Improving parents' knowledge of early signs of paediatric eye disease: A double-blind randomised controlled trial

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ABSTRACT

Importance: Educating parents to recognize signs of eye disease and consult a healthcare professional is critical to timely diagnosis, intervention, and outcomes.

Background: We evaluate the effectiveness of an eye-health information pamphlet on parents' level of concern and help-seeking intention should they hypothetically observe leukocoria or strabismus in their child.

Design: Double-blind, randomised controlled trial conducted at a metropolitan antenatal outpatient clinic.

Participants: 518 pregnant women were enrolled in the study.

Methods: After completing a study-specific pre-test survey describing hypothetical clinical scenarios at baseline, participants were randomly assigned to receive a pamphlet on either paediatric eye health (intervention) or infant play (control). The post-test survey was sent by email two weeks after baseline.

Main Outcome Measures: A change in the parents' level of concern if they observed leukocoria or strabismus and a change in their help-seeking intention if they hypothetically observed leukocoria or strabismus in their child.

Results: Of the 518 women, 382 (73.7%) completed the post-test survey. At follow-up, women who received the intervention were more likely to report a higher level of concern if they observed leukocoria (OR 1.711 [CI: 1.176-2.497] $p=0.005$) and were less likely to delay help-seeking (OR 0.560 [CI 0.382-0.817] $p=0.003$). No change in the level of concern for strabismus was identified between the groups; however, at follow-up, women who received the intervention were less likely to delay help-seeking (OR 0.318 [CI 0.125-0.806] $p=0.016$).

Conclusion and Relevance: Providing parents with relevant, evidence-based information can significantly improve their knowledge and positively influence help-seeking intentions if leukocoria or strabismus are observed.

Keywords: Leukocoria, strabismus, help-seeking intention

1. INTRODUCTION

The spectrum of paediatric eye disease can range from relatively minor (e.g. congenital nasolacrimal duct obstruction) to potentially blinding (e.g. cataract) or even fatal. (e.g. retinoblastoma). Generally, parents (or primary caregivers) will be the first to observe any direct clinical sign or symptom associated with these diseases prompting consultation with a health-care professional (help-seeking). To ensure timely diagnosis and treatment of paediatric eye disease, parents must be aware of otherwise asymptomatic signs that can occur during their child's early infancy and childhood, and where and when to seek eye-health consultation.

Systemically asymptomatic signs such as leukocoria (white pupil) and strabismus are commonly associated with significant eye disease such as cataract and retinoblastoma.^(1, 2) Delayed diagnosis of retinoblastoma is widely reported, and is attributed in part to parents not recognising leukocoria or strabismus as a sign of significant disease.⁽³⁻⁵⁾ Although a rare disease, a late or delayed diagnosis in retinoblastoma leads to poorer outcomes (unsalvageable blindness) and increased mortality.⁽⁶⁻⁸⁾ Leukocoria can easily be dismissed by parents due to the absence of concomitant physical symptoms; when it is only observed intermittently; or is only apparent in photographs (photo-leukocoria) and thought to arise as a photographic artefact.⁽⁹⁾

Although strabismus is usually idiopathic with a prevalence of between 1-6%⁽¹⁰⁻¹³⁾, undiagnosed and untreated it often leads to amblyopia and abnormal development

of stereopsis.^(10, 11) Less frequently, but more significantly, strabismus develops secondary to severe vision loss⁽¹⁴⁾; systemic disease⁽¹⁵⁾; or to intracranial⁽¹⁶⁾ or intraocular pathology.⁽¹⁾ Whilst intermittent or even constant strabismus is a common finding in healthy newborns, normal binocular co-ordination should be achieved by approximately 4 months of age.^(17, 18) Any persisting strabismus after this time should be investigated to exclude any serious secondary disease.

Currently, parents in Victoria, Australia are not provided with any information regarding signs of paediatric eye disease to be alert to. There is a pressing need to provide relevant information regarding ocular development during childhood and signs not to be ignored. Previous studies have demonstrated that providing health information to parents can lead to improved health outcomes in their children.⁽¹⁹⁻²²⁾ The aim of this study was to evaluate the effectiveness of an eye-health information pamphlet (intervention) for parents which was specifically designed to highlight leukocoria and strabismus as signs of eye disease in children. We hypothesised that compared to the control group, women receiving the intervention would be more likely to recognise leukocoria and strabismus as important signs of eye disease in a child and if observed, intend to seek health advice sooner.

2. METHODS

2.1 Study design

Using a pre- /post-test design, this double-blind, randomised controlled trial (RCT) compared participants' responses to two clinical scenarios and statements of belief when faced with observing leukocoria or strabismus in a child. This study was approved by the Royal Women's Hospital Human Research Ethics Committee (#17-38) and adhered to the tenets of the Declaration of Helsinki. Following study commencement, no significant changes were made to the study protocol. The study

was registered with the Australia and New Zealand Clinical Trials Registry.
(ACTRN12617001431314p)

2.2 Participant eligibility criteria and study setting

Participants were recruited from the antenatal outpatient clinic in a large metropolitan hospital in Victoria, Australia. Prima- or multiparous women aged over 18 years in their 2nd or 3rd trimester of pregnancy were invited to participate in the study. When both parents were present, the pregnant woman provided informed consent and completed the survey; however her partner was neither encouraged nor discouraged from contributing to the decision-making as this could not be controlled for when the participant completed the follow-up survey at home. The study materials were only available in English.

