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Instructional guides for filming infant movements at home are effective for the General Movements Assessment

Original Article

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Newborn Medicine", "Murdoch Children's Research Institute", "Pregnancy, Birth and Baby" and "Raising Children's Network" social media pages.

Conflicts of interest

Prof Alicia Spittle is a tutor with the General Movements Trust. There are no other conflicts of interest to declare.

ABSTRACT

AIM

To determine the effectiveness of two instructional guides to obtain video recordings for the General Movements Assessment (GMA).

METHODS

A cross-sectional study of a community sample of family-participants with low-risk term newborn infants, recruited via social media and randomly allocated to receive one of two instructional guides (detailed or quick versions) to film their infant's movements at home. Participants returned videos via a secure Research Electronic Database Capture link and videos were scored for quality across 10 criteria, along with scoring the GMA. Participants were surveyed about their perceptions of the instructional guides and electronic file transmission.

RESULTS

Seventy-six parents of infants were enrolled and randomly allocated to receive detailed (n=38) and quick (n=38) instructions to film their infant for a GMA. Videos were returned by 87% (95% confidence interval [CI] 72%, 96%) of detailed instruction users, and 84% (95% CI 69%, 94%) of quick instruction users. The GMA could be conducted on all returned videos. The mean score for video quality was 9.9/10 (standard deviation [SD] 0.4, 95% CI 9.7, 10.0) for detailed instructions, and 9.7 (SD 0.6, 95% CI 9.4, 9.9) for quick instructions. Overall, participants felt that either instructional guide was easy to use. Fifteen (20%) participants had difficulties with video file transmission, requiring additional support.

CONCLUSIONS

Parents can successfully use one of two different instructional guides for filming their infant's movements for GMA; however, support should be provided for safe and easy file transmission.

KEY WORDS:

General Movements Assessment

Infant development

Early detection

What is already known on this topic

- General movements are related to later childhood motor outcomes
- Families are able to record movements using smartphone apps
- There are limitations with smartphone apps with use in clinical practice due to barriers of cost, secure storage and compliance with relevant legislation

What this paper adds

- General movements can be recorded by families according to either a detailed or quick instructional guides
- Videos are large files which may provide a barrier to transmitting videos

Introduction

The General Movements Assessment (GMA) is a key assessment for screening for cerebral palsy (CP)[1] and abnormal GMA is also related to developmental delay.[2, 3] As an assessment that is evaluated from video recordings,[4] combined with the widespread availability of smartphone technology and reducing costs of electronics,[5] it is now possible to upskill parents/carers to record videos of their infants for clinical assessment.[6] While dedicated apps have been created to assist parents/carers to record and transmit videos,[7, 8] much variance in organisational and regional privacy and data storage policy limits the use of a cost-effective one-size-fits-all phone app.

General movements (GMs) are endogenous spontaneous movements which can be recognised by trained assessors in infants prior to term up until four months' corrected age when they are in an alert and calm state.[4] GMs are classified as normal or abnormal across three ages: preterm writhing (birth to term), term writhing (term-6 weeks' post-term) and fidgety (9-20 weeks' post-term), the latter having the highest predictive validity for CP.[9] Distractions to the infant, or the surrounding environment can create difficulties with assessing infant movements. Therefore, it is imperative that videos are recorded in optimal conditions for GMA.

Traditionally, infant GMs are filmed by trained clinicians within face-to-face clinical settings. However, empowering parents to record their infants' videos has multiple benefits including reducing the need for clinical appointments in the face of social isolation restrictions, geographical distance from trained assessors, and being able to film at an optimal time, even repeatedly, when GMs only appear during a small window of time.

Smartphone apps, such as Baby Moves and the In-Motion app, have been successfully used among parents of high-risk infants for filming GMs, [6 8] but are limited to research settings. The rapid advancement of technology and personal devices has afforded clinicians enhanced access to knowledge sharing between colleagues and patients, but legislation consensus on data storage and transfer policy is lacking, and even differs between research and clinical settings. For example, the

Health Insurance Portability and Accountability Act (HIPAA) of 1996 (U.S.A.) regulates the protection of confidentiality, exchange and security of electronic health information including identifiable information,[10] whereas the Data Protection Act 2018 (UK) specifies how organisations use and safeguard personal information.[11] In Australia, while legislation addresses the privacy of personal information, current acts do not adequately address the privacy, storage, and transmission of digital images, and can also vary between states.[12] Therefore, creating an app that can be used internationally and comply with individual legislation, clinical organisational policy and research requirements remains a challenge.

