

MS KATE L I CAMERON (Orcid ID : 0000-0001-5447-594X)

MS TARA LOUISE FITZGERALD (Orcid ID : 0000-0002-6138-7080)

DR ALICIA JANE SPITTLE (Orcid ID : 0000-0002-6535-661X)

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**Barriers and facilitators to community participation for preschool age children born very preterm: a prospective cohort study**

KATE L CAMERON<sup>1,2,3</sup> ORCID 0000-0001-5447-594X

TARA L FITZGERALD<sup>1,2,3</sup>

REEM A ALBESHER<sup>1,2,3,4</sup>

JENNIFER L MCGINLEY<sup>2</sup>

KIM ALLISON<sup>2</sup>

KATHERINE J LEE<sup>1,5</sup>

JEANIE LY CHEONG<sup>1,3,6</sup>

ALICIA J SPITTLE<sup>1,2,3</sup>

**1** Victorian Infant Brain Studies, Murdoch Children's Research Institute, Melbourne; **2** Department of Physiotherapy, University of Melbourne, Melbourne; **3** Neonatal Services,

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Royal Women's Hospital, Melbourne, Australia. **4** Physiotherapy Department, Princess Nourah Bint Abdulrahman University, Riyadh, Saudi Arabia. **5** Department of Paediatrics, University of Melbourne, The Royal Children's Hospital, Melbourne; **6** Department of Obstetrics & Gynaecology, University of Melbourne, The Royal Women's Hospital, Melbourne, Australia.

Correspondence to Kate L Cameron, Department of Physiotherapy, Level 7 Alan Gilbert Building, 161 Barry Street, Carlton, Victoria, Australia, 3053. E-mail: kate.cameron@mcri.edu.au

#### **PUBLICATION DATA**

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#### **ABBREVIATIONS**

L-DCDQ	Little Developmental Coordination Disorder Questionnaire
MABC-2	Movement Assessment Battery for Children, Second Edition
YC-PEM	Young Children's Participation and Environment Measure

**AIM** We compared preschool age children born very preterm with term-born controls to: (1) understand the association between very preterm birth and community participation, (2) determine if motor impairment or social risk affect participation differently between groups, and (3) understand environmental barriers and supports to participation for parents.

**METHOD** Forty-eight children born very preterm (<30wks' gestation; 22 males, 26 females) and 96 controls (47 males, 49 females) were assessed at 4 to 5 years' corrected age for

community participation using the Young Children's Participation and Environment Measure. Motor skills were assessed using the Movement Assessment Battery for Children, Second Edition and the Little Developmental Coordination Disorder Questionnaire.

**RESULTS** Children born very preterm participated less frequently than term-born children (difference in means = -0.28, 95% confidence interval [CI] -0.54 to -0.03,  $p=0.029$ ). Social risk was associated with lower frequency (interaction  $p<0.001$ ) and involvement (interaction  $p=0.05$ ) in community activities for children in the very preterm group only. Parents of children born very preterm perceived more barriers (odds ratio = 4.32, 95% CI 1.46–12.77,  $p=0.008$ ) and environmental factors to be less supportive of participation than parents of controls (difference in medians = -6.21, 95% CI -11.42 to -1.00,  $p=0.02$ ).

**INTERPRETATION** Children born very preterm may benefit from ongoing support to promote participation, especially in families of higher social risk.

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Community Participation for Children Born Preterm *Kate L Cameron et al.*

**What this paper adds**

- Children born preterm attend community activities less often than term-born children.
- When attending community activities, involvement was similar between preschool age children born preterm and at term.
- Social risk negatively impacted participation for children born preterm, but not at term.

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- Motor impairment did not appear to influence participation frequency or involvement.
- Parents of children born preterm perceived more barriers to participation than parents of term-born children.

