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Original article: The *Baby Moves* smartphone app for General Movements Assessment: Engagement amongst extremely preterm and term-born infants in a state-wide geographic study

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Abstract (250 words max – 248 words)

BACKGROUND

The *Baby Moves* smartphone application is designed for parents to video their infants' spontaneous movement for remote General Movements Assessment (GMA).

AIM

To assess the engagement with *Baby Moves* amongst high and low-risk infants' families, and the sociodemographic variables related to engagement.

METHODS

Families of extremely preterm (EP, <28 weeks' gestational age) or extremely low birthweight (ELBW, <1000 g) infants and term-born controls from a state-wide geographic cohort study were asked to download *Baby Moves. Baby Moves* provided reminders and instructions to capture videos of their infants' general movements. Parents were surveyed about *Baby Moves'* usability.

RESULTS

The parents of 451 infants (226 EP/ELBW; 225 control) were recruited, 416 (204 EP/ELBW; 212 control) downloaded *Baby Moves,* and 346 (158 EP/ELBW; 188 control) returned at least one scorable video for remote GMA. Fewer EP/ELBW families submitted a scorable video than controls (70% vs. 83%, respectively; odds ratio [OR] 0.48, 95% confidence interval [CI] 0.3-0.79; p=0.003), but the difference diminished when adjusted for sociodemographic variables (OR 1.09; 95% CI 0.59-2.0; p=0.79). Families who received government financial support (OR 0.28, 95% CI 0.1-0.78, p=0.015), who spoke limited English at home (OR 0.39, 95% CI 0.22-0.69, p=0.001) or with lower maternal education (OR 0.38, 95% CI 0.21-0.68, p=0.001), were less likely to return a scorable video. Surveyed parents responded mostly positively to *Baby Moves'* usability.

CONCLUSIONS

Most parents in this study successfully used *Baby Moves* to capture infant movements for remote GMA. Families of lower sociodemographic status used *Baby Moves* less.

Keywords

General Movements Assessment

Smartphone application

Sociodemographic status

Preterm infants

Cohort study

What is known on this topic:

- Smartphone apps for health data capturing are being rapidly developed, but rarely tested
- The General Movements Assessment has good predictive validity for cerebral palsy when assessed by clinicians

What this paper adds

- The *Baby Moves* app can be successfully used by most parents
- Lower maternal education, limited English and reliance of government financial support was related to poorer engagement with *Baby Moves*
- Most parents found *Baby Moves* easy and straightforward to use

Word count 2493 (max 2500 words)

INTRODUCTION

As clinicians move into the digital age, widespread use of smartphones has opened opportunities to share visual clinical data via the internet. One key assessment that can harness modern technology is the General Movements Assessment (GMA), where spontaneous infant movements are captured on video and scored by trained assessors, traditionally in a clinic and/or research setting.[1] Fidgety general movements (GMs) observed at 9-20 weeks' corrected age are spontaneous small amplitude, variable movements in all four limbs and body of an awake infant[1] and have good predictive validity for later cerebral palsy (CP).[2-4] Our team designed a smartphone application (app), called *Baby Moves*, to enable parents to record videos of their infants' movements after being discharged from hospital[5] with the aim of improving access to skilled clinicians for remote GMA, and to ensure timeliness of assessment during the fidgety period.

Despite widespread smartphone ownership and increasing numbers of apps for healthcare, smartphone apps are rarely assessed at the population level to test their uptake, acceptability, data security, and usability amongst a target cohort.[6] As *Baby Moves* has potential to be used as a population-based screening tool, it is important to assess its uptake and usability amongst families of infants who may be at higher or lower risk of later CP, and to determine any sociodemographic variables that influence engagement with the *Baby Moves* app.