Additionally, smartphone app production is costly, being $423 000 USD on average for the development and launch of an app, and can take, on average, 15 months to develop.[13] Post app-launch, the app's maintenance also remains an ongoing cost. Despite being resource-intensive, some have argued the economic benefits of investing in mHealth apps (apps used in mobile cellular smart-devices for the purposes of improving health outcomes), but the evidence to support this is poorly studied and understood.[14] Additionally, building translations into a smartphone app platform can be costly and requires specialist programmer knowledge; a barrier that needs to be overcome when working with culturally and linguistically diverse and/or low resource, non-English speaking countries. There is an urgent need to provide clinicians and parents/carers with a cost-effective resource to help them film an infant's movements that can also be easily translated to other languages.

To address this need, we developed two instructional guides to support families to take a video of their infant's general movements at the appropriate time with individualised information on how to transfer the data securely. We purposely developed two guides – a more "detailed guide" and a "quick guide" (see Supporting Information 1 & 2 also available for download at https://www.crenewbornmedicine.org.au/for-families/resources-for-download/). The detailed guide is for those who may require additional visual support or who are new to filming their infant's

movements. The quick version provides a summary of instructions with two main visual prompts of "dos" and "don'ts", intended to supplement existing handouts that may have already been developed by individual clinicians and that could be easily translated to languages other than English. As mentioned, there is a section in both guides for clinicians to communicate how the parent can transfer the data to the clinician, designed to allow the guides to be used in a variety of settings in the future. The purpose of this study was to examine whether the guides provide sufficient information for families to provide a video of infant movements in optimal conditions specified by the GMA manual such that the video can be scored using the GMA. Further, families were surveyed about their perceptions of the instructional guides and electronic file transmission. This study used the instructional guides in a low-risk Australian community-based population. We hypothesised that at least 90% of the videos returned by families could be used for the GMA. We hypothesised that the families would find the instructional guides easy to use.

Methods

Recruitment

A cross-sectional study was conducted on a community sample of low-risk infants living in Australia, recruited via social media advertisements. Families of infants born between April-August 2020 who were not older than 16 weeks' corrected age were invited to participate in the study. Participants needed to have at least one device with filming capabilities and be able to read and write in English, either independently or with the assistance of a family member, friend, or colleague. Participants were excluded if their infant had been admitted to a Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN), had prior experience with the Baby Moves app, or if they had other children involved in screening for CP, as we wanted participants with no prior knowledge of the GMA.

We aimed to recruit 50 families per instructional guide on the prediction that 90% of the recruited participants would return a video of sufficient quality with a standard error of 4% (95% confidence interval [CI] 82-98%).

The study was approved by The Royal Children's Hospital Human Research Ethics Committee.

Data collection

On recruitment, participants provided written electronic consent and completed demographic and birth details of their infant on a Research Electronic Data Capture (REDCap) survey. Once complete, participants were randomly allocated to receive the detailed or quick instructional guide according to a random allocation schedule embedded within REDCap. Both instructional guides contain a filming card where the child's identification number and filming date can be recorded at the beginning of the video. The instructional guides were developed with input from clinicians and a consumer advisory group of the National Health and Medical Research Council funded Centre of Research Excellence in Newborn Medicine. Participants were instructed to film their infant once between 14-15^{+6} weeks' corrected age according to their allocated instructional guide.

Participants were sent SMS reminders to film their infant's videos: before the 14-week time-point, three days after the 14-week time-point, and three days before 15^{+6}-week time-point. If a video was returned before the second SMS reminder was scheduled, no further SMS reminders were sent. Once recorded, participants uploaded their videos to an individualised secure REDCap survey that contained a video upload link.

The videos were reviewed within 1 week of receipt by a researcher unaware of group allocation and infant details and were scored for quality according to a checklist which was developed for the current study based on optimal filming conditions specified in the GMA manual (Supporting Information 3), and included whether the GMA could be conducted or not. GMA was scored by an

advanced assessor certified by the General Movements Trust (AK), also blinded to instructional guide allocation and infant details, who scored videos as fidgety (small amplitude, continuous, multi-directional, moderate velocity movements throughout the whole body), abnormal fidgety (exaggerated fidgety movements), or absent (no fidgety movements observed). Where an infant's GMA was classified as intermittent, sporadic, absent, or abnormal a second assessor (AE, JO, or AS), who were also GMs-trust-certified advanced assessors, double scored the video. Where possible, difficulties with uploading videos and/or reasons for not completing videos were recorded. Participants were provided feedback about their infant's movements, and any infant with absent/abnormal GMA were referred for further clinical assessment locally.