[main text]

At preschool age, children born very preterm (<32wks' gestation) have higher rates of motor impairment than term-born children.<sup>1</sup> Motor impairments persist throughout childhood and adolescence.<sup>2</sup> By school age, children with motor impairment participate less than their typically developing peers with a range of factors, including sex, socioeconomic status, and perceived motor competence, influencing participation.<sup>3,4</sup> This is of concern, as participation promotes social, cognitive, and motor development for children.<sup>5</sup> Defined as 'involvement in a life situation',<sup>6</sup> participation is a complex construct. For this study, we use the conceptualization of participation outlined in the Family of Participation-Related Constructs.<sup>5</sup> Participation includes two essential components: attendance and involvement (or the experience of participating), in situations or activities that are socially or personally meaningful.<sup>5</sup> This study focuses on community participation (hereafter referred to as participation) in a range of activities including: neighbourhood outings, classes and groups, social or community attractions, recreational activities, and holidays.

At school age, there is evidence to suggest children born preterm may participate less frequently in recreational and social activities<sup>7,8</sup> than term-born children, with motor impairment associated with lower physical activity participation in the preterm population.<sup>7</sup> Very little is known, however, about participation of preschool age children born very preterm.<sup>1</sup> As motor development and participation are closely linked at preschool age,<sup>5</sup> and children born very preterm are at higher risk of motor impairment than term-born children, even when age is corrected for preterm birth,<sup>1</sup> this is an important gap in the literature. Additionally, correlates affecting participation, such as motor impairment and social risk, may be different for children at preschool age compared with older children.<sup>9,10</sup> Further research into participation at preschool age for children born very preterm, and factors affecting participation in this population, may aid in explaining the trajectory towards lower levels of participation at school age, and help inform interventions that promote participation.

The aims of this study were to understand at preschool age: (1) the association between very preterm birth and frequency and quality of participation compared with term-born

children; (2) social risk and motor impairment as predictors of participation frequency and involvement, and whether these associations differ between children born very preterm and at term; and (3) the association between very preterm birth and perceived environmental barriers and supports to participation compared with term-born children.

## METHOD

### Study participants

Participants were recruited in the neonatal period as part of the Victorian Infant Brain Study-2, a longitudinal cohort study of 150 infants born at <30 weeks' gestation (referred to as very preterm) and 151 control children born with normal birthweight ( $\geq 2500$ g) at term. Infants were recruited between January 2011 and December 2013 from the Royal Women's Hospital, Melbourne, Australia. Participants were excluded if they had congenital abnormalities known to affect development or if they had non-English speaking parents, as funding was unavailable for translators. This substudy includes 48 children born very preterm and 96 term controls. The study was approved by the Royal Children's Hospital Human Research and Ethics Committee, Melbourne, Australia. Written informed consent was obtained from parents on behalf of their child.

### Assessment measures

Perinatal characteristics, including gestational age and birthweight, were collected in the newborn period. All children were invited to attend a half-day developmental follow-up with their primary caregiver at The Royal Children's Hospital, Melbourne, Australia at 4 to 5 years of age.<sup>11</sup> For assessments, each child's age was corrected for preterm birth (i.e. calculated from expected date of birth) to minimize the risk of underestimating performances of children born preterm,<sup>12</sup> and is referred to hereafter as corrected age at assessment. Relevant to this study, the following measures were collected at preschool age. In addition, children were assessed using the Weschler Preschool and Primary Scale of Intelligence, Fourth Edition, Australian and New Zealand Standardised Edition, and were classified as having cognitive impairment if they scored <70 on the full scale IQ.<sup>13</sup>

### Participation

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Participation was assessed using the community section of the Young Children's Participation and Environment Measure (YC-PEM). The YC-PEM is a caregiver completed questionnaire for children aged 0 to 5 years with and without developmental delays.<sup>14</sup> The YC-PEM is a valid measure of participation and has good internal consistency and test-retest reliability for the community section.<sup>14</sup> Specific details of all participation variables and how they were calculated are described in Table 1. The YC-PEM was completed by a parent via paper questionnaire and entered into a secure online database.