2.3 Intervention and Control Arms

The intervention consisted of a 4-sided, A5 information pamphlet for parents, "Your baby's eyes and what you need to know" (Fig. 1), describing normal developmental milestones for infant vision and ocular development; information about strabismus and leukocoria; and recommendations for seeking health advice if observed. The pamphlet as described in Supplementary Information A, was specifically designed using an evidence-based approach to developing health promotion materials¹⁴ and grounded in a theoretical model for behaviour change.^(23, 24) The control group received an A4 double-sided information pamphlet for parents: "Playing with your baby". This pamphlet encourages strategies for engagement with a newborn and is described in Supplementary Information B.

Figure 1: Intervention - Your baby's eyes and what you need to know"

2.4 Adherence to the intervention

Following informed consent, completion of the pre-test survey and randomisation (0-time), participants in both groups were verbally advised by the recruiting researcher SES to read the instructions and pamphlet enclosed in their allocated, sealed research envelope. Two-weeks after baseline (0-time + 2 weeks), participants were sent a secure link by email to complete the follow-up survey using the Research Electronic Data Capture tool (REDCap 7.2.2 © Vanderbilt University). Reminder emails were sent at 0-time + 4 weeks, and 0-time + 5 weeks and a final telephone call was made at 0-time + 6 weeks. Non-responders at the close of the study were recorded as being lost to follow-up. No inducements were offered, although at enrolment participants were advised that those who at the conclusion of the trial were found to have been randomised to the control group, would also receive the intervention.

2.5 Measures and Outcomes

A study-specific survey to evaluate the intervention was developed and tested on women prior to its use in the RCT. (Supplementary Information C1-3). This survey was iteratively modified in response to cognitive interviews with women and pilot-tested to ensure the questions were understood as intended. At baseline, participants answered socio-demographic questions pertaining to age, previous experience with infant development, primary language spoken at home, educational attainment, and professional background. Participant health literacy was measured by embedding the five questions of Domain 9 "Understanding Health Information" of the validated Health Literacy Questionnaire (HLO).⁽²⁵⁾

The study survey comprised four- or five-point Likert scale items and single item True/False questions specifically developed for six clinical scenarios and 20 statements of knowledge or belief. To maintain masking of the participants to the specific focus of the study, and to minimize any additional search for information

they would not otherwise be prompted to undertake, not all questions related to infant vision or ocular health.

To evaluate participants' level of concern and help-seeking intentions if they observed leukocoria or strabismus in their child, a single clinical scenario and statement of belief each pertaining to leukocoria and strabismus were embedded in the survey. (Supplementary Information C2) Socio-demographic questions were excluded from the follow-up survey and replaced with questions examining participants' pamphlet engagement. To account for any other sources of information that may contribute to their responses in the follow-up survey, questions relating to referring to their pamphlet or searching for more information were also included. (Supplementary Information C3) Either baseline or follow-up surveys took less than 10 minutes to complete.

2.6 Outcomes

The primary outcome measure for this study was a change in the level of concern as measured on a 4-point Likert scale if the participant observed leukocoria (Scenario 2, Supplementary Information C2) or strabismus (Scenario 6, Supplementary Information C2) in a clinical scenario. For example: *"How concerned are you?"* a) not at all concerned; b) somewhat concerned; c) concerned; d) very concerned; and in response to the statements of belief: #3 *"I would be concerned if I saw a white pupil in a photograph of my child"*; or #5 *"I would be concerned if I noticed my 2-year-old baby's eye turning (cross-eyed) some of the time"*: a) strongly agree; b) agree; c) disagree; d) strongly disagree. (Supplementary Information C2)

The secondary outcome measure was a change in help-seeking intention if the participant observed either leukocoria or strabismus as measured on a 5-point Likert

scale. *"How quickly would you seek advice?"* a) today/tomorrow; b) within 1 week; c) within 1 month; d) longer than 1 month; e) not at all.

2.7 Sample size and power calculation

Using STATA (Release 14, 2015),⁽²⁶⁾ a sample size of 398 participants (199 in each group) was calculated to confer 80% power to demonstrate a 10% effect with a two-sided $p=0.05$ as we could not be certain of the direction of the intervention effect. Allowing for a 30% attrition rate, the study aimed to recruit 520 participants. All analyses were performed on a "modified intention-to-treat (mITT)" method, regardless of whether those in the intervention group read the pamphlet or not. Participants who were randomised after completing the pre-test survey but withdrew or were lost to follow-up were excluded from the final analysis. Statistical analyses were computed using *R*, Version 3.5.0⁽²⁷⁾

2.8 Masking, randomisation and implementation

Sealed, opaque research envelopes labelled either Group A or B were prepared by two research assistants from the Centre for Eye Research Australia familiar with the conduct of clinical trials. The control pamphlet was folded in half to ensure the research envelopes in both groups were equal in weight and composition. Group allocation of the intervention was determined by the research assistants preparing the envelopes.

A concealed, randomisation allocation sequence generation table for two groups, Group A and B, with a 1:1 allocation [2,4,6, block design] was prepared by the statistician (PGS) using *R*, Version 3.5.0⁽²⁷⁾ and uploaded to REDCap. Using the REDCap randomisation module, upon completion of their pre-test survey each participant was automatically randomised to either Group A or B and given their corresponding research envelope by the recruiting researcher (SES). To ensure

masking of the researcher was maintained, participants were instructed to not open their research envelope until after leaving the hospital grounds at the conclusion of their antenatal appointment.

All research participants and researchers directly associated with the trial remained masked to participant group allocation until the conclusion of the study and data were analysed. The study was described to participants as one relating to maternal and child health, without disclosing the specific focus of the study or the intervention being tested.

