration, National Clinical Strategy, public health improvement and NHS Board reform.
- Research and innovation are a cross cutting theme in the plan, making commitments to: continuation to invest in NHS research, renewed coherent push on innovation, create governance structures to support the promotion and exploitation of health-related innovation, develop regional innovation clusters to translate research and innovation into
health care and supporting innovation and technology capacity building at national, regional and local levels.

- Refreshed Scottish life science strategy, with the ambition to grow the life sciences sector to £8 billion by 2025.
- Survey of key stakeholders in Scottish academic health research community on the implications of Leaving the EU. Based on UKCRC survey with similar issues and challenges identified to the UKCRC survey.
- Scottish Genomes Partnership with Genomics England which will progress all necessary agreements and approvals in place and referral of NHS Scotland rare disease patients into the 100,000 genomes programme in April 2017.
- Partnerships with other health research funders in health Data research UK and the UK Prevention Research partnership co-ordinated by the MRC.
- Appointment of Andrew Morris as Director of Health Data Research UK.
- Budget reduced by £2 million from last financial year and pressure for further savings.

Developments in Wales included:

- Welsh Government Strategies/Reviews, continuing to ensure the importance of strong health and social care R&D is recognised in the Welsh Government Strategies and by the Parliamentary Review of Health and Social Care in Wales and the Reid review on Research and Innovation in Wales.
- Renewal of Health and Care Research Wales Centres, Units, Infrastructure Support Groups and Clinical Trials Units, all groups are currently applying for two year extensions (April 2018 – March 2020) to their current grant terms.
- A recent advertising campaign has resulted in a significant increase in recruitment to HealthWise Wales. A strategic approach to recruitment in the NHS is now underway with over 10,000 individuals signing up.

Developments in Northern Ireland included:

- Publication of Systems not structures: Changing Health and Social Care (HSC), a ten year strategy. This includes the establishment of an Improvement Institute building on Improvement and Innovation Hubs in each NI Trust.
- Closure of the consultation period on Economy 2030: an Industrial Strategy for Northern Ireland. Responses are being considered with Life and Health Sciences being one of six areas with a focus on Diagnostics and Precision Medicine, Digital Health and Clinical Trials.
- Comprehensive review of HSC Research Infrastructure. The responses from the open consultation are being considered from which recommendations will be developed followed by further consultation and implementation.

Developments in England included:

- Progress with Genomics England: the programme is now UK wide; there is research data access to the first 20,000 genomes and now a boost to recruit cancer patients.
- The DH Policy Research Programme (national research funding programme) is being integrated into the NIHR.
- Establishment of 13 NIHR Global Health Groups, currently developing initiatives.
- Strengthening infrastructure via 5-year contracts for the 20 NIHR Biomedical Research Centres and 3 NIHR Translational Research Centres.
- Reduction of staff across the whole of the Department of Health by 30%, the science, research and evidence department were subjected to an 18% reduction.

The Board noted progress in these areas.
8. Update from NHS England

Lindsey Hughes reported that:
- The establishment of a new Innovation and Research Unit, amalgamating previous individual research and innovation teams.
- Following publication of the research plan for this year, development of a comprehensive strategy. This work is at the early stages of internal consultation and will respond to the Industrial Strategy and Life Sciences Industrial Strategy.
- A joint piece of work with the Science, Research and Evidence team at DH and PHE to review issues encountered with Excess Treatment Costs and to develop more effective solutions.
- Working with the Science, Research and Evidence team at DH to better articulate NHS England's and system research needs to identify alignment with current funding and understand any gaps.
- Working closely with MHRA to support further adoption of Clinical Practice Research Datalink (CPRD) within GP practices, including a cross organisational approach.

The Board noted progress in these areas.

9. Update from Health Research Authority

Teresa Allen reported that the HRA had largely overcome the initial problems encountered with the approval process throughout the UK. Rapid assessment was now taking place with evidence mounting that the rate limiting step was the missing information needed to support an ethics decision. HRA have introduced direct contact details and published hints and tips for applicants. The next phase would be service improvement and adding value by taking out wasteful steps in the process and using technology differently.