### **Motor skills**

Motor skills were measured using the Movement Assessment Battery for Children, Second Edition (MABC-2), a valid and reliable assessment of motor function for children with and without motor impairment,<sup>15</sup> and the Little Developmental Coordination Disorder Questionnaire (L-DCDQ), a parent-report questionnaire designed to identify subtle motor difficulties in children.<sup>16</sup> Children were considered at risk of motor impairment if they scored  $\leq 16$ th centile and as having significant motor impairment if they scored  $\leq 5$ th centile or had a diagnosis of cerebral palsy.<sup>15</sup> For the L-DCDQ, children were classified as suspect for developmental coordination disorder if they scored below 68 for females and 67 for males<sup>16</sup> and did not have a diagnosis of cerebral palsy. MABC-2 assessments were completed by trained physiotherapists blinded to the child's birth history and previous assessment results. Children who were unable to complete the assessment because of motor impairment were assigned the lowest possible standard score of 1 and a centile of 0.1. Incomplete questionnaires or missing MABC-2 scores from children who did not complete the assessment because of behavioural or cognitive impairment were treated as missing data. The L-DCDQ was completed online directly into the study database.

### **Social risk**

The Social Risk Index is a measure of family social risk used previously<sup>17</sup> and is comprised of six items: family structure, primary caregiver education, primary income earner occupation, employment status of primary income earner, language spoken at home, and maternal age at birth. Each item is scored on a 3-point scale (0–2), with a lower score reflecting lower risk. The summed total score was dichotomized into lower (total score  $< 2$ ) or higher social risk (total score  $\geq 2$ ) based upon the median of the complete cohort.<sup>11</sup> The Social Risk Index was elicited from information provided by the primary caregiver via a parent-completed questionnaire at

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the 4- to 5-year assessment. If social risk information was missing at this time point, data from the 2-year assessment were used.

### Statistical analysis

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Data were analysed using Stata (Version 15.1, StataCorp, College Station, TX, USA). Descriptive statistics for participant characteristics were calculated separately for: (1) children with and without YC-PEM data in each birth group; and (2) very preterm and term groups included in the study. Participation outcomes were plotted visually to examine the distribution of the data. Involvement, environmental helpfulness, and environmental resources (see Table 1 for variable descriptions) were not normally distributed and therefore were analysed using quantile regression. For aim 1, children born very preterm and at term were compared using linear (frequency) or quantile (involvement) regression, adjusted for social risk, corrected age at assessment, and sex. Social risk and corrected age at assessment were chosen as covariates as in our cohort children born very preterm were higher social risk and younger when assessed, both of which have been associated with lower participation for preschool age children.<sup>9,18</sup> For aim 2, social risk and motor impairment (MABC-2  $\leq$ 5th centile, MABC-2  $\leq$ 16th centile, and L-DCDQ suspect for developmental coordination disorder) were assessed as predictors of participation using linear (frequency) and quantile (involvement) regression, adjusted for birth group, corrected age at assessment, sex, and social risk (the latter adjusted for in the assessment of motor impairment only). Whether the effect of social risk or motor impairment on participation varied between children born very preterm/at term was assessed by including an interaction term in the model. Results from linear regression models are reported with clustered sandwich estimates of the standard errors to account for the correlation between twins. To ensure poor MABC-2 scores did not reflect cognitive rather than motor impairment, sensitivity analyses were conducted excluding children with cognitive impairment and MABC-2  $\leq$ 16th. Finally, for aim 3, descriptive statistics were used to report perceived environmental factors influencing participation separately for children born very preterm and at term. Differences in environmental supports, barriers, helpfulness, and resources between parents of children born very preterm and at term were assessed using logistic (perceived barriers and supports) or quantile (environmental helpfulness and resources) regression adjusted for birth group, corrected age at assessment, social risk, and sex.

