

Risk factors for non-participation in a universal developmental surveillance program in a population in Australia

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Abstract.

Objectives. This study examined the risk factors for non-participation in a developmental surveillance program in a population in south-west Sydney with a high proportion of culturally diverse and socioeconomically disadvantaged people.

Methods. Data from 850 and 625 12- and 18-month-old children respectively from the Watch Me Grow (WGM) birth cohort were used for this study. Logistic regression models were used to assess risk factors for 12- and 18-month non-attendance at Well Child Visits, as well as non-completion of the developmental surveillance questionnaire Parents' Evaluation of Developmental Status (PEDS) in the child's personal health record (PHR).

Results. Independent risk factors for non-attendance at Well Child Visits were female sex of the child (odds ratio (OR) 12 months 1.5; 95% confidence interval (CI) 1.0–2.3), mother's country of birth Australia (OR 18 months 1.8; 95% CI 1.2–2.7), annual household income less than A\$25 001 (OR 12 months 1.8; 95% CI 1.0–3.2) and residing in a socioeconomically disadvantaged neighbourhood (OR 12 months 1.7; 95% CI 1.1–2.5). Independent risk factors for non-completion of PEDS in those who did not attend the Well Child Visit compared with those who did attend and did complete PEDS were household annual income at birth less than A\$25 001 (OR 12 months 3.9; 95% CI 1.9–8.1) and residing in a socioeconomically disadvantaged neighbourhood (OR 12 months 2.1 (95% CI 1.2–3.7) and OR 18 months 2.0 (95% CI 1.2–3.6)).

Conclusions. In this population, children exposed to socioeconomic disadvantage are less likely to have attended a Well Child Visit and to have a completed PEDS in their PHR at 12 and/or 18 months of age.

What is known about the topic? Developmental problems are common in early childhood, and children from socioeconomically disadvantaged households are at higher risk. Universal developmental surveillance programs may be effective at early identification of children at risk of developmental problems. Early childhood interventions, when accessed, can lessen the effects of developmental problems in later years.

What does this paper add? This paper highlights that children exposed to socioeconomic disadvantage in early childhood who are at higher risk of having developmental problems are also at higher risk of missing out on early identification by non-participation in universal developmental surveillance.

What are the implications for practitioners? A more equitable model of developmental surveillance should include a framework of proportionate universalism to ensure optimal engagement of high-risk population groups.

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Introduction

Developmental disorders in children are common and encompass a diverse range of problems, including developmental delay, intellectual disability, autism spectrum disorder, attention deficit hyperactivity disorder and learning disorders. In Australia, it is estimated that 5–10% of 5- to 14-year-old children have a developmental, behavioural or learning disability,¹ and international studies suggest that the prevalence of developmental disorders may be increasing.^{2,3} An even larger proportion of children with developmental difficulties who do not necessarily fulfil the diagnostic criteria for a developmental disorder are described as 'developmentally vulnerable'.⁴ In Australia, one in five children is reported to be developmentally vulnerable by the time they start

their first year of primary school,⁵ which means that they are not equipped with the skills they need to flourish in the school environment. Furthermore, children living in lower socioeconomic status areas in Australia have significantly higher rates of adverse developmental outcomes.⁵

Early identification and intervention in child developmental disorders can reduce the effects of these disorders.^{6–10} One method of early identification of children with developmental problems is through universal developmental surveillance. In New South Wales (NSW), developmental surveillance is incorporated as part of Well Child Visits at 6, 12 and 18 months and 2, 3 and 4 years of age, usually with a general practitioner or child and family health nurse. Until recently, the Well Child Visits

involved the use of a validated developmental screening tool, the Parents' Evaluation of Developmental Status (PEDS),¹¹ incorporated in the child's personal health record (PHR; 'Blue Book'). The PEDS is a 10-item parent report questionnaire that is intended to be completed by the parents before or during the Well Child Visit, then scored and discussed with the health professional with appropriate follow-up organised.^{11,12}