Participants who completed a video were also sent a survey to provide feedback on their user experience of their instructional guide (Supporting Information 4).

Statistical analysis

The data were analysed using STATA version 16 (Stata corp. College Station, TX). Scores of video quality criteria were represented as frequency graphs. The proportion of videos that could be used for the GMA was described for each instructional guide with an exact 95% confidence interval. Survey results from participants were presented as frequency graphs for each of the 13 questions. Participants with missing data were not included in descriptive statistics.

Results

Seventy-six infants were enrolled in the study, with 38 infants receiving the detailed guide, and 38 infants receiving the quick guide. Participants were represented from all states and territories of Australia, except for the Northern Territory. The flowchart of participants is detailed in Figure 1 with participant characteristics detailed in Table 1. There were no significant differences between

participant characteristics of those receiving the detailed or quick instructional guides, although families recruited to this study had low rates of low education, low income and single-parent households. Mothers were the main relation of respondents, with the remainder being fathers (Table 1). Videos were returned by 87% (95% confidence interval [CI] 72%, 96%) of the participants using the detailed instructional guide, and 84% (95% CI 69%, 94%) of those using the quick guide. Fifteen participants required assistance to upload the video, with the main issue being a file size too large for the allowable REDCap upload limit (11 participants). All but one participant with difficulties uploading were able to upload a compressed video; the remaining participant declined to return their video. All videos returned were able to be scored using the GMA. All infants were scored as normal fidgety, except for one infant who had absent fidgety movements (detailed instructional guide group).

For the video quality checklist, the total number of "yes" (optimal) and "no" (suboptimal) items were recorded. The averages of the total optimal and suboptimal video conditions are presented in Table 2. The proportion of each individual filming condition fulfilled is represented in Figure 2. For users of the quick instructional guide, all video conditions were achieved with a proportion of 88% or more. For detailed instructional guide users, video conditions were achieved among 97% or more of the respondents.

The survey feedback on the use of the instructional guides is detailed in Figure 3. Users of both the quick and detailed instructional guides showed similar opinions about either guide. Participants were also asked to list barriers that they experienced to filming their infant (Table 3).

Generally, participants found either instructional guide easy to use, found that SMS reminders were helpful and did not experience increased concern while using the instructional guides.

Discussion

This cross-sectional study of two instructional guides for the GMA showed that both instructional guides could be used successfully among a community sample of parents. All videos that were returned were able to have a GMA conducted. The instructional guides provided a clear and easy-to-follow tool for participants to record a video of their infant's movements.

With rising smartphone ownership, the community has increased access to recording devices and internet services[15] and families can record clinical data using their personal devices. Clinicians should ensure that adequate instruction is provided to families to reduce data error and time lost to solving technical problems. The instructional guides used in this study were supported by clear visual prompts that were easy to understand. Additionally, as each clinical institution has its own data storage and transmission policy, the instructional guide can be tailored to an individual organisation's needs. Not only does this allow for versatility according to an individual organisation, but it is also cost-effective which may be advantageous to lower resource settings.

The return rate for the videos was higher than previous studies using smartphone apps with in-built app reminders (Baby Moves: 70% return rate for preterm infants, 83% for term infants; In-motion App 80% for high-risk infants).[6, 8] The Baby Moves study reported 21 videos from the whole cohort could not be used due to poor quality. By contrast, we successfully scored 100% of the videos received. The previous study using Baby Moves was able to establish differences in app usage depending on the family's sociodemographic factors, with families with lower levels of English, lower maternal education or received government support less likely to use the app. In comparison, the current study included few participants with low levels of English, low parent education or low income; further studies are needed to target the instructional guides' effectiveness in this population. The current findings can also be incorporated into the Baby Moves app as authors of both resources.