During discussion the following was raised:
- The approvals system had now developed into a relatively smooth process.
- R&D departments in NHS Trusts that did not allow investigators to contact the HRA directly were now becoming an issue.
- The Care Quality Commission (CQC) could be asked to monitor the R&D Departments to overcome this.
- The worst offenders could be named and shamed.
- Contracting continues to be a bottleneck; the introduction of further standardisation would overcome this.

The Board noted progress in these areas.

10. Open session of new research initiatives (Others)

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

Jonathan Weber (AUKUH) reported that it is pursuing its research agenda in conjunction with the Medical Schools Council.

Cyrus Cooper (Uni Rep) reported that universities will have a link to UK Research and Innovation (UKRI) and the creation of 4-6 new bio-informatics hubs.

David Lomas (MRC) reported that following the appointment of Andrew Morris as Director of Health Data Research UK further investment in the health records industry would be sought.

Nicola Perrin (Wellcome Trust) reported that it was leading a discussion on increasing vaccines expertise (regulators, policymakers, researchers and developers) via social media.
Mike Rawlins (MHRA) reported that the Royal College of Surgeons had transformed research in surgery via their surgical trial units. They were now considering allowing trainees to complete these ‘in programme’.

Naho Yamazaki (AMS) reported that it was undertaking a project examine how we can all best use evidence to judge the potential benefits and harms of medicine. The report is due to be published in June.

The Board noted progress in these areas.

Subgroups and Fora

11. Clinical Trials Unit Network  UKCRC/17/02
The Board noted this paper for information.

12. Translational Infection Research Initiative  UKCRC/17/03
The Board noted this paper for information.

Collaboration

13. Office for Strategic Co-ordination of Health Research (OSCHR)  Oral
Nathan Moore reported that the OSCHR Board had met twice since the last UKCRC Board meeting. Items discussed included, industrial strategy (feeding into the Life Sciences Industrial Strategy), nutrition research (following the recommendations of the MRC published report) and public health research (a sub-board has been created). The next OSCHR Board meeting would be on 8th June.

The Board noted progress in these areas.

Helen Bodmer reported that the Bill had received Royal Assent and has therefore become an Act. Mark Walport has been appointed the Chief Executive Designate of UKRI. Importantly the Haldane principle was enshrined within the Act and UKRI would operate as a non-departmental public body.

The advert for UKRI Board members is now closed with a very large number of applicants applying. Executive Chairs have been appointed in Research England; David Sweeney and the Arts and Humanities Research Council; Andrew Thompson.

The Board noted progress in this area.

15. Clinical Data Sharing  Oral
Nicola Perrin reported that it was decided that a platform was required to explain how data is used in the NHS and the Understand Patient Data website has now been developed by funders. Academics were now being given equivalent space on the site. During discussion it was raised that industry should now be integrated into this platform.

The Board noted progress in this area.
UKCRC General

16. UKCRC Partnership Manager's Report UKCRC/17/04

Sarah Qureshi reported that this was a standing item detailing the work of the Partnership Manager and the financial position of the UKCRC. There were no significant variances to report in the last financial year (2016-2017) and the running costs of the UKCRC were under budget.

The Board thanked the Partnership Manager and approved the budget (2017-2018).

17. Pregnancy Research Review UKCRC/17/05

Sarah Qureshi reported that Peter Brocklehurst had agreed to Chair this group. The Board was referred to the Terms of Reference of the group in the paper.

The Board agreed the Terms of Reference of the group and requested that Royal College of Paediatrics and Child Health (RCPCH), affiliated charities and NHS England be considered as additional members to the group.

Other

18. Any Other Business Oral

R&G Forum

The Chair reported that Jonathan Montgomery had agreed to Chair this Forum.

Code of Conduct for Companies

The BIA is reviewing its code of conduct for companies on rule for disclosure to the stock market in the light of recent developments in scientific publishing (online journals with peer reviewed material online etc.), the promotion of poster extracts the promotion of poster extracts and how companies with financial disclosure responsibilities can navigate this new world. Partners interested in participating were encouraged to contact the BIA/Steve Bates.

A Spotlight on Mental Health Research

Aisling Burnand brought to the attention of the Board this report that highlights the positive mental research charities are making for mental health patients. The link would be circulated.

The next Board meeting was confirmed as 12th October from 2pm-5pm.