**Table 1.** Questions exploring parents’ experiences of participation of their child with incurable cancer in a clinical trial

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| 1. **Did your child participate in a research study for a new treatment?**   Yes  No  Don’t know |
| 1. **If your child did, can you indicate why? (more than one answer possible)**   Prolonging my child’s life  It gave us hope for a cure  Treatment for future patients  Other,……………………………………………………………………………………………. |
| 1. **To what extent did you feel this was burdensome for your child?**   1-2-3-4-5 (1=not burdensome; 5=very burdensome) |
| 1. **Would you, given the same circumstances, participate (again) in a research study for a new treatment?**   Yes, because……………………………………………………………………………………..  No, because……………………………………………………………………………………...  Don’t know, because…………………………………………………………………………… |

**Table 2.** Parent and child characteristics

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|  | **Clinical trial participants** | **Non-clinical trial participants** |
| **Parents** | 24 | 45 |
| Gender  Male  Female  Age at time of questionnaire | 10 (42%)  14 (58%)  46 years [25-53 years] | 17 (38%)  28 (62%)  43 years [31-59 years] |
| **Child** | 16 | 31 |
| Gender  Male  Female  Age at death  Diagnosis  Haematological malignancy  Solid tumour  Brain tumour | 13 (81%)  3 (19%)  8 years [3-15 years]  9 (56%)  5 (31%)  2 (13%) | 22 (71%)  9 (29%)  8 years [1-17 years]  9 (29%)  8 (26%)  14 (45%) |

*Parent and child characteristics presented for participants and non-participants (n=69 parents; n=47 children). Continuous data are presented as median and range; categorical data are presented as numbers and percentages.*

**Table 3.** Parents’ motives for participating (again) in a clinical trial (n=14/17)

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| **Altruism**  *‘Otherwise successful new treatments will never be discovered’*  *‘Research is very important’*  *‘Hope for a better treatment’*  *‘Maybe other children can now be cured’*  *‘If others had not done the same in the past, they wouldn’t be able to cure as many children as they do now’*  *‘ [...] and you might be able to prevent others from experiencing this sadness’*  *‘The type of leukaemia was rare, and future patients could benefit from this research’*  *‘I still hope for cure for these children’*  *‘As long as the child doesn’t suffer any negative consequences it will help others’*  **Perceived benefits for the child**  *‘You want the best for your child’*  *‘Prolonged child’s life […].’*  **Having explored all possibilities**  *‘To pull out all the stops’*  *‘[…] gave us hope’*  *‘You want to try everything […]’*  **Child’s wish to participate**  *‘Our child really wanted this’* |