While the instructional guides appear easy and effective to use, careful attention to the method of video file transfer should be taken to ensure a balance between compliance with organisational data

policy, privacy and ease of transmission is achieved. Some participants (20%) required assistance to upload their video. In most of these cases, video files were too large to upload to the REDCap system and may have taken extra time to upload; however, most participants agreed that they had no issues uploading their video. The rate of upload assistance may have differed from using an app such as Baby Moves, or an alternative method of file transfer, and the rate of upload assistance may need to be compared with Baby Moves or other methods in a future study. We did consider other methods of data transfer, such as using commercially available and widely used applications. However, at the time of study, these applications did not meet the ethical and legal obligations of the current research setting or were not readily available for participants, and tailored digital solutions were not within the budget or scope of this project. However, future research may consider digital solutions to support researchers and clinicians collecting digital media from families/participants. Researchers should also consider how the use of data-intensive methods might create a barrier for participants without access to technology for sharing digital media.

Our study is not without limitations – a lower than expected cohort was recruited to the study. However, for the purposes of demonstrating the effectiveness of the instructional guides, the studied sample has provided adequate evidence of effectiveness with all returned videos being able to be scored with the GMA. This study was unable to determine differences in use of the instructional guides between higher and lower social risk profiles and therefore has limitations to its generalisability to the wider population. The parent survey was also only conducted on those who returned a video. Therefore, we cannot be sure about the reasons or perceptions for the participants who did not return a video. Finally, while the quick instructional guide was developed for easier translation, further studies are needed to determine the effectiveness of the guides in non-English speaking communities. Similarly, access to recording devices and internet may vary between communities, and therefore should be taken into consideration when using the instructional guides.

Conclusions:

Both the detailed and quick instructional guides can be used successfully with parents to record their infant's movements. Allowance for larger file size and safe file transfer should be considered when using the instructional guides. Further assessment of effectiveness in different populations and languages should be conducted.

References

1. Novak I, Morgan C, Adde L, et al. Early, accurate diagnosis and early intervention in cerebral palsy: Advances in diagnosis and treatment. JAMA Pediatr. 2017;**171**:897-907.
2. Spittle AJ, Spencer-Smith MM, Cheong JL, et al. General movements in very preterm children and neurodevelopment at 2 and 4 years. Pediatrics. 2013;**132**:e452-8.
3. Peyton C, Einspieler C, Fjortoft T, et al. Correlates of normal and abnormal general movements in infancy and long-term neurodevelopment of preterm infants: Insights from functional connectivity studies at term equivalence. J Clin Med. 2020;**9**:834.
4. Einspieler C, Prechtl HFR, Bos AF, Ferrari F, Cioni G. Prechtl's method on the qualitative assessment of general movements in preterm, term and young infants. London: Mac Keith Press; 2004.
5. Australian Communications and Media Authority. Communications report 2018-2019. Canberra, Australia: Cth Australia; 2020.
6. Kwong AKL, Eeles AL, Olsen JE, Cheong JLY, Doyle LW, Spittle AJ. The Baby Moves smartphone app for General Movements Assessment: Engagement amongst extremely preterm and term-born infants in a state-wide geographical study. J Paediatr Child Health. 2019;**55:**548-554.
7. Spittle AJ, Olsen J, Kwong A, et al. The Baby Moves prospective cohort study protocol: using a smartphone application with the General Movements Assessment to predict neurodevelopmental outcomes at age 2 years for extremely preterm or extremely low birthweight infants. BMJ Open. 2016;**6**:e013446.
8. Adde L, Brown A, van den Broeck C, et al. In-Motion-App for remote General Movement Assessment: a multi-site observational study. BMJ open. 2021;**11**:e042147.
9. Kwong AKL, Fitzgerald TL, Doyle LW, Cheong JLY, Spittle AJ. Predictive validity of spontaneous early infant movement for later cerebral palsy: a systematic review. Dev Med Child Neurol. 2018;**60**:480-489.
10. Office for Civil Rights (OCR). HIPAA for Professionals Washington, D.C.: U.S. Department of Health & Human Services, ; 2017 [Available from: https://www.hhs.gov/hipaa/for-professionals/index.html.]
11. Data Protection Act 2018, UK Government, 2018.
12. Dyer A, Garcia J, Rohr T. Doctors already use phones to share clinical images of patients - legislation needs to catch up 9 January 2018: The Conversation Media Group Ltd; 2018 [Available

from: https://theconversation.com/doctors-already-use-phones-to-share-clinical-images-of-patients-legislation-needs-to-catch-up-89152.]
13. Research2Guidance. mHealth Developer Econmics - How mHealth app publishers are monetizing their apps. Berlin, Germany: Research2Guidance; 2018.
14. Iribarren SJ, Cato K, Falzon L, Stone PW. What is the economic evidence for mHealth? A systematic review of economic evaluations of mHealth solutions. PLoS ONE. 2017;**12**:1-20.
15. Australian Communications and Media Authority. Mobile-only Australia: Living without a fixed line at home (Interactive report). Cth Australia; 2020.

