Should involvement in a trial be discussed at a bereavement follow up visit? Views of clinicians and bereaved parents from the bracelet study (bereavement and randomised controlled trials)

The Harvard community has made this article openly available. Please share how this access benefits you. Your story matters

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Published Version</td>
<td>doi:10.1186/1745-6215-14-S1-081</td>
</tr>
<tr>
<td>Citable link</td>
<td><a href="http://nrs.harvard.edu/urn-3:HUL.InstRepos:12152920">http://nrs.harvard.edu/urn-3:HUL.InstRepos:12152920</a></td>
</tr>
<tr>
<td>Terms of Use</td>
<td>This article was downloaded from Harvard University’s DASH repository, and is made available under the terms and conditions applicable to Other Posted Material, as set forth at <a href="http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA">http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA</a></td>
</tr>
</tbody>
</table>
Should involvement in a trial be discussed at a bereavement follow up visit? Views of clinicians and bereaved parents from the bracelet study (bereavement and randomised controlled trials)

Claire Snowdon¹, Peter Brocklehurst²,³, Robert Tasker⁴, Martin Ward Platt⁵, Diana Elbourne¹*

From 2nd Clinical Trials Methodology Conference: Methodology Matters
Edinburgh, UK. 18-19 November 2013

When patients die, bereaved families may be offered support by their local clinicians. Patients recruited into trials are both patients and trial participants. The BRACELET Study considered whether any response for parents of babies who died after enrolment in a neonatal intensive care (NIC) trial might be triggered by a baby’s status as trial participant, at a bereavement follow-up (BFU) appointment.

Thirty five clinicians and 51 bereaved parents involved with five NIC trials were interviewed. Most clinical interviewees stated they would not change their approach to supporting parents in the BFU because a baby had been enrolled in a trial as they believed it was not an issue parents wanted to discuss, it was not relevant, and/or it was not a topic for which relevant clinical information, such as impact of a trial intervention, would be available.

The parents largely confirmed these views. This could be because at the time of the BFU they did not want to discuss trial participation; and/or did not think about discussing trial participation.

The significance of a trial changed over time for the majority of parents. By the time of the interviews, mostly some years after the death, many had become more keen to engage in questions about the research. By this time however, they were usually no longer in contact with either the neonatologists or the trials coordinators.

Further research is needed to consider how best to provide longer term support for families whose relatives died after trial participation.

Authors’ details
¹London School of Hygiene and Tropical Medicine, London, UK. ²National Perinatal Epidemiology Unit, University of Oxford, Oxford, UK. ³Institute for Women’s Health, University College London, London, UK. ⁴Department of Neurology, and Anaesthesia (Pediatics), Harvard Medical School, Boston, USA. ⁵Newcastle Neonatal Service, Royal Victoria Infirmary, Newcastle-upon-Tyne, UK.

Published: 29 November 2013

doi:10.1186/1745-6215-14-S1-O81
Cite this article as: Snowdon et al.: Should involvement in a trial be discussed at a bereavement follow up visit? Views of clinicians and bereaved parents from the bracelet study (bereavement and randomised controlled trials). Trials 2013 14(Suppl 1):O81.

Submit your next manuscript to BioMed Central and take full advantage of:

• Convenient online submission
• Thorough peer review
• No space constraints or color figure charges
• Immediate publication on acceptance
• Inclusion in PubMed, CAS, Scopus and Google Scholar
• Research which is freely available for redistribution

Submit your manuscript at www.biomedcentral.com/submit

© 2013 Snowdon et al; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.