There is a paucity of research investigating factors that may predict universal developmental surveillance utilisation, especially in Australia. One of the first studies to identify risk factors for decreased utilisation of universal developmental surveillance used data for children at 6 months of age from the Watch Me Grow (WGM) cohort.¹³ Preterm birth, a mother who is not typically involved in employed work, decreased parental awareness of developmental surveillance and having a general practitioner rather than a child and family health nurse complete the surveillance were all risk factors for decreased utilisation of universal developmental surveillance at 6 months of age.¹³ Furthermore, as children grow older, it appears that the proportion undergoing developmental surveillance decreases.¹⁴

The purpose of this study was to examine in-depth the utilisation of developmental surveillance at 12- and 18-month visits, adding to what is already known about developmental surveillance at 6 months from our previous work,¹³ in a culturally diverse and socioeconomically disadvantaged area of NSW. Thus, the specific aim of the study was to describe risk factors for non-attendance at Well Child Visits and non-completion of PEDS in the PHR at 12 and 18 months of age.

Methods

Participants and recruitment

Participants were parents and their infants recruited at birth as part of the WGM study aimed at examining the uptake and accuracy of universal developmental surveillance as recommended in NSW in the PHR. Details of the recruitment process have been published elsewhere.¹⁵ In all, 2025 newborn infants and their parents were recruited into the WGM cohort study from two public hospital postnatal wards ($n = 1866$) and through child health nurses ($n = 159$) in south-west Sydney during the period November 2011–April 2013. The WGM cohort was broadly representative of the culturally diverse and socially disadvantaged local population from which it was sampled.¹⁶ Of the original 2025 participants enrolled, baseline socio-demographic and health service use data were obtained through questionnaire and electronic medical records at baseline for 1761 participants (Fig. 1). Prospective follow-up of the study participants was conducted when infants reached 6, 12 and 18 months of age by telephone interviews by trained research staff using a purposively developed questionnaire. At 12 and 18 months of age, follow-up data were available for 850/2025 (42%) and 625/2025 (31%) participants respectively (Fig. 1).

Measurement tools

Independent variables

All independent variables were collected at baseline (birth) by parent self-report using questionnaires designed for the WGM study. The questionnaire was informed by the existing literature, including from reviewing questionnaires from other

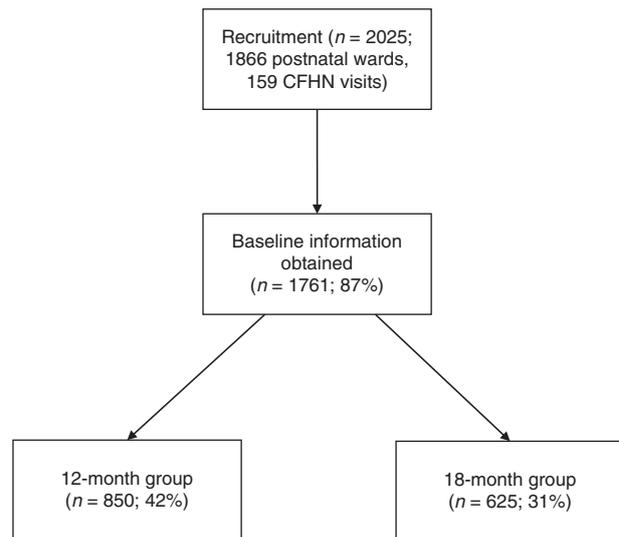


Fig. 1. Data collection. CFHN, child and family health nurse.

Australian cohort studies, such as the Longitudinal Study of Australian Children¹⁷ and the Gudaga study.¹⁸ In addition to English, questionnaires were available in the five non-English languages that were the most commonly spoken languages in this population (Assyrian, Arabic, Vietnamese, Khmer and Traditional Chinese).¹⁵ A bioecological framework was used to select independent variables at the child level (sex, preterm, low birthweight), parent level (maternal age, education level, employment status, partner status, country of birth, employment status, maternal health problems), household level (primary language spoken, income level, income covers costs or not, number of children) and the neighbourhood level (Socio-Economic Indexes for Areas (SEIFA) decile score).^{19,20} SEIFA Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) data for each family were calculated using the post-code of residence. SEIFA is a composite index based on 5-yearly Census information that ranks different areas in Australia according to relative socioeconomic advantage and disadvantage. The lowest SEIFA decile indicates the highest levels of disadvantage.²⁰