## RESULTS

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### Participant characteristics

The YC-PEM was administered to parents of 156 children, of which parents of 144 children (93%), 48 children born very preterm and 96 term-born children, completed the questionnaire; participant characteristics are described in Table 2. The characteristics were similar between children whose parents had completed the YC-PEM and those who did not, in both the very preterm and term-born groups (Table S1, online supporting information). Of the included participants, children born very preterm had poorer performance on motor assessment and were younger at time of assessment compared with term-born children. There were three children with cerebral palsy; all were born very preterm, were ambulant, and had an MABC-2 score  $\leq$ 16th centile.

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### Participation frequency and involvement

Children born very preterm participated less frequently in community activities (difference in means =  $-0.28$ , 95% confidence interval [CI]  $-0.54$  to  $-0.03$ ,  $p=0.03$ ), but had similar levels of involvement (difference in medians =  $0.05$ , 95% CI  $-0.25$  to  $0.34$ ,  $p=0.76$ ) compared with term-born children. Frequency and involvement for each of the 11 activities in the two birth groups is described in Table S2 (online supporting information). There was evidence that the relationship between social risk and participation varied between birth groups; higher social risk was associated with both lower participation frequency (very preterm: difference in means =  $-0.75$ , 95% CI  $-1.07$  to  $-0.43$ ; term: difference in means =  $0.08$ , 95% CI  $-0.18$  to  $0.33$ ; interaction  $p<0.001$ ) and involvement (very preterm: difference in means =  $-0.40$ , 95% CI  $-0.77$  to  $-0.02$ ; term: difference in means =  $0.09$ , 95% CI  $-0.20$  to  $0.39$ ; interaction  $p=0.045$ ) for children born very preterm, but not for children born at term (Fig. 1). There was little evidence that any of the motor impairment classifications were associated with participation frequency or involvement for preschool age children, or that these relationships varied between children born very preterm and at term (MABC-2  $\leq$ 5th: frequency interaction  $p=0.11$ , quality interaction  $p=0.06$ ; MABC-2  $\leq$ 16th: frequency interaction  $p=0.27$ ; L-DCDQ: frequency interaction  $p=0.69$ , quality interaction  $p=0.29$ ; Fig. 2). There was one exception. There was evidence that children born very preterm with risk of motor impairment (MABC-2  $\leq$ 16th centile) were less involved than children born very preterm without risk of motor impairment (difference in medians =  $-0.53$ , 95% CI  $-0.89$  to  $-0.18$ ), but little evidence of a similar relationship in children born at term (difference in medians =  $0.10$ , 95% CI  $-0.24$  to  $0.45$ , interaction  $p=0.012$ ).

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Sensitivity analyses excluding the two children with cognitive impairment and MABC-2  $\leq$ 16th made little difference to the results.

### **Environmental helpfulness, resources, supports, and barriers**

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Parents of children born very preterm were more likely to report environmental barriers than parents of term-born children (odds ratio [OR]=4.32, 95% CI 1.46–12.77,  $p=0.008$ ). There was little evidence, however, that perceived environmental supports varied between parents of children born very preterm and at term (OR=0.17, 95% CI 0.02–1.51,  $p=0.11$ ). The percentage of parents reporting each of the environmental factors as barriers, neutral, or supports in the two birth groups is illustrated in Figure S1 (online supporting information). There was little evidence that perceptions of environmental resources varied by birth group (difference in medians=0.00, 95% CI –4.82 to 4.82,  $p=1.00$ ). In contrast, there was evidence that parents of children born very preterm reported lower environmental helpfulness compared with parents of term-born children (difference in medians=–6.21, 95% CI –11.42 to –1.00,  $p=0.02$ ).

## **DISCUSSION**

Our study found evidence that children born very preterm participated less frequently than term-born children at preschool age, but for activities in which they did participate, involvement was similar. There was also evidence that higher social risk was associated with both lower frequency and involvement in community activities for children born very preterm, but not for term-born children. There was little evidence that motor impairment was associated with participation frequency or involvement in either group. Finally, parents of children born very preterm were more likely to report barriers to participation, and perceived environmental features to be less helpful in supporting participation, than parents of term-born children.