2.9 Statistical analysis

Differences among survey responses across treatment groups and follow-up periods were investigated using ordinal logistic mixed model regression analysis. Potentially confounding variables including age, English as a second language at home, previous experience with children, educational attainment, health literacy and past occupational experience in healthcare were adjusted for in the analyses. Specifically, for each outcome measure a 'Group x Time' interaction term was assessed and retained in the model if statistically significant, thus indicating a differential response rate across treatment groups at the follow-up compared to baseline visit. Unless otherwise specified, all statistical tests were two-sided, where $p \leq 0.05$ was considered statistically significant.

All participant demographic variables were used to screen for factors that could moderate the outcome of the intervention. Comparison between prima- and multiparous women served as a surrogate for 'usual care', providing insights into information parents may have already received or been exposed to while raising their other children.

Pre- and post-test surveys were self-administered using REDCap. This secure, password-protected, web-based data management system is hosted by The University of Melbourne under licence from Vanderbilt University. Each participant's record was allocated a unique study identifier and data de-identified for statistical analysis.

3. RESULTS

3.1 Participant recruitment and study flow

Figure 2 outlines participant recruitment during the study period of 8 March 2018 to 24 June 2018. Of the 692 invited to participate, 518 consented, completed the pre-test survey and were randomised to either the intervention or the control group, representing a 74.9% participation rate. The 20 women who 'failed to proceed' initially consented but were called to their antenatal appointment prior to completing the pre-test survey and did not wish to continue following their appointment. Six participants formally withdrew following randomisation and were excluded from the analysis.

Despite receiving reminders as outlined in the protocol, 382/518 women completed the post-test survey representing a 73.7% overall response rate.

Figure 2: CONSORT 2010 Recruitment Flow Diagram

3.2 Participant demographics

Generally, participants were tertiary educated with high health literacy. More than two-thirds of the cohort did not have any other children and few or none had had any previous experience with leukocoria or strabismus. There was no statistically significant difference in demographic characteristics between participants allocated to either the intervention or control group. (Table 1).

Table 1: Demographic characteristics of participants allocated to the intervention or control arms.

Characteristic		Control	Intervention	*p-
Age (years)	Mean (SD)	33.25 (4.13)	33.28 (4.33)	0.926
Weeks pregnant	Mean (SD)	28.85 (7.64)	27.56 (8.15)	0.064
Born in Australia				
No	n (%)	93 (35.9)	82 (31.7)	0.272
Years lived in Australia	Median [IQR]	6.00 [3.00, 19.75]	7.00 [3.00, 11.00]	0.935
English as a second language (ESL)				
Yes	n (%)	57 (22.0)	63 (24.3)	0.603
If ESL, English main language spoken at home				
Yes	n (%)	32 (57.1)	34 (53.1)	0.797
Confidence reading and understanding English				
Not at all confident	n (%)	0	0	0.293
Slightly confident		2 (0.8)	0 (0.0)	
Moderately confident		4 (1.5)	8 (3.1)	
Very confident		23 (8.9)	19 (7.3)	
Extremely confident		230 (88.8)	232 (89.6)	
Educational				
Year 10 or equivalent	n (%)	2 (0.8)	3 (1.2)	0.631
Year 11 or equivalent		3 (1.2)	2 (0.8)	
Year 12 or equivalent		28 (10.8)	19 (7.3)	
TAFE/apprenticeship		39 (15.1)	45 (17.4)	
University/Higher		187 (72.2)	190 (73.4)	
Field of Study				
Arts and Humanities		51 (23.0)	47 (20.3)	0.813
Business or		41 (18.5)	39 (16.8)	
Science - non-medical		26 (11.7)	25 (10.8)	
Science - medical		36 (16.2)	46 (19.8)	

Other		68 (30.6)	75 (32.3)	
Background experience in healthcare				
Yes	n (%)	51 (19.7)	61 (23.6)	0.337
Previously main carer of child <5y				
Yes	n (%)	98 (37.8)	91 (35.1)	0.584
Total number of	Median [IQR]	0.00 [0.00,	0.00 [0.00,	0.497
Previous experience with any of the following health conditions				
Yes	n (%)	n (%)		
Diarrhoea	92 (35.5)	85 (32.8)		0.578
Fever	108 (41.7)	105 (40.5)		0.858
Rash	79 (30.5)	78 (30.1)		1
Strabismus	9 (3.5)	10 (3.9)		1
Hearing loss	16 (6.2)	12 (4.6)		0.56
White pupil	0	0		0
Health literacy score (HLQ Domain 9 – Understanding Health Information)				
HLQ Domain 9 UHI	Median [IQR]	4.80 [4.10,	4.60 [4.00,	0.152

Abbreviations: SD – standard deviation; IQR – interquartile range; HLQ – health literacy

3.3 Primary outcomes

Primary outcomes for both leukocoria and strabismus are described in Table 2. At follow-up, participants randomised to the intervention group were more likely to report a higher level of concern when faced with the clinical scenario describing leukocoria in a photograph of their child. (OR 1.711, [CI 1.176,2.497] $p=0.005$) For all participants, those who searched for more information about leukocoria had an almost 3-fold higher odds of being more concerned (OR 2.778, [CI 1.743,4.455] $p<0.001$). Participants in the intervention group were less likely to disagree with the statement: “I would be concerned if I saw a white pupil in a photograph in my baby”

(OR 0.407, [CI 0.267,0.618] $p<0.001$). Searching for more information about strabismus was associated with a 62% decrease in the odds of disagreeing with this statement (OR 0.379, [CI 0.211,0.672] $p=0.001$). Moreover, participants referring to their pamphlet when completing the follow-up survey were less likely to disagree (OR 0.541, [CI 0.309,0.941] $p=0.030$).