Dependent variables

Attendance at Well Child Visits was assessed as a binary variable (attended or not-attended) at 12 and 18 months. Non-completion of PEDS was assessed as a binary variable by the following subgroup comparisons for 12 and 18 months: (1) non-completion of PEDS in those who did not attend the Well Child Visit versus those who did attend and completed PEDS; (2) non-completion of PEDS for those who did attend a Well Child Visit; and (3) those who did not complete PEDS and did not attend the Well Child Visit versus the group that did not complete PEDS and did attend the Well Child Visit. At both the 12- and 18-month follow-up, a telephone interview was conducted with parents by trained research staff. Parents were asked questions from a purposively developed questionnaire about attendance at Well Child Visits. Questions focused on whether the parents had taken their child for the recommended Well Child Visits as

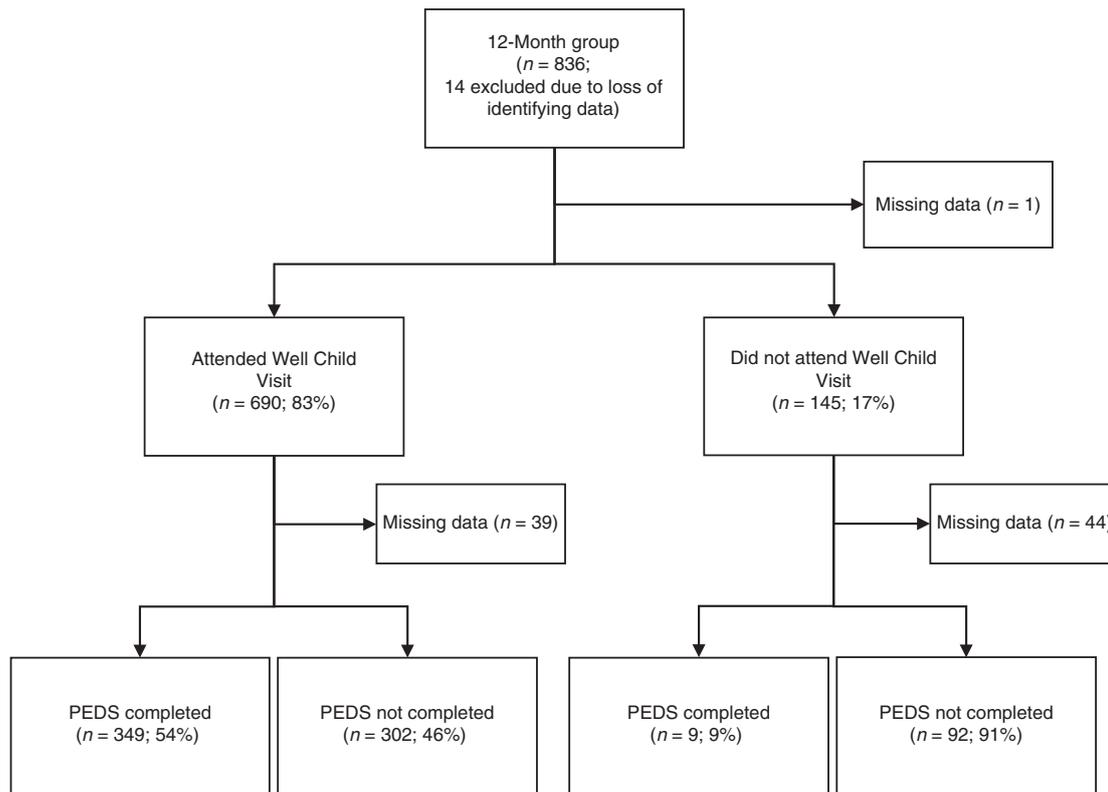


Fig. 2. Attendance at Well Child Visits and Parents’ Evaluation of Developmental Status (PEDS) completion at 12 months.

outlined in their child’s PHR, which service they used, what made it easy or difficult to access the service and whether the PEDS had been completed, by whom and what the results were.¹⁵ Bilingual health researchers were available to conduct telephone interviews with parents in commonly spoken non-English languages when needed.