List of Tables, Figures and Supporting Information

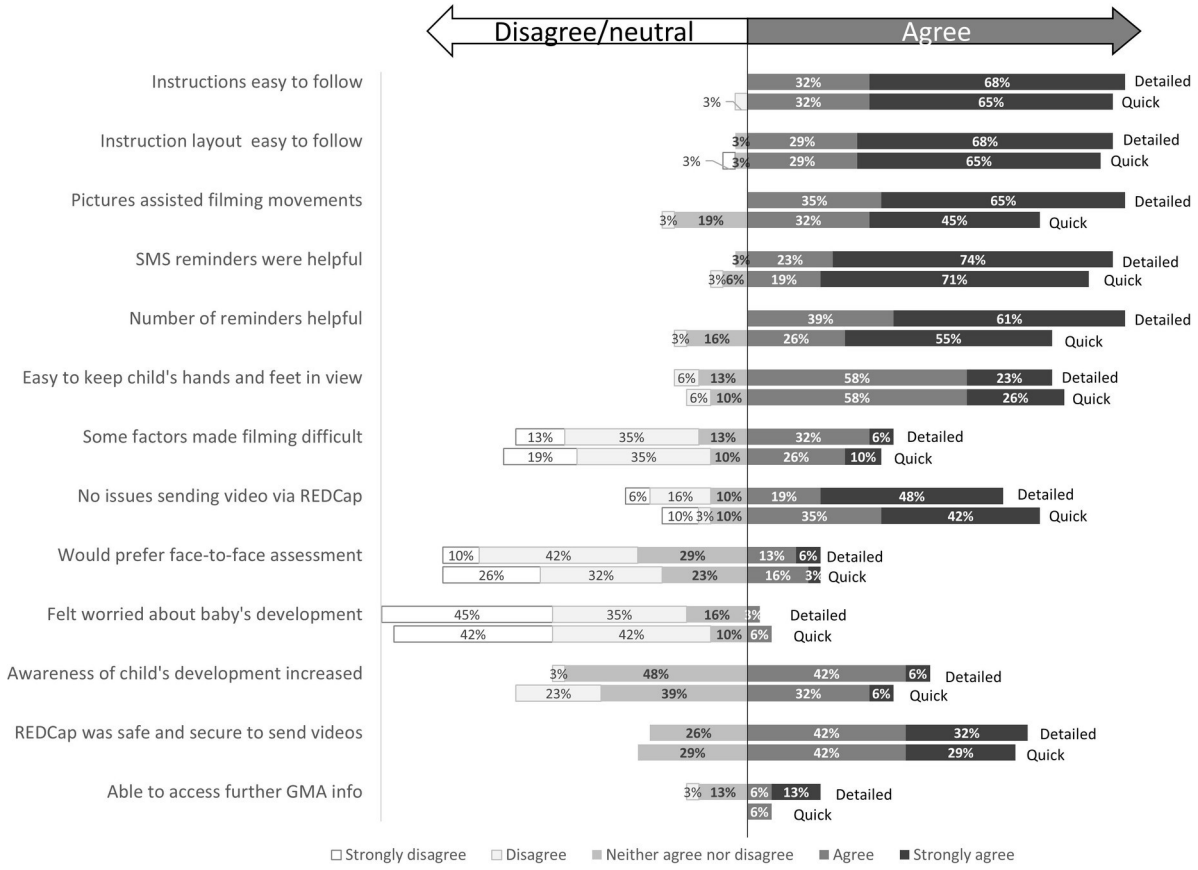