For the clinical scenario describing strabismus in a child, there was no statistically significant difference in the level of concern between the intervention and control groups at follow-up. However, participants who looked up more information about strabismus at follow-up had a 2-fold increase in the odds of being more concerned about this sign. (OR 2.009, [CI 1.128,3.579] $p=0.018$). Moreover, participants referring to their pamphlet to complete the follow-up survey were less likely to disagree with the statement: *"I would be concerned if I saw my 2-year-old baby's eye turning (cross-eyed) some of the time"* (OR 0.400, [CI 0.225,0.707] $p=0.002$).

Table 2: Level of concern if leukocoria or strabismus observed

Variable	OR	95% CI [LCI,UCI]	*p-value
Clinical scenario: Leukocoria - Level of concern			
Age	1.017	[0.972,1.063]	0.470
Intervention group	1.711	[1.176,2.497]	0.005
Searched for more information-white pupil	2.778	[1.743,4.455]	<0.001
Statement of concern: Leukocoria "I would be concerned if I saw a white pupil in a photograph of my baby"			

Age	0.980	[0.034,1.028]	0.400
Intervention group	0.407	[0.267,0.618]	<0.001
Searched for more information-strabismus	0.379	[0.211,0.672]	0.001
Referred to pamphlet for follow-up survey	0.541	[0.309,0.941]	0.030

Clinical scenario: Strabismus - Level of concern

Age	0.992	[0.945,1.042]	0.749
Intervention group	1.310	[0.886,1.940]	0.176
Year level of educational attainment			
<i>Year 9</i>	0.992	[0.207,4.336]	0.992
<i>Year 10</i>	1.045	[0.499,2.149]	0.905
<i>Year 11</i>	2.294	[1.336,3.950]	0.003
Searched for more information-strabismus	2.009	[1.128,3.579]	0.018

Statement of concern: Strabismus

**"I would be concerned if I saw my 2-year-old baby's eye
turning
(cross-eyed) some of the time"**

Age	1.038	[0.985,1.093]	0.161
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Intervention group	0.747	[0.482,1.156]	0.191
Referred to pamphlet for follow-up survey	0.400	[0.225,0.707]	0.002

Abbreviations: OR – odds ratio; LCI – lower confidence interval; UCI – upper confidence interval

3.4 Secondary outcomes

As shown in Table 3, responding to the clinical scenario for leukocoria, participants in the intervention group were less likely to delay seeking health advice (OR 0.560, [CI 0.382,0.817] $p=0.003$), as were participants who searched for more information on strabismus (OR 0.427, [CI 0.248,0.725] $p=0.002$). Responding to the clinical scenario for strabismus, for all participants there was a 2.7-fold increased odds of seeking advice sooner at follow-up (OR 2.744, [CI 1.384,5.442] $p=0.004$). Whilst group allocation in isolation did not have a predictive effect on help-seeking intention for the strabismus scenario, an interaction effect between follow-up visit and group allocation was observed, whereby at follow-up, participants who received the intervention were less likely to delay seeking advice (OR 0.318, [CI 0.125,0.806] $p=0.016$). Moreover, participants who spoke a language other than English at home were more likely to seek advice promptly (OR 0.218 [CI 0.098,0.482] $p<0.001$).

Table 3: Help-seeking intention if leukocoria or strabismus are observed

Variable	OR	95% CI [LCI, UCI]	*p-value
Help-seeking Intention - Leukocoria			

Age	0.982	[0.939,1.028]	0.436
Intervention group	0.560	[0.382,0.817]	0.003
Searched for more information-strabismus	0.427	[0.248,0.725]	0.002
Help-seeking Intention - Strabismus			
Age	1.001	[0.925,1.082]	0.986
Follow-up survey	2.744	[1.384,5.442]	0.004
Intervention group	1.341	[0.643,2.796]	0.433
Language other than English primarily spoken at home	0.218	[0.098,0.482]	<0.001
Follow-up survey: intervention group	0.318	[0.125,0.806]	0.016

Abbreviations: OR – odds ratio; LCI – lower confidence interval; UCI – upper confidence interval

4. DISCUSSION

This study demonstrated that providing women with information about leukocoria and strabismus could improve their level of concern and guide their help-seeking intentions if observed. Specifically, participants in the intervention group were more likely to demonstrate an increased level of concern and were more likely to intend to seek advice quickly if they observed leukocoria. However, if they observed strabismus, the intervention group's level of concern did not differ, although their intended time to help-seeking was significantly shorter than the control group.

Neither age of the participants nor whether they had other children predicted their level of concern or help-seeking intention.

Compared to the control group, those in the intervention group had a significant increase in their level of concern and help-seeking intention if they observed leukocoria, demonstrating the positive effect of the intervention for this sign. In the present study group allocation did not predict a participant's level of concern for strabismus. This may suggest they were already familiar with this condition. Previous studies have shown that whilst parents may be aware of strabismus as a childhood eye disease, they are not aware of its significance or the resulting effect it can have on visual acuity.⁽²⁸⁻³¹⁾ However, despite parents not being concerned about strabismus, the highly significant interaction effect observed between the intervention group at follow-up, positively predicted help-seeking intention for this sign. Here, we might conclude that whilst participants may be aware that strabismus could occur in children, they may have been unfamiliar with the potential consequences or urgency with which medical advice should be sought and the intervention appropriately guided their help-seeking intention.