Statistical analyses

Multivariable logistic regression was used to analyse risk factors for non-attendance at Well Child Visits at both 12 and 18 months. Multivariable logistic regression was then used to analyse risk factors for non-completion of PEDS between the different subgroups of individuals at 12 and 18 months separately. Results of the regression models are presented as odds ratios (ORs) and associated 95% confidence intervals (CIs). Statistical significance was set at two-tailed $P < 0.05$. Statistical analyses were performed using SAS Enterprise Guide version 7.1 (SAS Institute, Cary, NC, USA).²¹

Ethics approval

This study was approved by the Human Research Ethics Committees of the University of New South Wales and the South Western Sydney Local Health District (HREC/11/LPOOL/281).

Results

Participants and their characteristics

There were 850 participants at the 12-month follow-up. Fourteen participants were excluded from further analysis

due to loss of identifying information ($n = 836$ analysed). Of the 625 participants at the 18-month follow-up, six were excluded due to loss of identifying information ($n = 619$ analysed).

The overall attendance rate at the 12-month Well Child Visit was 83%. For the group that did attend a Well Child Visit, 54% had PEDS completed; of those who did not attend, 9% had completed the PEDS in their PHR (Fig. 2). The overall attendance rate at the 18-month Well Child Visit was 77%. For the group that attended a Well Child Visit, 45% had PEDS completed; of those who did not attend, 7% completed the PEDS (Fig. 3).

Table 1 outlines the characteristics of participants at the 12- and 18-month follow-up. Nearly 9% of infants were born preterm (<37 weeks); approximately one-third of families did not have English as the primary language in the household; approximately 12% of households had an income less than A\$25 001 and 35–36% of households were defined as living in SEIFA Decile 1 (most disadvantaged) neighbourhoods.

Risk factors for non-attendance at Well Child Visits

Multivariable logistic regression modelling revealed that non-attendance at Well Child Visits was associated with female sex of the child (OR 12 months 1.5; 95% CI 1.0–2.3), mother’s country of birth Australia (OR 18 months 1.8; 95% CI 1.2–2.7), annual household income at birth less than A\$25 001 (OR 12 months 1.8; 95% CI 1.0–3.2) and SEIFA lowest decile (OR 12 months 1.7; 95% CI 1.1–2.5; Table 2).