In keeping with published studies, more children born very preterm than at term had motor impairment in our cohort.<sup>2</sup> Children in the very preterm group were also more likely to be higher social risk than children in the term control group in our study, which has been found to be associated with lower participation for preschool age children.<sup>9</sup>

To our knowledge, this is the first study to use a participation outcome that measures both attendance (frequency) and involvement in community activities for preschool age children born very preterm compared with term-born children. The YC-PEM reflects an evidence-based definition of participation, consisting of both attendance (being there) and

involvement (the experience of participating).<sup>5</sup> Ensuring the outcomes of interest and the outcome measures are conceptually matched provides clarity in study results and supports internal validity.<sup>19</sup> Previous studies considering participation of preschool age children born preterm compared with term-born children have measured frequency or intensity (attendance), but not involvement.<sup>20,21</sup> In contrast to our study, these previous studies found no evidence of differences in play, active recreation, social activities,<sup>20</sup> or physical activity attendance<sup>21</sup> between birth groups. The disparity with our results may be explained by differences in study focus; we assessed participation for all children in our cohort across a range of community activities, whereas Killeen et al. assessed children born preterm who did not have a physical or intellectual disability<sup>20</sup> and Spiegler et al. measured only participation in structured and unstructured physical activity.<sup>21</sup>

Our results provide further evidence that higher social risk negatively affects participation.<sup>4,9</sup> Uniquely, we found evidence that higher social risk was associated with poorer participation frequency and involvement for children in the very preterm but not the term group. Ongoing support and participation-focused interventions should be targeted towards children born very preterm from higher social risk families, particularly as there is evidence that this group may benefit from early intervention to a greater extent than children from lower social risk families.<sup>22</sup> Furthermore, supporting children from higher social risk families is particularly important as social risk is known to adversely affect motor skill competency,<sup>23</sup> for which children born preterm are already at risk of poorer performance than their term-born peers.<sup>1</sup>

Our study found little evidence that motor impairment was associated with participation at preschool age. For most motor outcomes we assessed, the point estimates for the mean difference suggested that children without motor impairment were participating more often and were more involved than those with motor impairment, although the confidence intervals were wide and included no difference. It is possible that the small sample size may have affected our ability to identify differences. An alternative explanation is that children do not have an accurate perception of their motor competence at preschool age,<sup>10</sup> and so motor impairment is less likely to influence participation in the same way as for older children.<sup>24</sup> Further, activities at preschool age may not yet require a high level of motor skills, and differences could develop as participation with peers becomes more demanding.<sup>25</sup>

There is inconsistency in the literature regarding whether motor impairment adversely affects participation of preschool age children. This could be due to the range of outcome measures and participation situations explored, with some studies measuring enjoyment rather than involvement.<sup>9,26</sup> While enjoyment could be considered a proxy for involvement, it is worth noting that it is possible to be involved in unenjoyable activities.<sup>19</sup> Rosenblum et al. found that children with motor impairment participate less frequently, and with lower enjoyment, than children without motor impairment.<sup>26</sup> In contrast, Soref et al. found that motor impairment negatively influenced enjoyment, but not frequency,<sup>9</sup> while others found that motor impairment was not associated with participation in play, social life, and education,<sup>27</sup> or physical activity.<sup>28</sup> It could be viewed as encouraging that motor impairment was not associated with participation attendance or involvement in our cohort. Preschool age may therefore be an opportune time to intervene to promote participation in children with motor impairment, before patterns of reduced participation have become established.