Few participants confirmed searching for more information after completing their baseline survey and it is possible participants under-reported their self-directed research, which could bias these results. Curiously, self-directed research on white pupils as well as strabismus predicted an increase in their level of concern if they observed leukocoria. People who observe photo-leukocoria may regard it as an artefact caused by a camera flash or room lighting and thus overlook its potential seriousness.⁽³²⁾ Therefore, in this RCT, either some participants also did not think leukocoria could be a significant finding, remaining unmotivated to search for information, or the information encountered about leukocoria was not medically informative. It is not clear why searching for strabismus might have predicted an

increased level of concern for leukocoria. We postulate that information encountered during their searches about strabismus may have referenced leukocoria, and that when the two occur together, prompt attention is imperative.

Whilst few participants reported referring to their pamphlet or the internet to answer their follow-up survey, it is notable that participants in the intervention group were more likely to refer to their pamphlet. This could suggest they recalled the information was contained in their pamphlet, unlike the control group who referred to the internet. Moreover, referring to their pamphlet was weakly associated with increasing levels of concern for leukocoria and strabismus as well as predicting help-seeking intention for leukocoria. It is possible that the pamphlet clarified for the reader when strabismus might be normal or pathological, giving rise to poor vision or a sign of more sinister disease. Despite these findings, the numbers were small, and it is possible not all participants reported referring to their pamphlet to complete the follow-up survey.

An equal number of participants in both the control and intervention groups already had children. One might expect that those who already had children would have received any currently provided paediatric eye-health information; may have been exposed to information via print or social media; or that they might have been motivated to seek out information themselves if they felt it was required. Given a participant's previous experience with children did not predict level of concern or help-seeking intention suggests that information about leukocoria or strabismus is not currently provided.

The observed changes in the level of concern and help-seeking intention may be attributed to the Question-Behaviour Effect, whereby merely being asked a question, individuals will over-predict their behaviour.⁽³³⁾ That is, faced with a hypothetical

scenario, the individual would seek help sooner than if faced with the same situation in real life. Studies reporting delayed diagnosis of retinoblastoma attribute parents' slow response to strabismus because it is familiar or they expect it to resolve spontaneously; and leukocoria because it is not obvious or visible all the time.⁽⁴⁾ Together with the fact the child is otherwise well and is unlikely to demonstrate an overt sign of poor vision, parents delay seeking advice. Thus, one cannot be certain that the hypothetical responses observed in the RCT reported herein would necessarily translate to parents actually seeking health advice promptly.

Similarly, the "intention-behaviour gap" describes the disconnect between an "intention" to perform and actually carrying out the desired "behaviour".⁽³⁴⁾ In the present study, whilst women reported a change in "intended" behaviour, it is also possible this may not occur if they were faced with the same scenarios in real life even after being provided with relevant information highlighting leukocoria and strabismus. However, providing motivational factors and including behavioural skill, as described in the intervention, may support parents' execution of a behavioural intention. Indeed, once parents are systematically provided with information describing signs of leukocoria and strabismus, exploring their actual behaviour when faced with observing these signs could be studied.

Our single-centre study design may have unintentionally biased the outcomes. Although participants' demographic characteristics were equally distributed between the two groups and were adjusted for confounding variables, their unintended homogeneity (tertiary educated, high health literacy) may have contributed to the positive outcomes observed in this study. Strong literacy skills and command of the English language may have enabled them to engage more fully with, and understand the contents of, the intervention. Future studies could endeavour to explore ways to increase participation of parents from a broader educational or culturally and

linguistically diverse background to determine whether the same effect would be observed.

In this study, fathers or partners contributing to the RCT could neither be prevented nor controlled. Thus, it is not known whether a difference of opinion may have tempered or intensified their concern or help-seeking intention. Other than for mental health and behaviour⁽³⁵⁾, few studies have explored a father's (or partner's) role in child health and help-seeking compared to the mother's.⁽³⁶⁾ Although no significant differences between mothers' and fathers' knowledge and attitudes towards seeking eye-health care for their children have been identified⁽³⁷⁾, the distinction between maternal and paternal help-seeking behaviour is not usually made, referring only to 'parental' behaviour.⁽³⁸⁻⁴⁰⁾ Future studies could consider comparing responses between both parents to determine whether there are any differences, as these would need to be addressed to optimize health promotion initiatives.

The time between receipt of their pamphlet and the follow-up survey was short (2 weeks). Thus, participants may have had a better recall or retention of information than would normally occur. Nonetheless, this study did establish that providing information that can be understood and interpreted by parents can improve knowledge and help-seeking intentions. This study could be extended in the future by repeating the follow-up survey at a later time-point to better understand parent recall of information and effect on help-seeking intention.

4.1 Conclusion

This study demonstrates that providing parents with relevant information relating to recognising leukocoria and strabismus can improve their level of concern and help-seeking intentions if observed. Although not generalizable, these study findings do

provide significant, previously unreported insights into community knowledge of leukocoria and strabismus, and help-seeking intentions, and presents a strategy warranting further research.

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CENTRE FOR
Eye Research
Australia

Your baby's eyes and what you need to know...

Looking after your baby can be overwhelming.
There is so much to learn and know.

Like all parents, you want the best for your baby.

You will spend many hours looking at your baby's eyes and
taking lots of photographs. What you notice can be very important.

This pamphlet will help you recognise early signs of **eye problems**.

Saving sight. Changing lives.

ceo_13866_ceo-20-07-1089 figure 1.eps

Supplementary Information A - Development of the intervention

The Information-Motivation-Behavioural Skills theoretical framework specifies that effective health promotion material needs to: address information gaps [information]; provide arguments that motivate behaviour [motivation]; and provide instruction and explanation to perform the desired behaviour [behaviour skills].¹

The intervention content used in this trial was informed by an exploratory, qualitative study with parents identifying knowledge gaps and determining factors that influence parents' recognition and help-seeking for ocular signs and symptoms in young children. Pre-trial cognitive interviews were conducted with 18 parents and women of childbearing age to refine the intervention as well as test the baseline and follow-up survey instruments to ensure the survey to be used in the RCT were understood and measured the concepts in the way the researchers intended. Minor iterative changes were made to the survey reflecting their responses.

