**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  FemaleAge 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 FemaleAge at deathDiagnosis 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’* |