Therefore, applicability of the *Baby Moves* app was studied in a geographic cohort of families who had infants born extremely preterm (EP, <28 weeks' gestation) or extremely low birthweight (ELBW, <1000 g), and who were at higher risk of developing CP,[7] and a control group of term-born infants, who were at low risk of developing CP. Our aims were to determine if parents of EP/ELBW and term control infants were able to use the *Baby Moves* app to provide a video of sufficient quality where GMA could be assessed, and if sociodemographic variables affected submission rates for videos. We also investigated the usability and acceptability of the *Baby Moves* app from a parent's perspective.

METHODS

Participants

The families of all infants born either EP or ELBW in the 12 months from April 1, 2016 in the state of Victoria, Australia were approached for participation in this study with inclusion criteria described

previously.[5] For each infant born EP/ELBW, a term control infant was recruited and matched for age, sex, mother's country of birth, primary language English or otherwise, and health insurance status as a proxy for sociodemographic status. All other sociodemographic data were collected as per Table 1. We excluded infants born with lethal anomalies. All participants provided written informed consent and ethics was approved by the Human Research Ethics Committees at the Royal Children's Hospital, Mercy Hospital for Women, Monash Medical Centre, and the Royal Women's Hospital.

Data collection

At recruitment, participants were assisted by a research nurse coordinator to download and install the *Baby Moves* app. The app is linked to a secure online Research Electronic Data Capture (REDCap) database hosted at the Murdoch Children's Research Institute. The app was available for iOS 7.0/8.0/9.0 and Android V4.2-5.1 systems. The app provided notifications at 12 and 14 weeks' corrected age to prompt parents to record GMs according to simple instructions.[5] If infants were inpatients at 12-16 weeks' corrected age, parents were encouraged to record the video in the hospital setting. These two time points aimed to capture infants' fidgety movements to account for any changes in GMs and provided a second opportunity for parents to video their infant(s) if the first video was of suboptimal quality, or if they had not returned a video before 14 weeks' corrected age. The app linked with the phone's camera to provide filming guidelines as per Appendix A. Once the video was completed, parents had the option of refilming or uploading the video.

When parents had not returned a 12-week video, they were contacted at the commencement of the 14-week filming period by email or phone, in addition to their app's notification to establish reasons why videos were not uploaded before 14 weeks' corrected age.

Videos that were returned and of sufficient quality to be used with the GMA were classified as "scorable", and videos that were not returned at all, or were of poor quality, were considered "unscorable", with reasons for non-submission listed in Figure 1, and reasons for poor video quality listed in Appendix B.

Assessment of General Movements

Videos were accumulated and assessed weekly by two of three assessors (AE, JO, AK). All assessors had passed advanced GMs courses under the General Movements Trust.[8] Assessors AE and JO were blinded to the infant's clinical history, and assessor AK partially blinded, with knowledge if the

infants were EP/ELBW or term controls, but no other clinical history was known. Videos were scored and classified as normal, intermittent, sporadic, abnormal, or absent fidgety movements according to Prechtl's method of assessing general movements.[1] Disagreement between assessors was resolved by a third assessor (AS), who is a qualified GMs instructor, and who was blind to clinical details of the infants. Participants with videos scored as sporadic, abnormal, or absent fidgety movements were invited to receive clinical follow-up and further neurodevelopmental assessment as these movement categories have predictive validity for later CP.[9] Some infant videos that were scored as intermittent fidgety were followed up clinically if there were additional movement concerns noted in the video (e.g. fisted hand, asymmetries).

Parents' perceptions

Once videos were submitted by the second time point and videos had been scored using the GMA, parents' opinions about the *Baby Moves* app were recorded using an online REDcap survey as per Appendix C. The questions were based on a tool developed by Jin & Kim (2015) to evaluate information and instruction clarity, interface intuitiveness and data security of healthcare apps.[10] One survey was sent per family via parents' emails or by post if parents did not have a valid email address.