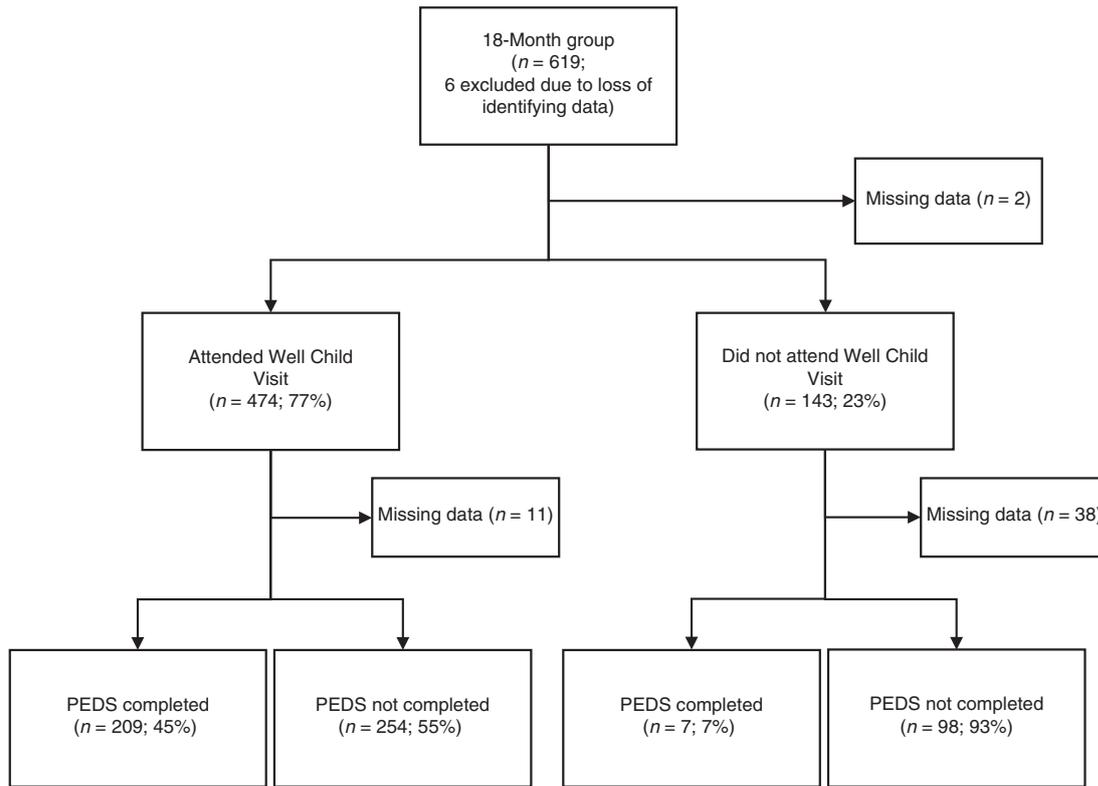


Fig. 3. Attendance at Well Child Visits and Parents' Evaluation of Developmental Status (PEDS) completion at 18 months.

Table 1. Participant characteristics

Data are given as n (%). Note, characteristics are arranged according to bioecological level.¹⁹ SEIFA, Socio-Economic Indexes for Areas (the lowest SEIFA decile indicates the highest levels of disadvantage²⁰)

Characteristic	Baseline ^A (n = 1761)	12 months (n = 836)	18 months (n = 619)
Child			
Female sex	916 (52.0)	439 (52.5)	330 (53.3)
Low birthweight (<2500 g)	126 (7.2)	58 (6.9)	41 (6.6)
Preterm (<37 weeks)	157 (8.9)	72 (8.6)	54 (8.7)
Parent			
Single parent at time of birth	115 (6.5)	35 (4.2)	28 (4.5)
Mother's age <25 years at birth	285 (16.2)	103 (12.3)	83 (13.4)
Mother did not complete Year 10	67 (3.8)	36 (4.3)	29 (4.7)
Father did not complete Year 10	80 (4.5)	37 (4.4)	24 (3.9)
Mother's employment not full-time at birth	1096 (62.2)	512 (61.2)	382 (61.7)
Father unemployed at birth	186 (10.6)	89 (10.6)	63 (10.2)
Mother born in Australia	735 (41.7)	379 (45.3)	280 (45.2)
Father born in Australia	641 (36.4)	355 (42.5)	257 (41.5)
Maternal health problems prior to or during pregnancy	505 (28.7)	252 (30.3)	185 (29.9)
Household			
Primary language not English	589 (33.4)	271 (32.4)	194 (31.3)
Household annual income less than A\$25 001	277 (15.7)	100 (12.0)	68 (12.2)
Income does not cover costs as reported by parent at birth	147 (8.3)	59 (7.1)	38 (6.1)
More than one child in family	998 (56.7)	490 (58.6)	360 (58.2)
Neighbourhood			
SEIFA Decile 1 at baseline	720 (40.9)	301 (36.0)	220 (35.5)

^ABaseline is at the time of birth.

Table 2. Independent risk factors for non-attendance at Well Child Visits at 12 and 18 months identified by multivariable analysis

CI, confidence interval; OR, odds ratio; SEIFA, Socio-Economic Indexes for Areas (the lowest SEIFA decile indicates the highest levels of disadvantage²⁰)

Risk factor	Non-attendance at Well Child Visits				
	12 months		18 months		
	OR (95% CI)	P-value	OR (95% CI)	P-value	
Female sex	1.5 (1.0–2.3)	0.044	–	–	
Mother’s country of birth Australia	–	–	1.8 (1.2–2.7)	0.009	
Household annual income less than A\$25 001	1.8 (1.0–3.2)	0.042	–	–	
SEIFA lowest decile	1.7 (1.1–2.5)	0.016	–	–	

