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**Visit by Rare Diseases Policy Team, 19th January 2015**

**Chestnut Suite, Hinxton Hall**

**From 13.30 Meadow Room, EBI South Building**

**AGENDA**

**Sanger Institute Participants:**

Julia Wilson, Associate Director External Relations

Matthew Hurles, Group Leader Human Genetics Human Genetics Programme

Caroline Wright, Senior Scientific Manager, Human Genetics Programme

Helen Firth, Honorary Faculty Member, Human Genetics Programme/ Consultant Clinical Geneticist,

Anna Middleton, Senior Staff Scientist, DDD Human Genetics Programme

Jeff Barrett, Group Leader, Human Genetics Programme

**EBI Participants:**

Janet Thornton, Director

Rolf Apweiler, Joint Associate Director and Senior Scientist

Ewan Birney, Joint Associate Director and Senior Scientist

Lindsey Crosswell, Head of External Relations

Steven Newhouse, Head Technical Services

John Overington, ChEMBL, Group Leader - ChEMBL

John Marioni, Research Group Leader

Alvis Brazma, Senior Team Leader, Functional Genomics

**DoH Participants:**

Mark Bale Sinead Lane

Sylvia Pratt Julie Pettman

Ray Smith Catherine Byers

Francesa Orpen Mel Peffer

Alice-Nancy Terry Ben Halliday

Robin Herbert Ian McKay

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| 10:00 | Sign in at Security Reception and walk to Hinxton Hall | Met by Francesca Gale |
| 10:30 | Welcome, coffee and Introductions  Overview and purpose of visit | Julia Wilson and Mark Bale |
| 11:00 | Deciphering Developmental Disorders   * Research Programme * Ethics and Society considerations * Wider application to other rare diseases | Matt Hurles  Anna Middleton  Helen Firth / Caroline Wright |
| 12:15 | Wrap up discussions |  |
| 12:30 | Joint lunch with Sanger Institute and EBI | Chestnut Suite |
| 13:30 | **Meadow Room, EMBL-EBI South building**  Overview of EBI (Janet Thornton)  Tea and Coffee | Janet Thornton  Rolf Apweiler  Ewan Birney  Lindsey Crosswell |
| 14:30 | Current Health Research at EMBL-EBI (Ewan Birney)   * 100k genomes * Addenbrookes collaborations * Research | As above, joined by :  John Overington  John Marioni  Alvis Brazma  Steven Newhouse |
| 15.30 | Wrap up meeting | Janet Thornton  Ewan Birney  Rolf Apweiler  Lindsey Crosswell |
| 16.00 | Depart |  |