Data analysis

Data were analysed using STATA version 14 (Stata Corp, College Station, TX). To analyse differences between EP/ELBW and term control characteristics, we used the independent t-test for continuous data and $Ç^2$ test for categorical data. Differences between the proportions of videos returned that could be scored using the GMA were analysed using the $Ç^2$ statistic. We accounted for multiple births from the same family using linear models fitted with generalised estimating equations to analyse data for the likelihood of videos being uploaded with respect to EP/ELBW and control groups. If there were problems with convergence, sandwich estimators of variance were used to account for clustering of multiples within the family. The relationships between video return rates and sociodemographic variables, including maternal education, primary language spoken at home (English only or otherwise), family structure, maternal age at birth, primary income source, and skilled/unskilled occupation of the primary income earner, were assessed by linear regression models, and these variables were included as covariates in the model comparing the families of EP/ELBW and control infants. Differences between groups were expressed as odds ratios (OR) with 95% confidence intervals (CI). Survey responses from families were presented visually as a bar graph with distribution

of responses expressed as percentages, and differences in proportions between EP/ELBW and term control groups were contrasted using the χ^2 statistic.

RESULTS

Four-hundred and fifty-one infants (EP/ELBW, *n*=226; term control, *n*=225) were recruited to the current study (Figure 1) and participant characteristics are summarised in Table 1,which reflected previous cohorts of infants born EP/ELBW in the state of Victoria.[11] EP/ELBW families who ultimately participated in this sub-study were disadvantaged sociodemographically compared with controls (Table 1).

Only 21 videos could not be used with the GMA with reasons for poor quality detailed in Appendix B.

There were significantly fewer scorable videos of EP/ELBW infants returned (69.9%; 158/226) compared with term controls (82.7%; 186/225), (Figure 1. OR 0.48, 95% CI 0.30-0.79, *p*=0.003). However, the difference between families of infants born EP/ELBW and term controls for returning videos diminished when corrected for the sociodemographic variables listed in Table 1 (OR 1.09, 95% CI 0.59–2.0, p=0.79).

Families were less likely to return a scorable video if they were reliant on government or spouse income support (OR 0.28, 95% CI 0.1-0.78, p=0.015), if they spoke limited English at home (OR 0.39, 95% CI 0.22-0.69, p=0.001), or if the mother only had a high school level of education (OR 0.38, 95% CI 0.21-0.68, p=0.001) (Figure 2). There was little evidence that families with fewer than two caregivers, primary income earners in unskilled labour, and maternal age at birth less than 21 years of age were associated with returning a scorable video (Figure 2).

Of all infants consented, survey responses were received from 50.8% (101/199) of families of infants born EP/ELBW, fewer than the 63.7% (142/223*)* of term controls (OR 0.58, 95% CI 0.39-0.85, *p*=0.005) (Figure 1). The majority of respondents found the *Baby Moves* interface user-friendly, agreed that the reminder notifications and upload functions of the app were useful, and agreed that *Baby Moves* provided a safe way to send videos to clinicians. Responses between term-born and EP/ELBW infants did not differ significantly for most individual items, with the exception of higher preference for face-to-face assessments, feeling worried while using the app, and increasing their

awareness of their baby's development in families with infants born EP/ELBW than controls (Figure 3).

DISCUSSION

In our population-based study, most families submitted scorable videos of their infants for the GMA at 12-14 weeks' corrected age. Fewer families of infants born EP/ELBW submitted scorable videos than families of controls, even though EP/ELBW infants are well known to be at higher risk of later CP compared with term-born peers.[7] However, lower maternal education, limited English, and a family's primary income earner's reliance on government income support represented the main limiting variables for submitting a scorable video. When adjusted for sociodemographic variables, the difference in scorable videos between EP/ELBW and control families diminished. While the response rate was not high, there was an overall positive response from parents towards using the *Baby Moves* app.