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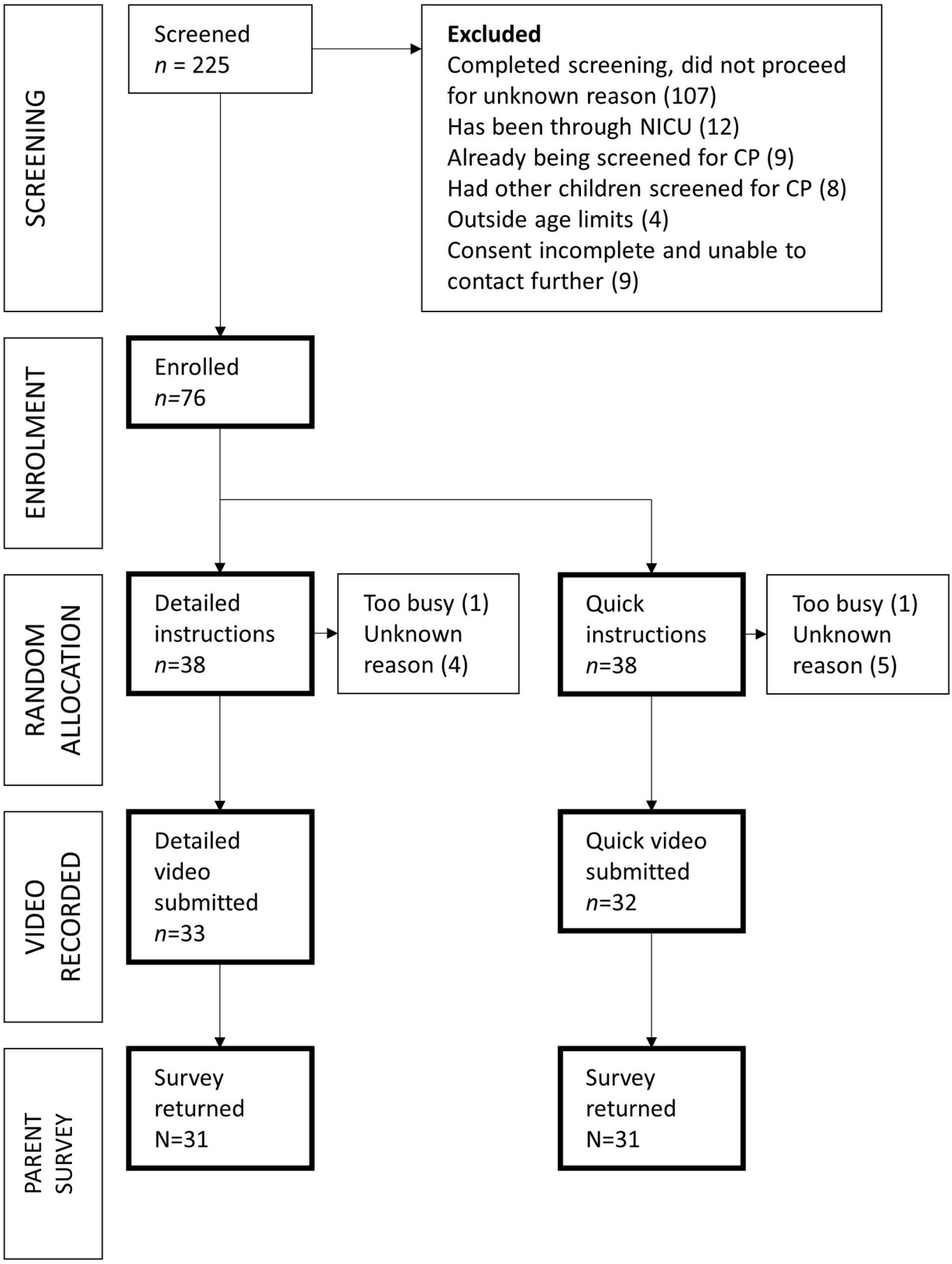
Figure 1: flowchart of participants



