

**Minutes of the Second Meeting of the Steering Group for the Born Healthy Programme held on 27<sup>th</sup> June 2011, Royal College of Obstetricians and Gynaecologists, London, UK**

**Members present:**

Hilary Burton (HB)	Director, PHG Foundation, Cambridge
Arnold Christianson (AC)	Professor and Principal Specialist, Division of Human Genetics, National Health Laboratories Service, University of the Witwatersrand, Johannesburg, S Africa
Lavinia Schuler Faccini (LF)	Department of Genetics, Federal University of Rio Grande do Sul, Porto Alegre, Brazil
Particia Gomez (PG)	Senior Technical Advisor, Maternal & Newborn Health, Jhpiego - Innovating to Save Lives, an Affiliate of John Hopkins University, USA
Christopher Howson (CH)	Vice-President for Global Programs, The March of Dimes Foundation, White Plains, New York, USA
Betty Kirkwood (BK)	Professor of Epidemiology & International Health, London School of Hygiene & Tropical Medicine, London
Irmgard Nippert (IN)	Professor and Chair for Women's Health Research, Institute for Human Genetics, Universitaetsklinikum Muenster, Muenster, Germany
Ysbrand Poortman (YP)	Chair, Preparing for Life Initiative, International Genetic Alliance, Baarn, Netherlands
Severin von Xylander (SX)	Medical Officer, Department of Newborn, Child and Adolescent Health, WHO, Geneva, Switzerland

**Also in attendance:** Corinna Alberg, Carol Lyon, Luis Nacul (all PHG Foundation, Cambridge)

**Apologies:** Apologies were received from Alan Bittles, Alastair Kent, Bernadette Modell and Peter Turnpenny

Item	Notes	Action
1	<b>Introduction</b> HB welcomed participants to the second steering group meeting of the Born Healthy Programme and thanked participants for their attendance. Participants introduced themselves. HB noted that this was a meeting to consider the business aspects of the Programme and that the PHG Foundation was grateful for the support from steering group members in both shaping the Programme and for future guidance to establish a sustainable long term home. Steering group members were asked for additional items for inclusion on the agenda - no items were identified.	
2.	<b>Minutes of the last meeting</b> These were approved.	
3.	<b>Matters arising</b> Lavinia Schuler Faccini had agreed to join the steering group in response to the recommendation from the first meeting that there should be an additional member from the south. CH asked what the PHG aimed to achieve over the next few days. HB, LN and CA clarified that the expert workshop	

	<p>following on from the steering group meeting on the 27<sup>th</sup> June would focus on the content of the Toolkit and aimed to assemble key experts to validate the Toolkit content and make suggestions for changes, if such changes were necessary. The expert workshop and the conference on the 28<sup>th</sup> June would provide an opportunity for those who have piloted the Toolkit to report back on the usefulness of the Toolkit and what they had achieved. The final workshop on the 29<sup>th</sup> June would focus on setting up the next stage of field trials. The PHG Foundation would also like to establish partnerships for funding to take the work and community of interest forward.</p>	
4.	<p><b>Programme report</b></p> <p>HB outlined the contents of the report and in particular the team of those involved from the PHG Foundation who had worked on the Toolkit and Born Healthy Programme, the terminology changes, the branding of the Programme and the engagement with key stakeholders that had taken place. AC noted that the terms ‘birth defects’ and ‘congenital disorders’ can be used interchangeably. CH was thanked for his support in facilitating the inclusion of a workshop on the Toolkit in the 5th International Conference on Birth Defects and Disabilities in Developing World.</p> <p>SX noted that the Toolkit could include an additional chapter on pedal conditions such as clubfoot. AC noted that the Toolkit should focus on common conditions and significant conditions - which may not be common but are treatable. AC also noted that haemophilia is an important issue partly because it is expensive to treat. BK felt that there should be some guidance for countries on which chapters are likely to be of more significance for their particular country. Equity and public health significance should be underlying reasons for suggesting particular chapters. SX noted that the Toolkit should look at how funded programmes such as malaria and HIV link to the Toolkit.</p> <p>HB outlined the planned dissemination activities - particularly those as part of the 5th International Conference on Birth Defects and Disabilities in Lodz and a workshop in India.</p> <p>There was discussion as to whether official endorsement by WHO for the Toolkit should be sought but SX warned that this could be a very time consuming involving the guidelines review committee. The fragmentary way WHO is organized would require the involvement of many different departments.</p>	<p><b>PHG to consider the inclusion of a chapter of pedal congenital disorders. A chapter including haemophilia is planned.</b></p> <p><b>PHG to undertake dissemination as indicated.</b></p>
5	<p><b>Development of Community of Interest</b></p> <p>CL described the development of the community of interest. She noted that the next phase was to publicise the Toolkit and website portal to health professionals outside of the UK and to 3rd sector organisations. The PHG Foundation would depend on the steering group and others to facilitate this process as it is a new area for the Foundation and would require funding.</p>	<p><b>All to support publicizing Toolkit and portal.</b></p>
6	<p><b>Dissemination and implementation</b></p> <p>AC commented on the importance of developing a literature</p>	<p><b>Articles on development</b></p>