To our knowledge, this is the first study to test a parent-operated smartphone app at a population level for a high-risk population. The uptake of the *Baby Moves* app was much higher than previously reported clinical follow-up rates within a similar population, with only 32% of infants followed up in a clinical setting.[12] Additionally, a recent survey of caregivers for children presenting to a surgical outpatient clinic found that ethnicity, low employment, non-English speakers, low education, and health insurance status predicted a low level of engagement in mobile health technologies, which was consistent with some of the characteristics of the participants who did not use *Baby Moves* in the current study.[13] Positive interest in using health-related smartphone apps amongst caregivers has been demonstrated in previous surveys,[13-15] with 72% of respondents from Russo et al.'s survey of Italian caregivers showing interest in using an app to facilitate telehealth. A similar rate of actual uptake was reflected with the *Baby Moves* app within our study.

Smartphone apps such as *Baby Moves* have potential to revolutionise the way we engage with families in the care of their infants by capitalising on the functionality of smartphones as affordable, portable, and powerful data capturing devices. However, many have raised concerns with medical apps' patient confidentiality, secure information transmission, and data storage.[16, 17] Additionally, there may be less access to internet-enabled technologies from people of lower sociodemographic status or health literacy.[13] Therefore, it is important to assess the user experience of smartphone apps to ensure they are targeted and used by their intended audience.[18]

Our study highlights the sociodemographic profiles of families less likely to use *Baby Moves.* Therefore, the app should not be used as a standalone tool; it should act as a complement to comprehensive clinical assessment and neuroimaging with the appropriate population, as recommended by recent early CP diagnosis guidelines.[19] This was evident among the EP/ELBW population with families tending to prefer face-to-face assessment. Identification of at-risk families who are less likely to engage with an app such as *Baby Moves* can assist clinicians to target those who would be better suited to receive face-to-face support. This in turn may facilitate earlier referral for further assessment and intervention for our most vulnerable infants.

Widespread smartphone ownership was apparent within the studied cohort, but phones were not always fully functional. There were more parents of infants born EP/ELBW who changed phones between recruitment and 12 weeks' corrected age (Figure 1). Therefore, it may be more beneficial for *Baby Moves* to be installed closer to the first video time point (12 weeks' corrected age) or prior to discharge from hospital at near-term age. Significantly more parents of infants in the EP/ELBW group had phones that did not work compared with term-born controls, and this may reflect the higher rate of social disadvantage in the EP/ELBW group. Variables such as financial stress, coupled with a lack of time when caring for a preterm infant, may have affected the ability of some participants to harness the full potential of their smartphones, e.g. access to WiFi, payment of data plans, affordability of phones with larger storage capacity, or to repair faulty smartphones. Therefore, we cannot assume that smartphone ownership alone will translate to successful uptake of apps, regardless of the app's simplicity.

Limitations existed with respect to selection bias. The recruited control group may be overrepresented by those who are more concerned about their infants' health compared with the general population and therefore may be more motivated to consent to study participation, potentially artificially inflating the response rate of the videos submitted for term-born controls. Additionally, our study did not have scorable videos from 24% of the entire cohort, which may have led to bias in the proportion of videos that could be scored using the GMA. However, as we were able to correct for sociodemographic variables, we were able to establish that being born EP/ELBW per se was not related to videos being returned for remote GMA.

While the primary focus of this study was to assess the engagement with the *Baby Moves* smartphone app with regards to the app's usability and uptake, further studies need to be conducted to assess the accuracy of the GMs assessed via *Baby Moves* and its predictive validity for later CP. In the

meantime, the current study provides promising results for use of *Baby Moves* by parents for capturing infant GMs for remote assessment within a state-wide geographical cohort.

CONCLUSIONS

The *Baby Moves* app provides a unique opportunity to ensure that infants at high risk of developing CP are assessed with the GMA in a timely manner by transcending families' isolation from expert clinical services. This study demonstrates that the *Baby Moves* app can be successfully used by the majority of parents of infants born EP/ELBW and their term-born controls to submit videos for remote GMA. Families who require government income support, have lower maternal education, or speak minimal English at home were less likely to use the *Baby Moves* app and may require additional support to ensure that a timely GMA is completed. Further studies are required to assess the predictive validity of GMs assessed via *Baby Moves*.

