

Improving quality of care and outcome at very preterm birth programme grant

NEWSLETTER 2

Spring 2012

Welcome to the second edition of the Preterm Birth Programme newsletter.

This issue announces the launch of the new website, focuses on the work package that is looking at parents' views, and includes an interview with Gill Gyte, NCT, a service representative on the programme.

SURVEY!!

Please fill in and forward the Priority Setting Partnership Survey

Health professionals and service users are being asked to complete an online survey as part of the process to identify and prioritise research gaps relevant to preterm birth. By bringing together people with experience of preterm birth and premature babies the project team will find out which uncertainties have not already been addressed by research. To date there have been 406 hits and 160 questions collected. Participants break down into approximately 58% service users, 29% health care professionals and 13% both. For more information go to the project website - <http://eppi.ioe.ac.uk/pretermbirth>.

www.surveymonkey.com/s/prembabies

The closing date for the return of the survey is Sunday 15th of July 2012

New programme website

The programme website was launched on 14 May 2012 and has had positive feedback so far. It is hosted by the University of Nottingham and currently part of the School of Community Health Sciences but will be moving to a new home within the new Nottingham Clinical Trials Unit website later this year.

The aim is to provide a resource for all programme stakeholders such as clinicians, service users, students and parents. It is also a tool for programme teams to utilise to highlight and publicise their work. Please let Charlotte know if there are items that you would like adding to the website.

The site will also contain a restricted access area for programme documents that programme associates have access to via a specified user name and password to be issued soon. The URL is: www.nottingham.ac.uk/pretermbirth



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NIHR Programme Grant for Applied Research

NCTU
Nottingham Clinical Trials Unit



The University of
Nottingham

Please remember the Priority Setting Partnership survey

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Measuring Placental Transfusion

Congratulations to Jon Dorling, Sam Oddie, Bernard Schoonakker and the rest of the 'baby weighing' team for the progress they have made with the baby weighing study. After some delay due to difficulties obtaining ethics and R&D approval the team are now recruiting at all three sites (Queen's Medical Centre, Nottingham City Hospital and Bradford NHS Trust). The research teams are currently weighing babies born at term for training purposes and a stepwise decrease in the gestational age of infants that are recruited will be used before weighing very premature babies for the study.

BASICS

Welcome to two new colleagues that have been appointed as research team members on the BASICS project in Liverpool. Margaret Thomas is an ANNP researcher and Louise Goodwin is the new Qualitative researcher.

Andrew Weeks and Bill Yoxall introduced the Mark II BASICS trolley prototype at the Steering Committee meeting in February. This new version has been engineered by Inditherm the industry partner. The general feedback from the committee was extremely positive. The next step is to obtain ethics approval for the evaluation study.

Programme babies

We are delighted to announce that there are two new arrivals expected within the programme community later this year. Congratulations go to Alexandra Sawyer who is working at the University of Sussex on the Assessing Parent's Views project, and also to Eleanor Wilman at the University of Leeds who is working with Chris Megone on the Review of Ethical Issues. We wish them both the very best.

Publication

[Petit-Zeman, S., Uhm, S. \(2012\). Identifying research priorities in preterm birth. Infant. Vol 8 Issue 3](#)

This publication has been co-authored by Seilin Uhm, Postgraduate Researcher working on 'Identifying and prioritising research gaps relevant to preterm birth', and Dr Sophie Petit-Zeman, Adviser, Public Involvement and Engagement, Association of Medical Research Charities (AMRC).

Lay newsletter

An important part of the programme management is to provide information for stakeholders during the duration of the programme. Therefore, in addition to the newsletter for researchers, a lay newsletter is also being produced allowing those involved or interested in the research an opportunity to be kept up-to-date with the work of the programme and how they may have made a difference to premature babies and their families in the future. The lay newsletter will be published every six months and the first edition, published in May 2012, has been distributed to all the parents who have given their permission to be added to the database of contacts.

Please download as a pdf from the website at

www.nottingham.ac.uk/pretermbirth/publications or let Charlotte know if you require any hard copies to distribute.



Programme logo

Following the Steering Committee meeting there has been a small change to the programme logo to emphasise the programme name. If you require a copy for the new logo for your work package please email Charlotte.



Important dates

WP1—Identifying and prioritising research gaps steering group

18th June 2012

The University of Nottingham

Programme Steering Group Meetings

19th June 2012

The University of Nottingham

30 October 2012

The University of Nottingham

Service users involvement—Gillian Gyte, NCT



Gillian Gyte from the National Childbirth Trust is one of two service user representatives participating in the preterm birth programme along with Jane Abbott from Bliss. In the following interview Gill tells us how she became involved in the programme and why service user representatives play an important part in the development and delivery of the research.

When did you first become involved in the NCT?

In 1980, John and I went to NCT antenatal classes with our first baby. They were highly recommended by a close friend, and I gained far more from them than I ever anticipated. I then went on to train as an NCT antenatal teacher myself and taught for 25 years.

How did you make the move into research within the charity?

After qualifying as an NCT advanced antenatal teacher, I took on a role to coordinate the on-going assessments which antenatal teachers have a year after qualifying. This took me to meetings at NCT headquarters in London, and there I learned of, and met people on, the NCT Research and Information Group. As I have a research background (biochemistry and haematology) I was interested, and I was invited to join this group in 1991, and I took over as chairperson of the group in 1994.

What is your main area of interest within the area of pregnancy and childbirth research?