	<p>on the development of the Toolkit, how it is being used and where possible outcomes from its use. It will also be important to have the Toolkit available on the web. There was discussion about the value of having a Lancet series on congenital disorders and although it would be of use in raising the profile of the congenital disorders agenda, currently it was felt that there is insufficient material. In the future BK might be able to approach Richard Horton to request a Lancet series. A meeting with Liz Mason of WHO should be set up after the workshops and conference to examine how the agenda can be progressed.</p>	<p>and use of Toolkit to be submitted by PHG and Pilots. PHG/SX to set up a meeting with Liz Mason of WHO.</p>
7	<p><b>International strategic developments</b>  It was felt that it is important to link into some key networks such as the Countdown to 2015 network on preventing maternal and child deaths. BK and SX could provide contacts. There will be a conference on the Countdown Programme and it would be useful to include a workshop on the Toolkit. Other dissemination opportunities are country specific meetings of societies of clinical genetics such as the Montreal conference and also societies of paediatricians. The Women Deliver conference in Washington may be another opportunity for dissemination. PG noted the importance of linking in congenital disorders with existing programmes/agendas. In some countries vertical programmes are more effective eg: on rubella, syphilis and nutritional interventions. Advocacy is required to include congenital disorders on these agendas and the Toolkit is potentially a powerful way to convince those involved in such vertical programmes that they should include congenital disorders. HB asked steering group members to help with such introductions.</p>	<p>PHG to make links to Countdown to 2015 aided by BK and SX and investigate possibility of conference workshop. Steering group to provide introductions to other existing programmes.</p>
8	<p><b>Funding and Fundraising</b>  Carol Lyon described the PHG Foundation's financial investment in the Born Healthy programme to date and clarified that external funding would be needed to disseminate the Toolkit more widely and for field trials beyond the current piloting of the materials.</p> <p>A call has been put out for bids for EUFP7 funding on developing research capacity. In many ways the Born Healthy Programme fits neatly to the call. It was noted that there are tensions over whether this research is to be pure research or to have a practical orientation of a 'learn by doing' focus. The PHG Foundation could put in a joint bid and such funding might provide the financial support to take the work forward.</p>	<p>PHG to investigate the possibility of a joint bid for EUFP7 funding. IN to advise on this.</p>
9	<p><b>Next steps</b>  Steering Group members would receive a report of the June workshop; follow-up actions would be undertaken with individuals as appropriate.</p>	
10	<p><b>Date of next meeting</b>  No date agreed. <i>A further meeting, either in person or by tele-conference should be arranged for mid 2012.</i></p>	