Table 3. Independent risk factors for non-completion of Parents’ Evaluation of Developmental Status (PEDS) at 12 and 18 months in those who did not attend the Well Child Visit versus those who did complete PEDS and attended Well Child Visits

CI, confidence interval; OR, odds ratio; SEIFA, Socio-Economic Indexes for Areas (the lowest SEIFA decile indicates the highest levels of disadvantage²⁰)

Risk factor	PEDS non-completion				
	12 months		18 months		
	OR (95% CI)	P-value	OR (95% CI)	P-value	
Household annual income less than A\$25 001	3.9 (1.9–8.1)	0.0003	–	–	
SEIFA lowest decile	2.1 (1.2–3.7)	0.0084	2.0 (1.2–3.6)	0.0019	

Table 4. Independent risk factors for non-completion of Parents’ Evaluation of Developmental Status (PEDS) at 12 and 18 months for only those who did attend a Well Child Visit

CI, confidence interval; OR, odds ratio; SEIFA, Socio-Economic Indexes for Areas (the lowest SEIFA decile indicates the highest levels of disadvantage²⁰)

Risk factor	PEDS non-completion				
	12 months		18 months		
	OR (95% CI)	P-value	OR (95% CI)	P-value	
Mother’s age <25 years	2.3 (1.3–4.1)	0.0032	–	–	
Father’s country of birth not Australia	2.3 (1.5–3.3)	<0.0001	1.8 (1.2–2.9)	0.0064	
Maternal health problems	1.6 (1.0–2.3)	0.0285	–	–	
Income does not cover costs	–	–	3.3 (1.1–10)	0.0384	
SEIFA lowest decile	1.5 (1.0–2.2)	0.0455	1.6 (1.0–2.6)	0.048	

Risk factors for non-attendance and non-completion of PEDS

Independent risk factors for non-attendance and non-completion of PEDS were examined by comparing those who did not complete the PEDS and did not attend Well Child Visits (the group potentially most at risk of having a neurodevelopmental vulnerability missed) with those who attended and completed the PEDS. Independent risk factors for non-attendance and non-completion of PEDS were household annual income at birth less than A\$25 001 (OR 12 months 3.9; 95% CI 1.9–8.1) and SEIFA lowest decile (OR 12 months 2.1 (95% CI 1.2–3.7) and OR 18 months 2.0 (95% CI 1.2–3.6); [Table 3](#)).

Risk factors for PEDS non-completion among those attending Well Child Visits

Independent risk factors for non-completion of PEDS among those who did attend a Well Child Visit were examined. Risk factors identified were mother’s age <25 years at birth (OR 12 months 2.3; 95% CI 1.3–4.1), father’s country of birth not

being Australia (OR 12 months 2.3 (95% CI 1.5, 3.3) and OR 18 months 1.8 (95% CI 1.2–2.9)), the presence of maternal health problems prior to or during pregnancy (OR 12 months 1.6; 95% CI 1.0–2.3), income not covering costs as reported by the parent at birth (OR 18 months 3.3; 95% CI 1.1–10.0) and residing in an area in the lowest SEIFA decile (OR 12 months 1.5 (95% CI 1.0–2.2) and OR 18 months 1.8 (95% CI 1.1–2.8); [Table 4](#)).

Risk factors for non-attendance among those who did not complete PEDS

Groups who did not complete the PEDS were compared to assess independent risk factors for non-attendance. Non-attendance was associated with mother not completing Year 10 (OR 18 months 2.6; 95% CI 1.0–6.5), mother’s country of birth not Australia (OR 18 months 2.6; 95% CI 1.5–4.3), father’s country of birth not Australia (OR 12 months 2.4; 95% CI 1.4–4.2) and household annual income at birth less than A\$25 001 (OR 12 months 2.2; 95% CI 1.1–4.4; [Table 5](#)).