The final version of the intervention was scored by 13 key stakeholders in pediatric health using the Suitability Assessment of Materials (SAM) Scoresheet. Developed by Doak, Doak and Root², this validated tool aids in the development of purposeful health education materials. Six evaluation criteria are scored from '0' (not suitable) to '2' (superior) to assess the content, readability, graphics, layout, learning stimulation and motivation, and where relevant, cultural appropriateness. Mean scores are summed to arrive at a total score and expressed as a percentage of the highest possible score achievable. Adjusting for the exclusion of the sixth domain, (cultural appropriateness) the mean score for the intervention used in this clinical trial was 91.9%, rating it as 'superior health information'.

The final pamphlet used as the intervention can be viewed via the following link:

<https://www.cera.org.au/wp-content/uploads/2018/09/20170707-CG-Glint-or-squint-A5-brochure-V6.pdf>

1. Fisher JD, Fisher WA. Changing AIDS-risk behavior. *Psychological bulletin*. 1992;111(3):455-474.
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Supplementary Information B - Control Pamphlet

The comparator (control) used in the RCT was used with permission from the Department of Education and Training and can be accessed using the link below.

https://www.education.vic.gov.au/Documents/childhood/parents/mch/2015_PLG_postcard_newborn_web.PDF (accessed 15th March 2017)

Baseline Survey

Please complete the survey below.

Thank you!

[baseline_arm_1][first_name] before we begin, it is important that we understand a little bit about you.

Please answer the following questions.

How many weeks pregnant are you?

(Please enter whole number between 12 and 42)

Which country were you born in?

- ☐ Australia
- ☐ China
- ☐ Fiji
- ☐ New Zealand
- ☐ UK
- ☐ USA
- ☐ Other

If other, in which country were you born?

If you were not born in Australia, how many years have you lived in Australia?

(Please enter whole number ie: 5)

Do you speak a language other than English at home?

- ☐ Yes
- ☐ No

What is the main language you speak at home?

How well do you speak English?

- ☐ Not at all
- ☐ Not well
- ☐ Well
- ☐ Very well

How confident are you reading and understanding English?

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

What is your highest level of education?

- ☐ Year 9 or equivalent
- ☐ Year 10 or equivalent
- ☐ Year 11 or equivalent
- ☐ Year 12 or equivalent
- ☐ Finished TAFE/course/apprenticeship
- ☐ Finished Bachelor or Higher Degree

Please specify your field of study

- ☐ 1. Arts and Humanities
- ☐ 2. Business or Management
- ☐ 3. Science - non-medical
- ☐ 4. Science - medical
- ☐ 5. Other

It is important we know whether you have any previous work experience in health

Do you have any background experience in healthcare?

- ☐ Yes
☐ No

Please specify your area of experience

- ☐ 1. Health administration
☐ 2. Nurse
☐ 3. Doctor
☐ 4. Allied Health Professional
☐ 5. Eye health care professional

Author Manuscript

It is important we understand whether you have had any previous experience the main carer of children

Have you been the main carer for a child under the age of 5 years?

- ☐ Yes
☐ No

Number of own children

(Whole number ie: 3)

Number of step-children

(Whole number ie. 2)

Number of children as a nanny/relative

(Whole Number ie. 4)

Total Number of Children

Please enter child 1 date of birth

Child 1 Age

Please enter child 2 date of birth

Child 2 Age

Please enter child 3 date of birth

Child 3 Age

Please enter child 4 date of birth

Child 4 Age

Please enter child 5 date of birth

Child 5 Age

Please enter child 6 date of birth

Child 6 Age

Please enter child 7 date of birth

Child 7 Age

It is important we understand what previous experience you have with health problems

Have you or anyone in your family seen a doctor or received treatment for any of the following?

- ☐ Diarrhoea
 - ☐ Fever
 - ☐ Rash
 - ☐ Crossed eye/turned eye
 - ☐ Hearing loss
- ((Check any or all that apply))

Author Manuscript

It is important we understand how confident you are with reading and understanding health information

Please indicate how difficult or easy the following tasks are for you now.

Remember to check only one box for each statement

Confidently fill medical forms in the correct way

- ☐ Cannot do or always difficult
- ☐ Usually difficult
- ☐ Sometimes difficult
- ☐ Usually easy
- ☐ Always easy

Accurately follow instructions from healthcare providers

- ☐ Cannot do or always difficult
- ☐ Usually difficult
- ☐ Sometimes difficult
- ☐ Usually easy
- ☐ Always easy

Read and understand written health information

- ☐ Cannot do or always difficult
- ☐ Usually difficult
- ☐ Sometimes difficult
- ☐ Usually easy
- ☐ Always easy

Read and understand all the information on medical labels

- ☐ Cannot do or always difficult
- ☐ Usually difficult
- ☐ Sometimes difficult
- ☐ Usually easy
- ☐ Always easy

Understand what healthcare providers are asking you to do

- ☐ Cannot do or always difficult
- ☐ Usually difficult
- ☐ Sometimes difficult
- ☐ Usually easy
- ☐ Always easy

What would you do?

As a parent, there will be many times when you might be concerned about health problems in yourself or your child. This study will explore your response to 6 situations you may experience as a parent. Please answer the following questions for each scenario.

Scenario 1 - You delivered your baby 3 weeks ago. You are in the shower and you notice your breast is red

Your breast is red and feels hot and painful to touch, you feel like you might have a fever

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 2 - Your baby is 18 months old.