This paper presents the results of a substudy, which includes a greater proportion of children born at term than very preterm compared with the full cohort, as we made the decision not to contact the 99 families who had completed their assessment before adding the YC-PEM to the protocol, to minimize the burden on families. Despite this, the current substudy appears to be representative of the larger cohort, with similar characteristics at baseline between children who were and were not included in this study (Table S1). In addition to very preterm birth, our study focuses on motor impairment and social risk as predictors of participation. There are, however, other possible contributing factors, such as cognitive impairment or participation habits of parents,<sup>7</sup> which, while beyond the scope of this paper, should be considered in future research. Further research is also needed to ascertain if observed participation differences are meaningful to families as the YC-PEM has no established clinically important difference,<sup>14</sup> while the use of a more detailed social risk measure in future studies may provide a greater understanding of the relationships between socioeconomic factors and participation in community activities. Participation variables, excluding environment supports and barriers (Table 1), were treated as continuous data in our analysis. While it would not be appropriate to analyse a single Likert response as a continuous rather than categorial outcome, the participation variables in this study were calculated by taking the average of Likert scale responses across the questionnaire,<sup>14</sup> a method used previously by the author of this outcome measure.<sup>29</sup> Further limitations of our study include a small sample size. Strengths of this study include the use of a term-born control group, employing an outcome

measure conceptually matched to an evidence-based definition of participation, and considering the influence of relevant correlates of participation (motor impairment and social risk) that are associated with decreased participation in older children.<sup>3,4</sup>

It is concerning that at preschool age, children born very preterm are participating less frequently than their term-born peers, particularly as very preterm birth is a risk factor for motor impairment.<sup>2</sup> A focus on participation is important as not only is it a meaningful outcome for children,<sup>5</sup> but interventions that promote participation may also improve impairments.<sup>30</sup> An understanding of the environmental barriers and facilitators perceived by parents may provide information on modifiable factors which could promote participation.<sup>31</sup> For example, the Pathways and Resources for Engagement and Participation intervention effectively improved participation for adolescents with physical disabilities by modifying environmental barriers to a participant-chosen activity.<sup>32</sup> There is little evidence available on participation interventions for preschool age children,<sup>33</sup> and the perceived environmental barriers and supports reported in this study may facilitate the use of similar interventions in this age group.

In our study, the most commonly reported environmental factors that ‘make it harder’ to participate were the social and physical demands of the activity, physical layout, and sensory qualities. This suggests that strategies such as modifying the task or environment or adapting expectations to meet the child’s needs may promote participation. Further research is warranted to explore participation-focused interventions for preschool age children to determine if an ecological approach, in which the environment is modified, is successful in this age group. Furthermore, parents of children born very preterm were less likely to view factors such as access to public transport, availability of appropriate services, or policies as supportive of participation compared with parents of term-born children. It is possible these findings are partially explained by the greater number of higher social risk families in the very preterm group, as socioeconomic status is associated with access to community resources.<sup>4</sup> Importantly, however, these findings highlight the value of environmental factors that may not be modifiable by clinicians, and underline that community participation needs to be supported by broader social policies.

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### Supporting information

The following additional material may be found online:

**Figure S1:** Parent-perceived helpfulness of environmental factors to community participation presented separately for children born very preterm and at term.

**Table S1:** Participant characteristics of children born very preterm and at term

**Table S2:** Participation frequency and involvement for each community activity item presented separately for children born very preterm and at term

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**Table 1:** Summary of participation outcomes captured on the Young Children’s Participation and Environment Measure

Participation outcome	Explanation
Frequency of participation	Parents are asked to score ‘how often’ their child participates in 11 community activities on an ordinal Likert scale, ranging from 1 (once in the last 4mo) to 7 (once or more each day). These scores are summed and divided by the number of activities in which that child participates.
Involvement	Parents are asked to score ‘how involved’ their child is in each activity using an ordinal Likert scale from 1 (not very involved) to 5 (very involved). These scores are summed and divided by the number of activities in which that child participates.

