1. Welcome and Apologies

The Chair welcomed the Board to the meeting.

Apologies

Phil McCarvill – NHS Confederation
Ian Young – Health & Social Care, Northern Ireland (NI)
Phil Brown – Association of British HealthTech Industries (ABHI)
2. **Minutes of the thirty-fifth UKCRC Board Meeting**

The Board approved the minutes of the last meeting.

3. **Matters arising**

The Board were informed that an update on Antimicrobial Resistance (AMR) by the Deputy CMO Jonathan Van Tam has been arranged for the next UKCRC Board meeting in October along with the proposal of cross-funder consortium on clinical academic workforce.

All other matters arising were covered in the agenda.

**Discussion**

4. **Non-Medical Trainees**

Lisa Cotterill presented ‘Clinical Academic Careers for Non-Medical Professionals’. She highlighted the following:

- Since the publication of the Finch Report by the UKCRC in 2007, academic training programmes had been launched and refreshed resulting in a consolidated programme with an extended remit.
- The success rates between applications and awards was a particular problem in nurses and midwives.
- Dentists were doing well.
- It was found that progression after completion of the Masters in Research (MRes) was largely back to clinical practice.
- Progression to combined clinical and academic practice following completion of Clinical Doctoral Research Fellowships offered by the NIHR and Health Education England (HEE) was good.
- Following the NIHR Training review a cross-funder review group led by the NIHR and HEE was established to address career pathways for non-medical clinicians.
- Role models and advocates were being developed.
- Key Challenges included awareness of opportunities, variability in NHS Trust support across the country and within them, competing demands on time, supporting trainees during transitions (e.g. pre-doc to PhD), multi-professional support and training, UK wide support and the role of the Clinical Academic Training stakeholder group.

During discussion, the following was raised:

- The rate of entry was encouraging but was not fast enough to close the gap already generated.
- Cultural issues still remain, particularly in nursing and midwifery and tend to be due to service requirements.
- Frustrations remained on funding and remit.
- There is a need to pool resources.
- Engagement with the Royal College of Nursing would be beneficial.
- A career stream for technology may need to be developed. The UK Research and Innovation (UKRI) Innovation Fellowships could address some of the issues in this area.

The Board asked for a future discussion item to be on basic scientists trainees and that a meeting be convened for relevant parties to decide the way forward for Non-Medical trainees.
5. **Genomics England and 100,000 Genome Project Update**

Mark Caulfield presented ‘Update on 1000,000 Genome Project’. He highlighted the following:

- 70,000 of the people required for the project have been recruited.
- Genomic data will assist in detecting rare genetic disease earlier and therefore reduce clinical costs.
- 24 countries across 364 academic institutions are involved in the Genomics England Clinical Interpretation Partnership.
- The UK are world leaders in this area.
- This work will result in new diagnostics, therapies and opportunities for patients.

During discussion, the following was raised:

- The deadline for sequencing 100,000 genomes by the 31st December 2018, remains ambitious.
- Patient confidence and suspicions of data sharing could affect a successful outcome.
- The conduct of PPI participation from the outset has demonstrated how well this partnership can work. For example, PPI were part of the development of consent procedures.
- Tribute was paid to Sue Hill (Senior Responsible Officer for Genomics in NHS England) and Ellen Graham (Deputy Director Genomics – NHS England).
- Expansion could include sequencing of the UK Biobank.
- Collecting tumours to determine germ lines could become routine if the capacity for interpreting the results is available.
- There is a need to manage expectations of patients and clinicians.
- This work displays a great opportunity to create an industry and was driven by the Life Sciences Strategy.

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

6. **Leaving the EU**

The Chair introduced this discussion. Since the last Board meeting Government negotiation on the principles were ongoing, a transition period has been agreed and the European Medicine Agency (EMA) would relocate to Amsterdam. A useful discussion followed and Partners were encouraged to highlight the specific benefit to European countries in any proposals put forward.

This item would remain a standing discussion item.

**Subgroups and Fora**

7. **Pregnancy Research Review Subgroup**

The Chair reported that this Subgroup had put together a proposal that a research project be commissioned to collect and map data on current pregnancy research funding activity and explore the research needs and priorities in the area of pregnancy research. The NIHR have agreed to commission the report.

The Board approved the proposal.

8. **Clinical Trials Unit Network**

The Board noted this paper for information.
9. Experimental Medicine Funders Group

The Board noted this paper for information.

