

# Next steps for genomic medicine in the NHS - regulation, challenges for adoption and priorities for research 20<sup>th</sup> November 2018

### **CONDITIONS FOR USE OF TRANSCRIPTS:**

This document is intended to provide a timely reference for interested parties who are unable to attend the event to which it refers. Some portions are based on transcripts of proceedings and others consist of text submitted by speakers or authors, and are clearly marked as such. As such, apart from where it is indicated that the text was supplied by the speaker, it has not been possible for the transcript to be checked by speakers and so this portion of the document does not represent a formal record of proceedings. Despite best endeavours by Westminster Forum Projects and its suppliers to ensure accuracy, text based on transcription may contain errors which could alter the intended meaning of any portion of the reported content. Anyone who intends to publicly use or refer to any text based on the transcript should make clear that speakers have not had the opportunity for any corrections, or check first with the speaker in question. If in doubt please contact the forum first.

# **Contents**

About this Publication	3
<u>Agenda</u>	4
Session Chair's opening remarks Rt Hon the Baroness Neville-Jones, Vice Chair, All-Party Parliamentary Group for Rare, Genetic and Undiagnosed Conditions (transcript)	6
The future for personalised medicine and genomics in the NHS - progress since Generation Genome  Dr Siddharth Banka, Clinical Senior Lecturer, University of Manchester and Consultant Clinical Geneticist,  Manchester University NHS Foundation Trust (transcript)	7
Findings from the 100,000 Genomes Project and next steps for shared learning Sir John Chisholm, Executive Chair, Genomics England (transcript)	10
Questions and comments from the floor (transcript)	13
'Genomic Medicine Centres: supporting the NHS Genomic Medicine Service'  Professor Dian Donnai, Consultant Clinical Geneticist, Manchester Centre for Genomic Medicine, Manchester University NHS Foundation Trust and Professor of Medical Genetics, University of Manchester (transcript)	19
<u>'From genomics to personalised medicine'</u> <b>Dr Sobia Raza</b> , Associate and former Head of Science, PHG Foundation (transcript)	22
Questions and comments from the floor with <b>Dr Siddharth Banka</b> , Clinical Senior Lecturer, University of Manchester and Consultant Clinical Geneticist, Manchester University NHS Foundation Trust and <b>Sir John Chisholm</b> , Executive Chair, Genomics England ( <i>transcript</i> )	
Session Chair's closing remarks Rt Hon the Baroness Neville-Jones, Vice Chair, All-Party Parliamentary Group for Rare, Genetic and Undiagnosed Conditions (transcript)	30
<u>Session Chair's opening remarks</u> Rt Hon the Lord Willis, Vice Chair, All-Party Parliamentary Group for Medical Research (transcript)	31
Implications for the regulation of personalised medicine post-Brexit  Dr Krishna Prasad, Licensing Groups Manager & Expert Clinical Assessor, MHRA (transcript)  Dr Sarah Byron, Associate Director, Diagnostics Assessment Programme, NICE (transcript)  Questions and comments from the floor (transcript)	32 35 38
Overcoming challenges for accelerating the uptake and adoption of genomic medicine: data, training and engagement  Dr Alina Roser, General Practitioner and Honorary Clinical Lecturer, Queen Mary University of London (transcript)  Professor Nick Loman, Professor of Microbial Genomics and Bioinformatics, University of Birmingham and Turing Fellow, Alan Turing Institute, London (transcript)	42 44
Karen Lightning-Jones, Head of Personalisation and Strategic Partnerships, Roche Products (transcript)  Dr Jayne Spink, Chief Executive Officer, Genetic Alliance UK (transcript)  Questions and comments from the floor with Professor Dian Donnai, Consultant Clinical Geneticist,  Manchester Centre for Genomic Medicine, Manchester University NHS Foundation Trust and  Professor of Medical Genetics, University of Manchester (transcript)	47 49 51
Next steps for the new NHS Genomic Medicine Service  Professor Dame Sue Hill, Chief Scientific Officer for England, NHS England (transcript)	58
Session Chair's and Westminster Health Forum closing remarks Rt Hon the Lord Willis, Vice Chair, All-Party Parliamentary Group for Medical Research (transcript) Stephanie Thomson, Senior Researcher, Westminster Health Forum (transcript)	65 66
List of Delegates Registered for Seminar	67
Contributor Biographies	72
About the Core Sponsors of the Westminster Health Forum	75

Please be advised that speakers' PowerPoint presentations are included within the transcript itself, just beneath the relevant speaker's text. Please note that not all speakers are able to grant permission for us to include their slides.

# **About this Publication**

This publication reflects proceedings at the Westminster Health Forum Keynote Seminar: Next steps for genomic medicine in the NHS - regulation, challenges for adoption and priorities for research held on 20<sup>th</sup> November 2018. The views expressed in the articles are those of the named authors, not those of the Forum or the sponsors, apart from their own articles.

Although Westminster Health Forum is grateful to all sponsors for the funding on which we depend, participation in events and publications is never conditional on being a sponsor. As well as funding ongoing operations, sponsorship enables the Forum to distribute complimentary copies of publications, and offer complimentary tickets for events, to Government ministers, parliamentarians and officials most involved in policy.

This publication is copyright. Its copying, in whole or in part, is not permitted without the prior written consent of the publishers. However, extracts of the text may be reproduced for academic or review purposes, subject to the conditions of use outlined in the previous page, providing they are accurate, are not used in a misleading context and the author, their organisation and the Westminster Health Forum are acknowledged. We would also appreciate being informed.

### **Westminster Health Forum**

UK Headquarters 4 Bracknell Beeches Old Bracknell Lane West Bracknell Berkshire RG12 7BW

T: 01344 864796 F: 01344 420121 publications@westminsterforumprojects.co.uk

## **Directors**

Peter van Gelder Chris Whitehouse