You notice a white pupil in ONE of your photographs. You can't see anything just looking at her. Baby is otherwise well and healthy and does not show any signs of not being able to see.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 3 - Your baby is 2 years old.

You notice your baby has been unsettled over the last 24 hours. She is not feeding well, her frequent dirty nappies look unusual, as if she has diarrhoea

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 4 - Your 6-month old baby's eye has been watering on and off for weeks.

You notice this discharge in the eye on waking and throughout the day.
The eye is not red and your baby is otherwise well.
She is feeding and sleeping well.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 5

Your 10-month old baby has developed a rash on her leg during the day.

Her body is hot to touch, it feels like she has a fever.
She is refusing to eat or drink and is unsettled.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 6**Your baby is 12 months' old.**

Some of the time you notice her eye is turning in towards her nose.
She is not bumping into things or showing any signs of not being able to see.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Please read the following statements carefully.

To what extent do you agree or disagree with each of the following statements?

I expect to receive important information about my baby's health and development when he/she is born.

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I understand how my baby's vision will develop in the first few months of life.

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I would be concerned if I saw a white pupil in a photograph of my baby

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I would be concerned if I noticed my 2-year old baby's eye turning (cross-eyed) some of the time

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I would feel judged taking my child for an eye check just because I was worried

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

Please read the following statements carefully.

Rate your confidence for each of the following statements

I can recognise signs of eye problems in my baby

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I know what to do if I am concerned about my baby's vision

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I know where to find more information about eye problems in infants and children

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I would feel confident talking to a doctor or nurse about my baby's vision

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I would feel confident talking to a doctor or nurse about my baby's feeding

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

Please read the following statements carefully.

Indicate whether you feel these statements are true, false or if you are unsure

Babies can follow moving objects with their eyes from 2 months of age

- ☐ True
☐ False
☐ Unsure
☐ I don't know

A rapidly developing rash with a high fever in my baby is cause for concern

- ☐ True
☐ False
☐ Unsure
☐ I don't know

A baby's vision develops from birth until 7 years of age

- ☐ True
☐ False
☐ Unsure
☐ I don't know

It is normal for a baby to have an eye turn at 1 year of age

- ☐ True
☐ False
☐ Unsure
☐ I don't know

An eye turn can cause problems with a baby or child's vision development

- ☐ True
☐ False
☐ Unsure
☐ I don't know

An eye turn will disappear by itself by the age of 3 years

- ☐ True
☐ False
☐ Unsure
☐ I don't know

Only eye turns that are obvious all the time are worth worrying about

- ☐ True
☐ False
☐ Unsure
☐ I don't know

A family history of crossed/turned eye turn is not important

- ☐ True
☐ False
☐ Unsure
☐ I don't know

Thank you [baseline_arm_1][first_name] for completing the first survey.

In 2 weeks' time you will be sent a second survey to complete via your nominated email address.

The link will only be available to you.

Follow-up Survey

Please complete the survey below.

Thank you!

Welcome back [followup_arm_1][first_name] and thank you for completing the second survey

Today's date

(Please enter whole number between 12 and 42)

It is important that we understand how useful you found your pamphlet, if at all

What did you do with the pamphlet you received in your research envelope?

- ☐ Put where I could see it
- ☐ Put where I could find it
- ☐ Threw it away
- ☐ Didn't notice it
- ☐ I did not receive one
- ☐ Other

Where did you put the pamphlet?

Did you read the information in the pamphlet you received in your research envelope?

- ☐ Yes
- ☐ No

How many times did you read the pamphlet you received in your research envelope?

- ☐ Didn't look at it
- ☐ Glanced at it
- ☐ Read once
- ☐ Read a few times

To what extent did you understand the information contained in the pamphlet?

- ☐ Read but did not understand any information
- ☐ Read and understood slightly
- ☐ Read and understood moderately
- ☐ Read and understood very well

After reading the pamphlet I felt...

- ☐ Very anxious
- ☐ Moderately anxious
- ☐ A little bit anxious
- ☐ Not at all anxious

I found the information in the pamphlet...

- ☐ Very useful
- ☐ Moderately useful
- ☐ Slightly useful
- ☐ Not at all useful

It is important that we understand if you looked for more information about children's health

Since completing the first survey, please indicate if you looked for any information about infant health other than what was included in your research envelope.

- ☐ I did not look for any information
 - ☐ I looked at websites
 - ☐ I looked at parenting books
 - ☐ I read other pamphlets
 - ☐ I talked with family/friends
 - ☐ I talked with a health professional
 - ☐ I looked for further information but could not find any
- (Tick all or any that apply)

I looked for more information on the following topics

- ☐ Breastfeeding
 - ☐ Breast infections
 - ☐ White pupils in children
 - ☐ Rashes in children
 - ☐ Eye turns (cross-eye) in children
 - ☐ Diarrhoea in children
 - ☐ Watery eyes in children
- (Tick all or any that apply)

What would you do?

As a parent, there will be many times when you might be concerned about health problems in yourself or your child. This study will explore your response to 6 situations you may experience as a parent. Please answer the following questions for each scenario.

Scenario 1 - You delivered your baby 3 weeks ago. You are in the shower and you notice your breast is red

Scenario 1

Your baby is breastfed. You notice your breast is red and feels hot and painful to touch

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 2 - Your baby is 18 months old.

You notice a white pupil in ONE of your photographs. You can't see anything just looking at her. Baby is otherwise well and healthy and does not show any signs of not being able to see.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 3 - Your baby is 2 years old.