10. Health Research Analysis Forum

Sarah Qureshi reported that the Forum had put together a proposal for conducting the fourth UK Health Research Analysis in 2019. This would involve a mixed of methodology of autocoded and manual coded grants. Costs would be absorbed by the MRC who would led the co-ordination.

The Board approved the proposal.

Collaboration

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

The Chair reported that following the National Audit Office report on cross government funding of research and development and discussion of the report at the Public Accounts Committee of the House of Commons both OSCHR and the UKCRC had been praised for the role that they played in strategic coordination, decision making and prioritisation in health research. At their last meeting in February, other main items of discussions were:

- This was the Chair John Bell’s last meeting as well the MRC’s representative John Savill. A new Chair would now be recruited and restructuring of the group was possible.
- The Health of the Public Research Sub-board was now established and was making an encouraging start.
- Progress was being made in health informatics following the formation of Health Data Research UK and the Informatics Board.

During discussion it was decided that Public Health and Prevention should be an agenda item for a future UKCRC Board meeting.

12. Mental Health Review Oral

The Chair reported that work was now centred upon on the implementation of the recommendations in the Framework for Mental Health Research via for example Grand Challenges. Partners could expect consultations to be forthcoming to strengthen capability and capacity in the UK.

During discussion it was raised that trainees may be best placed to provide knowledge and ideas of improvements in the system and whether phase II trials in mental health could be conducted.

The Board requested that Mental Health continue to be on the agenda.

13. Data Update Oral

Sara Marshall reported that:
- The Cochrane Database of Systematic Reviews (CDSR) which collects trial data from pharma has been open to academics since March.
- An independent review panel considers the requests to access the data of over 4000 trials in the CDSR. To date 350 requests had been received, 50 of which were not granted due to the statistical plan not being robust enough.
- Understanding Patient Data has published animations regarding how ‘Data saves lives’. These have received 1.5 million views reflecting the interest in this area.
• The MRC Regulatory Support Centre had produced some comprehensive guidance for researchers regarding General Data Protection Regulation (GDPR). Researchers now had to be encouraged to access this.
• The National Data Opt-out Programme was going ahead. The approach is very different to previous failed programmes, however the final communications strategy had not yet been finalised.

The Board noted progress in these areas.

14. Clinical Pharmacological Skills Alliance Oral

The Board noted this paper for information.

Activities

15. Update from Health Departments Oral

Developments in Scotland included:
• Scottish Science Advisory Council has begun an inquiry at the request of the Scottish Government on the development of genomic medicine in Scotland. Report is expected in June. Likely to include assessment of the importance of genomic medicine, the current landscape and assets, the opportunities for healthcare, research and life sciences in Scotland and how to make recommendations to realise the opportunities.
• University of Glasgow coordinating a Scottish consortium on a BEIS Science and Innovation Audit into Precision Medicine. Submission is expected in June.
• £1.7M to Stratified Medicine Scotland Innovation Centre (SMS-IC) and Eagle Genomics to develop new tests and treatments for Non-Alcoholic Fatty Liver Disease (NAFLD).
• Coordination of consortium bid for Industrial Challenge Strategy Fund (ICSF) for digital pathology and radiography.
• PPI standards test beds in Edinburgh and Glasgow.
• Joint funding of a PhD in biomedical research into the underlying aetiology, diagnosis or treatment of Myalgic Encephalomyelitis (ME). Funding is up to £90,000 for three years.

Developments in Wales included:
• Jonathan Bisson, Director of Health and Research Care Wales, leaving at the end of July. His duties will be shared by existing staff until a replacement is appointed.
• Refresh of strategic plan and infrastructure. The long-term plan is to put together a task and finish group.
• The Reid Review of Research and Innovation in Wales. This is a review of strengths, gaps and future potential to sustain and grow strong research activity and builds on recent reviews of student finance and funding, and post-compulsory education.
• Annual NHS R&D forum on 14 & 15th May.