Environmental helpfulness	Parents are asked to consider the helpfulness of 10 environmental features: physical layout, sensory qualities, physical demands, cognitive demands, social demands, attitudes of others, child's relationships, weather, safety, and policies. Answers are coded as 3 (usually helps or no impact), 2 (sometimes helps, sometimes makes harder), or 1 (usually makes harder). Scores are summed and expressed as a percentage of each individual's total possible score (number of questions answered multiplied by 3, the highest score for any given question).
Environmental resources	Parents are asked to consider the availability or adequacy of seven environmental resources: public transportation, private transportation, programmes in the community, equipment or supplies, information about activities, time, and money. Answers are coded as 3 (usually yes or not needed), 2 (sometimes yes, sometimes no), or 1 (usually no). Calculated as per 'environmental helpfulness'.
Environmental supports	Binary outcome indicating whether or not a parent perceived one or more environmental features or resources to be supportive of participation (responded usually helps/usually yes).
Environmental barriers	Binary outcome indicating whether or not parents perceived one or more environmental features or resources to be barriers to participation (responded usually makes harder/usually no).

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**Table 2:** Characteristics of the study participants

Participant characteristics	Very preterm, <i>n</i> =48	Term, <i>n</i> =96
Corrected age at assessment, mean (SD), y:mo	4:8 (0:2)	4:10 (0:2)
Gestational age, mean (SD), wks	27.7 (1.7)	39.9 (1.2)
Birthweight, mean (SD), g	1029 (276)	3504 (431)
Male sex, <i>n</i> (%)	22 (45)	47 (49)
Multiple births, <i>n</i> (%)	23 (48)	2 (2)
Cerebral palsy, <i>n</i> (%)	3 (6)	0 (0)
MABC-2 ≤5th centile and/or cerebral palsy, <i>n</i> (%) <sup>a</sup>	9 (19)	6 (6.25)
MABC-2 ≤16th centile, <i>n</i> (%) <sup>a</sup>	18 (38)	14 (15)
L-DCDQ suspect for DCD, <i>n</i> (%) <sup>b</sup>	18 (38)	29 (30)
Cognitive impairment, <i>n</i> (%) <sup>c</sup>	3 (6)	0 (0)
Higher social risk, <i>n</i> (%) <sup>d</sup>	24 (50)	26 (27)

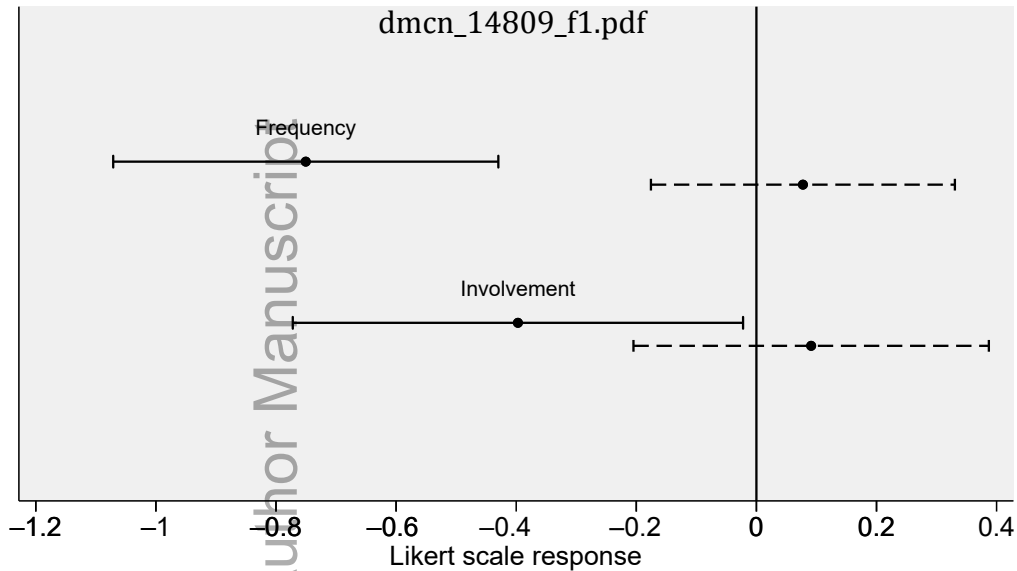
<sup>a</sup>Missing data for one child born very preterm and two term-born children. <sup>b</sup>Does not include children with a cerebral palsy diagnosis. Missing data for seven children born very preterm and 13 term-born children. <sup>c</sup>Cognitive impairment defined as full-scale IQ <70 on the Weschler Preschool and Primary Scale of Intelligence; missing data from three child born preterm and one term-born child. <sup>d</sup>Missing data for one child born very preterm and one term-born child. SD, standard deviation; MABC-2, Movement Assessment Battery for Children, Second Edition; L-DCDQ, Little Developmental Coordination Disorder Questionnaire; DCD, developmental coordination disorder.