ACKNOWLEDGEMENTS

[see title page]

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Table 1 – Summary of participant characteristics

	EP/ELBW (*n*=226)	**Term control** (*n*=225)	***p*-value**
Birth characteristics (all consented infants)			
Gestational age (weeks), mean (SD, range)	26.7(1.9, 23-32^{+6})	39.6 (1.2, 37-42)	
Birth weight (g), mean (SD, range)	831 (176, 466-1434)	3476 (432, 2510-4650)	
Male sex	116 (51.3)	117 (52.0)	-
Multiple births	58 (25.7)	4 (1.8)	
Vaginal birth†	65/199 (32.7)	137/223 (61.4)	
Perinatal data			
Antenatal corticosteroids administered	206 (91.2)	8 (3.5)	
Duration of invasive ventilation, days; median (IQR)	6.6 (0.5-29)	-	-
Grade 3-4 IVH	12 (5.3) ‡	-	
Cystic PVL	6 (2.7) ‡	-	
Oxygen dependent at 36weeks' GA	120/221 (54.3)	-	
	EP/ELBW families (*n*=199)	**Term control families** (*n*=223)	
Sociodemographic data†			
Private health insurance status	75 (37.9) ‡	105 (47.3) ‡	0.05
Maternal education - high school only	73/175 (41.7)	35/201 (17.4)	<0.001
Primary language at home - some or no English	71 (35.7)	58 (26.0)	0.03
Family structure – shared or one caregiver	20 (10.1) ‡	5 (2.2)	0.001
Maternal age at birth, 21 yrs or younger	12 (6.0)	3 (1.4)	0.009
Partial or all primary income source from government assistance	35/195 (18.0)	5/216 (2.3)	<0.001
Primary income earner in unskilled occupation	37/179 (20.7)	3/203 (1.5)	<0.001
iOS vs Android† **(survey respondents only)**			
iOS users	77/101 (76.2)	107/143 (74.8)	0.80

Data are *n*(%) unless otherwise specified
†values calculated based on families, not individual infants
‡n=1 missing data
Abbreviations: SD – standard deviation; EP – extremely preterm (<28 weeks' gestational age); ELBW – extremely low birthweight (<1000 g); GA – gestational age; NVD – normal vaginal delivery; IQR – inter-quartile range; IVH – intraventricular haemorrhage; PVL – peri-ventricular leukomalacia; iOS – i-operating system; yrs – years

FIGURE LEGENDS

Figure 1 - Flow chart of participants

Figure 2 Graph of odds ratios for sociodemographic variables for being able to submit a video to use with the GMA.