Developments in England included:
• Open competition call for research collaborations addressing research challenges in primary care and public health in an aging society.
• Launch of NIHR Medtech and In vitro diagnostics Co-operatives (MICs). £14 million over 5 years awarded across 11 operatives, replacing NIHR Healthcare Technology Co-operatives and NIHR Diagnostic Evidence Co-operatives.
• Jonathan Sheffield, CEO of the NIHR CRN Network announced provisional data on recruitment participation of patients in research as 750,000 over 2017/2018.
• Global Health Research Groups Official Development Assistance (ODA) funded 20 new groups bringing total to 53 groups, on a diversity of topics.
• Proposition to alleviate problems and simplify system of Excess Treatment Costs (ETCs).
• NIHR Strategy Board consideration of a success framework (link to WT Success Framework) to get better evidence of gain e.g. health, economic investment etc. and patient engagement.

The Board noted progress in these areas.

16. Update from NHS England  
Oral

Sam Roberts reported that following on from the paper, 12 Actions to Support and Apply Research in the NHS in November 2017 by Ian Dodge, National Director for Strategy and Innovation the following was being undertaken:

• Excess Treatment Costs (ETCs) consultation and the proposal that these costs are met from sub-regional budgets. Provisional go-live in October, data will be collected for analysis after three months.
• Central commercial contract for multi-trials, therefore single negotiation only required.
• Evaluation of NHS England’s research needs. Initial comments on first articulation are welcome by the end of the month, PPI comments are particularly welcome. Gary Ford is leading workshops in Oxford on the broader NHS needs. From these regional plans will emerge and then the emerging needs nationally.
• Uptake to the Clinical Practice Research Datalink (CPRD) continues to grow.
• The establishment of 2-5 Digital Innovation Hubs each covering a region of 3-5 million people.
• Re-alignment of the Academic Health Science Networks.
• Simplification of the innovation landscape.

During discussion, the following was raised:

• That this was a very positive update and that NHS England is in a better position than it was 18 months ago. Partners around the Board were very happy to get involved and contribute their expertise.
• More work was required regarding the speed of commercialisation contracts.
• That the celebration of the 70 years of the NHS should include research and that PPI should be engaged in the same way that the Understanding Patient Data (UPD) campaign has done so.
• Regular annual review would be included in the systems development for ETCs.
• Digital innovation is back on the agenda for research funders, particularly the evidence for research methodologies.

The Board noted progress in these areas.

17. Open session of new research initiatives (Regulation)  
Oral

Regulation Partners were invited to given an update on research initiatives that their organisations are involved in.

Michael Rawlins (MHRA)

• Exploring the option of a single application with a single decision and ethics approval with the HRA. A pilot would be run.
• The growing importance of novel trials designs.
• The UK ran 104 first in human trials last year in comparison to 69 in EU countries.
Teresa Allen (HRA)

- In a step towards greater UK compatibility, Wales has adopted all HRA processes.
- A new IRAS platform is being procured. Working to a timeline of spring 2019.
- Working with Experimental Cancer Medicine Centres to agree good practice and minimise regulatory burden for Platform trials (also known as adaptive or complex trials).
- Emerging data from HRA Service Improvement programme indicates improving timelines from regulatory application to first participant.
- Exploration of ways to make the amendments process more efficient.

Nick Crabb (NICE)

- The Internal Research Advisory Group has identified 9 priority topics for methodological research; real world evidence, data science, adaptive pathways, patient preferences, improving cross sector comparisons, expert elicitation, complex data visualisation, precision medicine and implementation of NICE guidelines.
- Scoping project to determine whether NICE is equipped to face the challenges of Precision Medicine over the next ten years.
- Several grant funded projects via EU partnerships. Such as: ‘Get Real Initiative’ funded by Innovation Medicines Initiative (IMI) to establish task forces to develop tangible solutions to key challenges associated with using real-world data in drug development; ‘Impact HTA’ funded by Horizon 2020 assessing NICE’s role in performance of a range of statistical methods used to analyses non-randomised studies; Roadmap (Alzheimer’s disease) and Harmony (blood cancers) funded by IMI, working to create real world evidence platforms and ‘Do-it’ coordinating knowledge generated from bid data for better outcomes projects, funded by IMI.
- Scoping project to explore use of expert elicitation (obtaining quantitative values from experts for use in decision modelling), supporting guidance development.
- Informatics and big data are major discussion items at NICE Board level.

The Board noted progress in these areas.

UKCRC General

18. **UKCRC Partnership Manager’s Report**

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 (2017-2018).

The Board thanked the Partnership Manager and approved the budget (2018-2019).

19. **Any Other Business**

No other items of business were declared.

The next Board meeting was confirmed as 11th October from 2pm-5pm.