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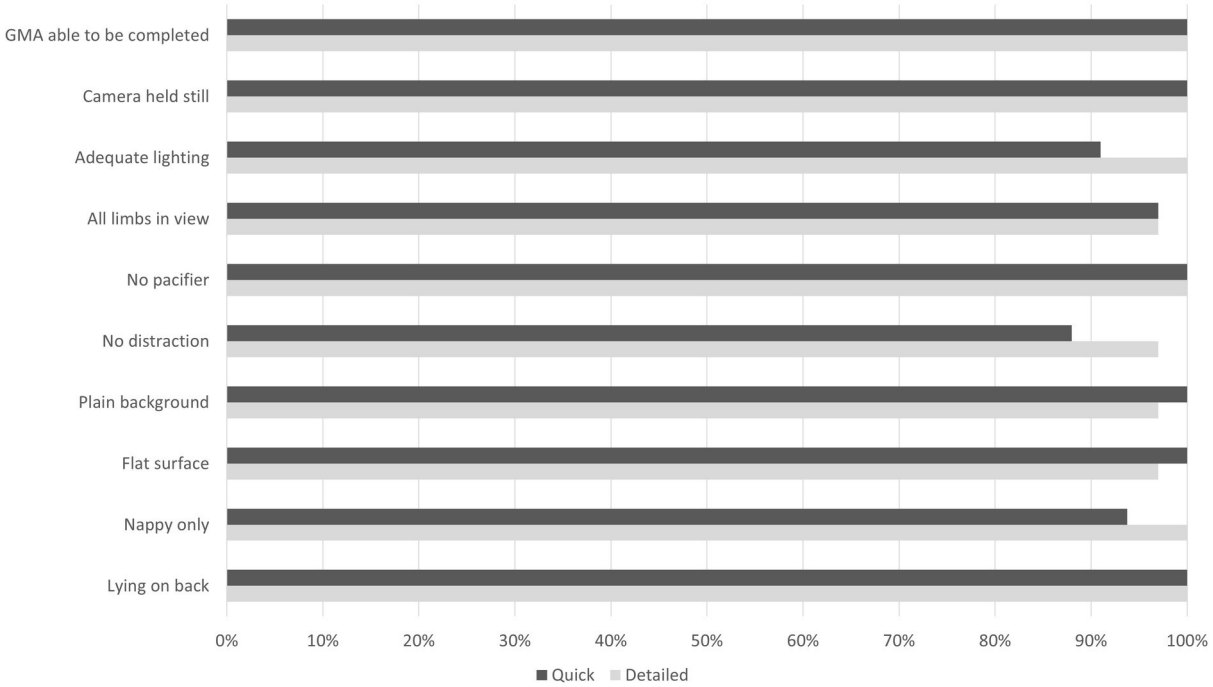

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Original Article

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Conflicts of interest

Prof Alicia Spittle is a tutor with the General Movements Trust. There are no other conflicts of interest to declare.

Table 1: Participant characteristics

	Detailed handout N=38	Quick handout N=38
Gestational age, weeks mean (SD)	39.6 (1.2)	39.2 (1.3)
Birthweight, grams mean (SD)	3518.2 (454.4)	3469.6 (404.3)
Female sex (%)	16 (42)	16 (42)
Multiple births (%)	0 (0)	1 (3)
Age at assessment, weeks mean (SD)	15.2 (0.6)	15.2 (0.7)
Respondent relationship to child (mother) (%)	36 (95)	36 (95)
Language other than English spoken at home (%)	3 (8)	2 (5)
Single parent household (%)	0 (0)	1 (3)
Other children living at home (%)	22 (58)	20 (53)
Lower education (year 11 or lower without trade qualification) (%)	0 (0)	0 (0)
Lower income (%)	0/31 (0)	3/34 (9)

Abbreviations: SD – standard deviation

All data are n(%) unless otherwise specified

Table 2: Summary of quality of videos returned for detailed and quick handouts

	Detailed handout	Quick handout
Mean number of video quality checklist items – yes (SD, 95% CI)	9.9 (0.4) (9.7, 10.0)	9.7 (0.6) (9.4, 9.9)
Proportion of videos returned (95% CI)	87% (72%, 96%)	84% (69%, 94%)
GMA score (normal)	32/33 (97%)	32/32 (100%)

Abbreviations: SD – standard deviation; CI – confidence interval

Table 3: Participant-described infant, environment and combined barriers to completing videos

Infant barriers	Environment barriers	Combined barriers
• Unwell infant • Infant behaviour (e.g. sucking on hand, unsettled, hungry) • Soiled nappy • Advanced motor skills – rolling and not staying on back	• Siblings causing distraction or needing to care for other children • Having extra people at home during COVID-19 causing distraction • Pets interrupting the video • Poor lighting • Cold weather • Lack of large enough rug/mat to film on • Blanket moved/kicked by infant	• Finding the right time (generally) • Busy lifestyle • Family sickness • Parents refraining from interacting