Figure 3 - Parent responses to *Baby Moves* questionnaire. *$p<0.05$

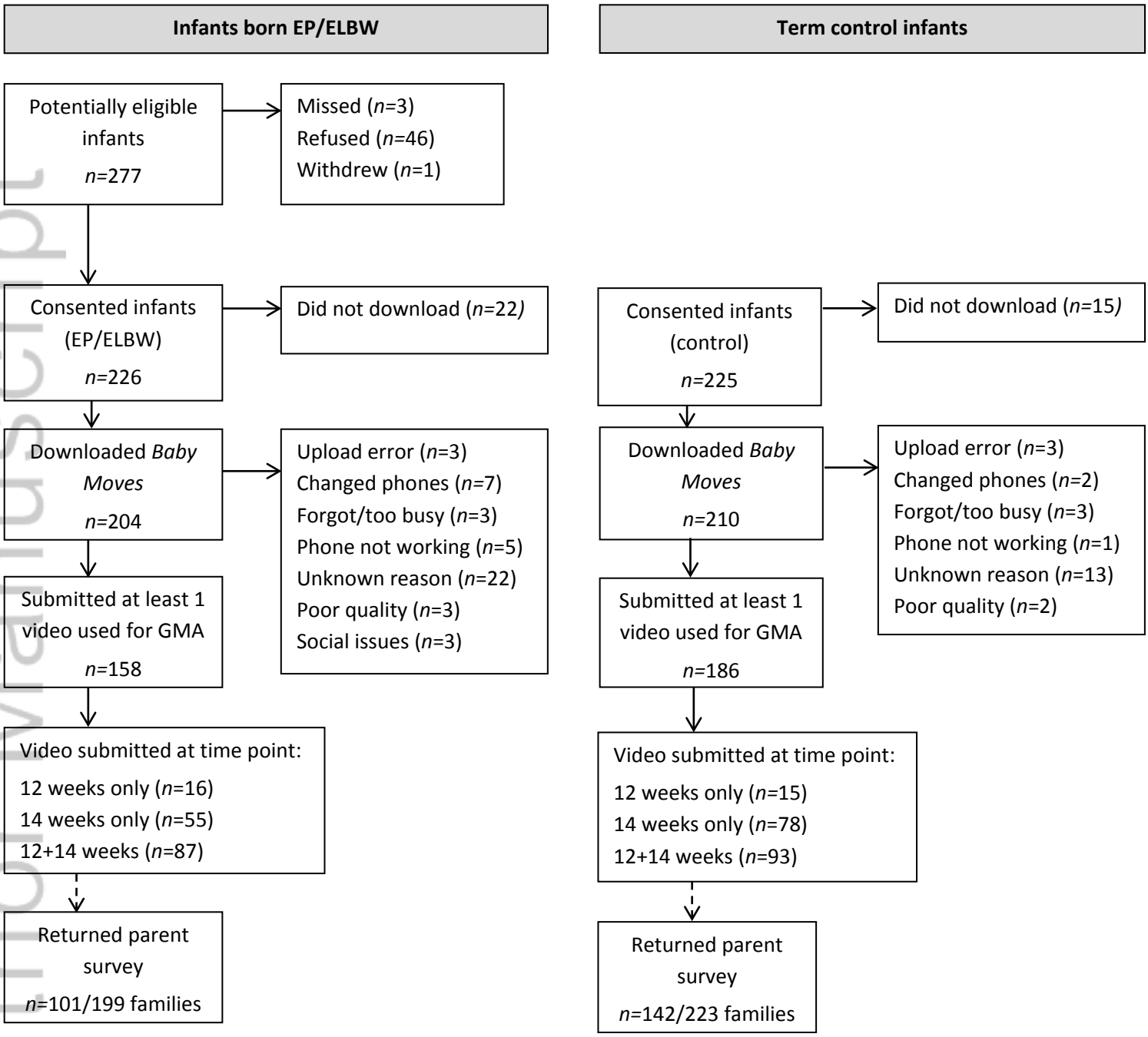
APPENDICES

Appendix A – Baby Moves interface, (outline and countdown timer)

Appendix B - Individual infants' poor video quality reasons at 12 week video time point. *Infants born EP/ELBW