I have many areas of interest, but in particular the third stage of labour

(delivery of the placenta) and mainly the timing of the clamping and cutting of the cord; place of birth; working with pain; anaemia; care during labour; mobility and positions in labour and any of the interventions in pregnancy and birth.

You have a role in the Cochrane Consumer Network. When did you get involved and why did you think it important to do so?

Iain Chalmers (an obstetrician and one of the founders of the Collaboration) had always believed in consumer involvement and he invited NCT to send him comments on the large two volume book 'Effective Care in Pregnancy and Childbirth'. I sent my comments along with other members of RIG. I was then invited to a Pregnancy and Childbirth Group meeting at the annual Cochrane UK Contributors meeting and I accepted the invitation to help the group get consumer input on the draft protocol and reviews prior to publication. From there, I became involved with the wider Cochrane Collaboration Consumer Network and represented the Network on the Collaboration Steering Group from 1997-2000.

How did you hear about the NIHR Preterm Birth Programme Grant?

I have always been interested in the timing of cord clamping and I met Lelia as she is one of the editors in the Cochrane Pregnancy and Childbirth Group. We talked about our ideas and so I was involved with the funding applications from the beginning (we also wanted to study timing of cord clamping in term infants but did not get funding for this).

How important is it for a representative from a service user organisation to be involved in this research?

Service users are the people for whom the research is supposed to benefit and to they are key stakeholders. Service users bring a very different perspective to a research proposal and can contribute by, for example, suggesting outcome measures in trials that are important to service users (and not always considered important by clinicians). They can also suggest questions to ask, and questions not to ask, in interviews and surveys to draw out parents views. They can also bring attention to possibly sensitive language. We can help in understanding the possible acceptability of interventions in trials and to how to

phrase questions in surveys so parents understand what is being asked.

Service users have a major role in developing the information sheet to explain the research to people being invited to participate. Representatives from service user organisations can bring a wider perspective to this input by their contact with a wider network of service users.

How do you feel this research will benefit premature babies and their families?

There are many aspects to this programme of research, and so hopefully each will bring a benefit in some way. So to pick out just a few: The priorities for research will help to set the future research agenda to evidence can be gathered in issues important to parents of very premature babies. The interviews and surveys can shed light on how parents feel and what support they need during and after a very preterm birth. The pilot trial will hopefully lead onto a full trial which will shed light on the best time to clamp of the cord at birth and to show whether there are benefits for premature babies. The BASICS trolley enables initial care to be given to the baby at the bedside rather than having the baby taken away immediately it is born. This has the potential to allow parents the option to be with their baby during this initial care or they may prefer the current system where the baby is taken away – this will be a new choice for parents in what is a traumatic situation. Hopefully, there will be more benefits too.



The National Childbirth Trust are the UK's largest charity for parents, and campaign as the voice for parents on the issues they care about.

<http://www.nct.org.uk>

Focus on a work package—Parents' views of care at the bedside

This project is being lead from the University of Sussex by Dr Susan Ayers in collaboration with Brighton and Sussex University Hospitals.

The aim of this study is to ascertain parents' views and experiences of preterm birth; in particular whether this was affected by the initial care of their preterm baby being provided at the bedside, allowing for delayed cord clamping, or at the room-side. There are two studies involved in this project, a qualitative study of parents' views of care at the birth of their premature baby in hospitals and a larger-scale survey of parental satisfaction in maternity units that provide initial care at the bedside or initial care at the room-side.

The qualitative study of parents' views took place from June to November 2011 and a total of 39 parents of preterm babies born in hospitals with care at the bedside or care at the room-side were interviewed (32 mothers & 7 fathers). Parents were recruited from three hospitals (Brighton and Sussex University Hospitals, Homerton University Hospital, and Croydon University Hospital). Analysis is now complete and a paper based on parents' views of care at delivery is being drafted for publication and it is hoped will

be published in 2012. Results showed the majority of parents were very satisfied with the care during the birth. Analysis identified four key determinants of satisfaction : 1) staff professionalism, which included information and explanation, staff being calm in a crisis, staff appearing confident and in control, staff not responding to the patient; 2) staff empathy, which included caring and emotional support, encouragement and reassurance; 3) birth environment; and 4) involvement of father.

"The interviews provided a good insight into parents' experiences and perceptions of care during preterm birth. Parents were really positive about their care experiences and what stood out as being particularly important was making sure parents were kept informed, kind and supportive interactions with staff, and fathers being made to feel involved".

Alexandra Sawyer, Qualitative Researcher

A questionnaire was then developed from the interviews and this is currently being sent to parents whose premature baby was born up to a year ago to gather data on parental satisfaction during the birth of

their baby. A sample size of approximately 300 is required and there are five sites involved in this study that have different procedures for providing care at the bedside or room-side. These are:

- Brighton and Sussex University Hospitals
- Homerton University Hospital
- University Hospitals of Leicester
- Nottingham University Hospitals
- Portsmouth Hospitals NHS Trust

Data will be collected and analysed by the end of 2012 and a second paper will be drafted and published in 2013.

The questionnaire is also being used in collaboration with the BASICS work package who will use it as part of the assessment of the new trolley which will be tested on babies born in Liverpool Women's Hospital. Parents who agree to have the BASICS trolley used for initial care at the bedside will be asked to complete the questionnaire to measure their experiences. These will then be compared to the experiences of parents in WP3.2 who had room-side or bedside care but without BASICS.

NIHR Programme in Applied Health Research Improving quality of care and outcome at very preterm birth

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