Genomics in Medicine: Policy Meeting Programme

12.00	**Registration**
12:30 - 13:15	**Refreshments**
13:30 - 13:45	**Welcome and Opening remarks** ***Professor Richard Muscat*** *Director, Centre for Molecular Medicine and Biobanking*
CHAIR, Dr Christopher Barbara	
13:45 - 14:15	**Improving patient's outcome through the 100,000 Genomes Project** ***Professor Dame Sally Davies*** *Chief Medical Officer and Senior Medical Adviser to the UK Government*
14:15 - 14:45	**EMBL-EBI, ELIXER and Health Data** ***Dr Rolf Apweiler*** *Director of the EMBL-European Bioinformatics Institute*
14:45 - 15:00	**Open discussion**
15:00 - 15:30	**Break and Refreshments**
CHAIR, Professor Richard Muscat	
15:30 - 16:00	**Ethical and legal considerations in the delivery of a genomic medicine service** ***Professor Anneke Lucassen*** *Professor of Clinical Genetics within Medicine at the University of Southampton*
16:00 - 16:30	**The Genome test result: What do I tell my patients and why** ***Professor Kathleen Freson*** *Head of the Center for Molecular and Vascular Biology, University of Leuven*
16:30 - 16:45	**Discussion and summing up** **Professor Willem Ouwerhand** *University of Cambridge Professor of Experimental Haematology, Honorary Faculty member Wellcome Trust Sanger Institute, Honorary NHSBT Consultant in Haematology*
16:45	**Close**

This meeting has been organised by the *TrainMALTA HORIZON 2020 TWINNING Action (EU grant agreement No. 692041)* which is co-ordinated by Dr Rosienne Farrugia and is designed to accelerate capacity building in Malta through training in Bioinformatics and Model Systems for the analysis of genomic data.

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Genomics in Medicine: Policy Meeting

29th September 2017

VALLETTA CAMPUS
UNIVERSITY OF MALTA

Guest Speakers

Professor Dame Sally C Davies FRS is the Chief Medical Officer and Senior Medical Adviser to the UK government. Previously she headed the National Institute for Health Research, England. Dame Sally also chairs the UK Clinical Research Collaboration, and is a member of the WHO Global Advisory Committee on Health Research, the board of the Office for Strategic Co-ordination of Health Research, the Medical Research Council and Genomics England. She advises many organisations on research strategy and evaluation. Dame Sally is a haematologist by training with a specific interest in thalassaemia and sickle cell disease.

Professor Anneke Lucassen is Professor of Clinical Genetics within Medicine at the University of Southampton and combines key clinical, laboratory and ethico-legal expertise to research developments in genetic medicine and to affect improved delivery of genomic services to individuals and families. Prof Lucassen has been on the Nuffield Council of Bioethics since 2009. She chairs the British Society of Genomic Medicine's ethics and policy committee, is a member of Genomics England ethics advisory committee and plays a key role in the current development of the NHS Wessex Genomic Medicine Centre in South England.

Dr Rolf Apweiler is joint Director of the EMBL-European Bioinformatics Institute (EBI), together with Professor Ewan Birney, and they have strategic oversight of all EBI services and research programmes. Prior to taking on this position he led protein resources, including the team responsible for EBI's contribution to the UniProt Consortium. Dr Apweiler has made a major contribution to methods for the automatic annotation of proteins. He has spearheaded the development of standards for proteomics data, and his teams have maintained major collections of protein identifications from proteomics experiments (PRIDE) and molecular interactions (IntAct). He also leads EBI's contribution to the Gene Ontology.

Professor Kathleen Freson is Professor at the University of Leuven and head of the Centre for Molecular and Vascular Biology since 2016. She has a background in bioscience engineering and her research focussed on genetic and biology studies using platelets to unravel new bleeding disorders but she has also studied neurological diseases where the platelet was used as a model cell for the disease. She co-chairs the Multi Disciplinary Team for the clinical high-throughput sequencing platform ThromboGenomics and is member of the NHIR-rare diseases project for Bleeding and Platelet Disorders.