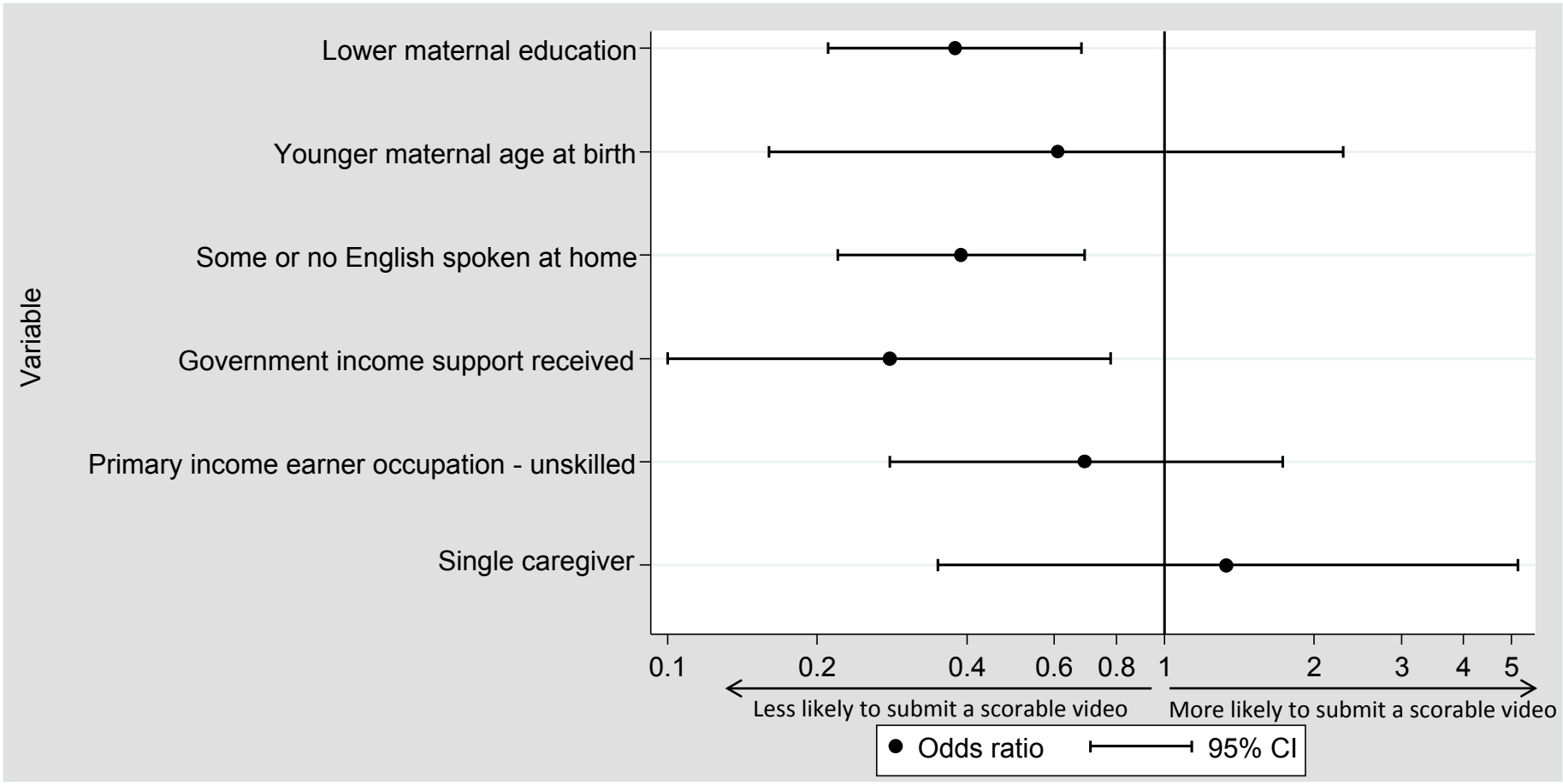
Appendix C – Parent survey

Figure 1 – flow chart of participants



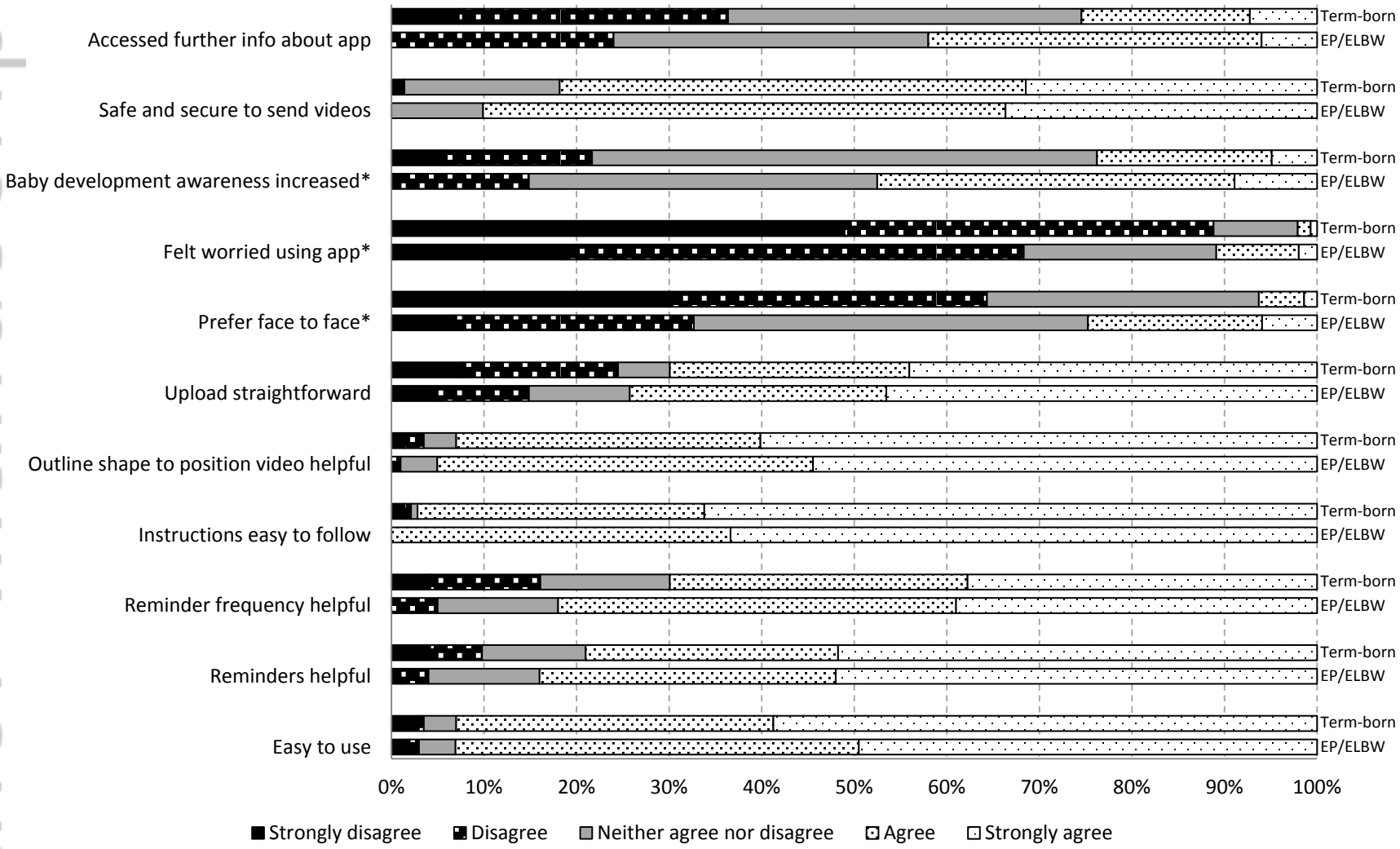
Abbreviations: EP – extremely preterm (<28 weeks' gestational age); ELBW – extremely low birthweight (<1000 g); NICU – neonatal intensive care unit; GMA – General Movements Assessment

Figure 2 Graph of odds ratios for sociodemographic variables for being able to submit a video to use with the GMA.



Abbreviations: EP – extremely preterm (<28 weeks' gestational age); ELBW – extremely low birthweight (<1000 g); CI – confidence interval

Figure 3 - Parent responses to Baby Moves questionnaire.



*p<0.05, between EP/ELBW and control groups

Abbreviations: EP – extremely preterm (<28 weeks' gestational age); ELBW – extremely low birthweight (<1000 g)

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