[Figure legends]

**Figure 1:** Effect of higher social risk on participation frequency and involvement of preschool age children born very preterm (VP) and at term. Results adjusted for sex and corrected age at assessment. Error bars represent 95% confidence intervals.

**Figure 2:** Difference in participation frequency and involvement of preschool age children with and without motor impairment, considering three measures of motor impairment:

Movement Assessment Battery for Children, Second Edition (MABC-2),  $\leq 5$ th centile, MABC-2  $\leq 16$ th centile, and Little Developmental Coordination Disorder Questionnaire (L-DCDQ) suspect for developmental coordination disorder (DCD) score. Analyses adjusted for very preterm birth, social risk, corrected age at assessment, and sex. Error bars represent 95% confidence intervals. Involvement results are presented separately for MABC-2  $\leq 16$ th for children born very preterm (VP) and at term, as there was evidence of an interaction between birth group and motor impairment.

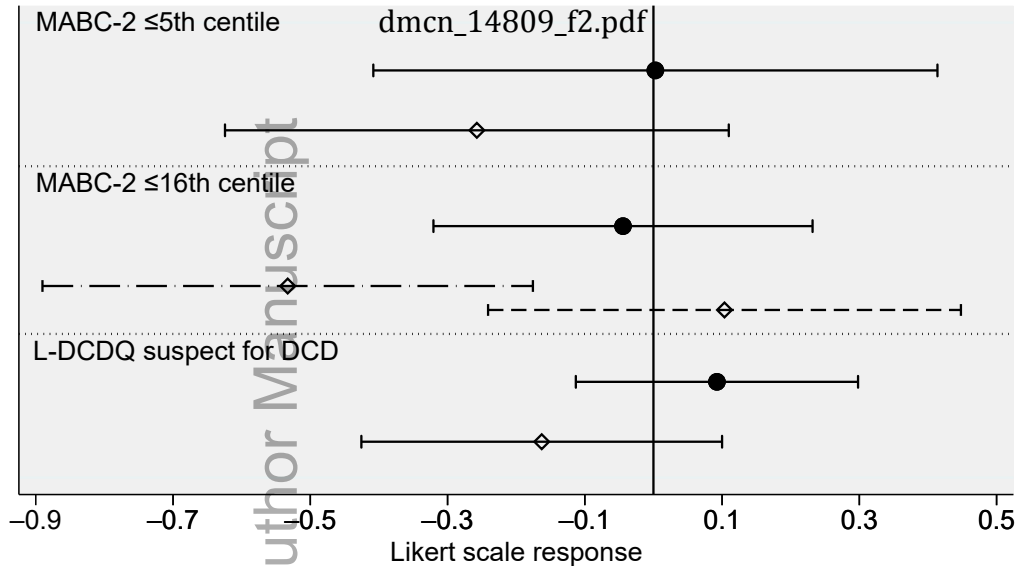


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Mean difference

Children born very preterm

Children born at term



Mean difference: Frequency



Children born very preterm and term



Mean difference: Involvement



Children born very preterm



Children born term