You notice your baby has been unsettled over the last 24 hours. She is not feeding well, her frequent dirty nappies look like she has diarrhoea

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 4 - Your 6-month old baby's eye has been watering on and off for weeks.

You notice this discharge in the eye on waking and throughout the day.
The eye is not red and your baby is otherwise well.
She is feeding and sleeping well.

How concerned are you?

- ☐ Not at all concerned
☐ Somewhat concerned
☐ Concerned
☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
☐ Within a week
☐ Within 1 month
☐ Longer than 1 month
☐ Not at all

Where would you go/look for information?

- ☐ Social media
☐ Maternal & Child Health Nurse
☐ Internet
☐ GP/local doctor
☐ Nurse-on-call telephone help-line
☐ Other
 (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 5

Your 10-month old baby has developed a rash on her leg during the day.

Her body is hot to touch, it feels like she has a fever.
She is refusing to eat or drink and is unsettled.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Scenario 6

Your baby is 12 months' old.

Some of the time you notice her eye is turning in towards her nose.
She is not bumping into things or showing any signs of not being able to see.

How concerned are you?

- ☐ Not at all concerned
- ☐ Somewhat concerned
- ☐ Concerned
- ☐ Very concerned

How quickly would you seek medical advice?

- ☐ Today/tomorrow
- ☐ Within a week
- ☐ Within 1 month
- ☐ Longer than 1 month
- ☐ Not at all

Where would you go/look for information?

- ☐ Social media
 - ☐ Maternal & Child Health Nurse
 - ☐ Internet
 - ☐ GP/local doctor
 - ☐ Nurse-on-call telephone help-line
 - ☐ Other
- (Tick all or any that apply)

Please specify where else you would seek advice or information

Please read the following statements carefully.

To what extent do you agree or disagree with each of the following statements?

I expect to receive important information about my baby's health and development when he/she is born.

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I understand how my baby's vision will develop in the first few months of life.

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I would be concerned if I saw a white pupil in a photograph of my baby

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I would be concerned if I noticed my 2-year old baby's eye turning (cross-eyed) some of the time

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

I would feel judged taking my child for an eye check just because I was worried

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree

Please read the following statements carefully.

Rate your confidence for each of the following statements

I can recognise signs of eye problems in my baby

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I know what to do if I am concerned about my baby's vision

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I know where to find more information about eye problems in infants and children

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I would feel confident talking to a doctor or nurse about my baby's vision

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

I would feel confident talking to a doctor or nurse about my baby's feeding

- ☐ Not at all confident
- ☐ Slightly confident
- ☐ Moderately confident
- ☐ Very confident
- ☐ Extremely confident

Please read the following statements carefully.

Indicate whether you feel these statements are true, false or if you are unsure

Babies can follow moving objects with their eyes from 2 months of age

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

A rapidly developing rash with a high fever in my baby is cause for concern

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

A baby's vision develops from birth until 7 years of age

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

It is normal for a baby to have an eye turn at 1 year of age

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

An eye turn can cause problems with a baby or child's vision development

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

An eye turn will disappear by itself by the age of 3 years

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

Only eye turns that are obvious all the time are worth worrying about

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

A family history of crossed/turned eye is not important

- ☐ True
- ☐ False
- ☐ Unsure
- ☐ I don't know

Finally, 2 more questions

Did you refer to your pamphlet on eye problems in children to answer the questions in this survey?

- ☐ No
☐ Yes
☐ I didn't receive one

Did you refer to the internet to answer the questions about eye problems in this survey?

- ☐ No
☐ Yes

Thank you for completing this survey and participating in our research.

At the end of this research study, you will be sent information about how you have contributed to child health.

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Supplementary Information C1 – Pamphlet Evaluation Survey and Schedule

Supplementary Information C1 summarises the survey instruments that formed the questionnaire administered at baseline and/or follow-up.

The evaluation survey was developed and iteratively modified in response to cognitive interviews with women and pilot-tested to ensure the questions were understood as intended.

‘Registration information’ included the collection of contact information to facilitate completion of the follow-up survey.

‘Demographic Characteristics’ collected data pertaining to age, educational attainment, country of birth and language spoken at home, number and age of own children or as a previous full-time carer of children under the age of 5 years and any previous experience in health or medical sectors. Domain 9 of the validated tool ‘Health Literacy Questionnaire’ consists of 5 questions exploring the participants’ confidence with reading and understanding health information.

The “Survey” was administered at both baseline and follow-up and consisted of six clinical scenarios using photographic prompts exploring parental responses to maternal and childhood health problems including: mastitis, leukocoria (white pupil in a photograph), diarrhoea in a child, fever with a rash and strabismus. These were followed by 20 statements of confidence or belief relating to recognising health problems in children.

“Engagement with pamphlet” explored the extent to which parents read, understood or stored their pamphlet for future reference, and whether they were prompted to seek information from other sources after completing the baseline survey.

The final short instrument: “Looking up answers” asked participants to declare whether they referred to their pamphlet or looked up information elsewhere to answer the follow-up survey. According to the schedule below, each instrument was

seamlessly combined within REDCap such that a single survey was administered at baseline and follow-up.

Schedule of Survey Instruments administered at Baseline and Follow-up:

<i>Survey instrument</i>	<i>Study Time point administered</i>	
	<u>Baseline [0-time]</u>	<u>Follow-up [0+2 weeks]</u>
Registration Information	X	
Demographic Characteristics	X	
Health Literacy Questionnaire (HLQ Domain 9) ¹	X	
Engagement with pamphlet		X
Survey- clinical scenarios and statements of confidence and belief	X	X
Looking up answers		X

1. Osborne RH, Batterham RW, Elsworth GR, et al. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health 2013;13:658.

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