Table 5. Comparison of the group that did not complete Parents' Evaluation of Developmental Status (PEDS) and did not attend a Well Child Visit with the group that did not complete PEDS and did attend Well Child Visits at 12 and 18 monthsCI, confidence interval; OR, odds ratio; SEIFA, Socio-Economic Indexes for Areas (the lowest SEIFA decile indicates the highest levels of disadvantage²⁰)

Risk factor	PEDS non-completion			
	12 months		18 months	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Mother did not complete Year 10	–	–	2.6 (1.0–6.5)	0.0479
Mother's country of birth not Australia	–	–	2.6 (1.5–4.3)	0.0005
Father's country of birth not Australia	2.4 (1.4–4.2)	0.0028	–	–
Household annual income less than A\$25 001	2.2 (1.1–4.4)	0.0282	–	–

Discussion

This study provides new and important information on risk factors to uptake of universal developmental surveillance. Consistent with previous findings from the literature,¹⁴ we found that a relatively low proportion of children attended a Well Child Visit at 12 months of age, with the proportion decreasing even further at 18 months of age. Furthermore, of the children who attended a Well Child Visit, only approximately half had a completed PEDS in their PHR at 12 months, with an even lower proportion at 18 months. This pattern of decreasing utilisation of universal developmental surveillance between 12 and 18 months of age observed in this study suggests the need for proactive engagement with parents during this critical period of life to facilitate the uptake of the developmental surveillance program.

This study found that children from a household whose income is below A\$25 001 or a family residing in a more socioeconomically disadvantaged neighbourhood were more likely not to attend a Well Child Visit at 12 or 18 months of age. This result is similar to our earlier finding of developmental surveillance uptake at 6 months of age in the same cohort, and is in keeping with other research showing an association between socioeconomic disadvantage and inequitable access to universal primary healthcare services.^{13,22} Furthermore, we found that being a mother born in Australia or having a baby who was female were independent risk factors for non-attendance at Well Child Visits for at least one of the age groups. Although the underlying mechanisms are unclear from the present study, it is interesting to note that at least one other Australian study has found that being a mother who is born in Australia is a risk factor for decreased attendance at a community baby clinic.²³ Further, female sex is well known to affect access to primary health care in many societies, especially where there are strong sociocultural practices and beliefs systems around gender roles.²⁴

Living in a socioeconomically disadvantaged neighbourhood or being from a household whose income is less than A\$25 001 persisted as independent risk factors for PEDS non-completion over the 12- to 18-month time points. The finding in this study that significant socioeconomic disadvantage is a risk factor for low utilisation of developmental surveillance services in this population is a concern because of the already well-recognised association between low socioeconomic status and developmental vulnerability.^{5,25,26} In effect, this means that children who are arguably most at risk of developmental vulnerability and could therefore benefit most from developmental surveillance are also the ones who are at greatest risk of missing out.

Furthermore, compared with PEDS non-completers who did attend a Well Child Visit, the mothers in the PEDS non-completers group who did not attend were less educated and both parents were less likely to have been born in Australia. The mechanism/s by which these additional factors alter attendance is an important consideration that may relate to other markers of socioeconomic disadvantage, such as lack of social supports and lack of health literacy, or to differences in interpersonal communication with health professionals; these possibilities require exploration in further studies. Several important barriers to families from culturally and linguistically diverse (CALD) backgrounds accessing primary health care and developmental surveillance have been identified previously and include social isolation, level of English proficiency, cultural insensitivity in health systems and insufficient knowledge of child development.^{27,28}

Limitations and strengths

The WMG birth cohort is a large, prospective cohort set within a real-life health service. Although our sample is broadly representative of the CALD population from which it was drawn,¹⁶ there was a low rate of retention from birth to the 18-month follow-up, decreasing the power and generalisability of the study, with participants at greater psychosocial risk less likely to be followed-up, resulting in differential participation.¹⁶

By relying on parental self-report for information recorded in their PHR, including attendance and PEDS completion, there is the possibility of measurement bias. However, the availability of trained researchers to facilitate and assist parents in data gathering should have minimised the possibility of measurement bias. Similarly, recall bias was minimised by conducting telephone interviews with parents in a timely fashion after the 12- or 18-month developmental check time points. In measuring PEDS completion, we cannot discount the possibility of some parents having used an alternative developmental screening tool to the PEDS, but because there is no other systematic developmental surveillance program currently disseminated in this region that we know of, it is unlikely that this occurred in a substantial proportion of households.

Conclusions

This study has illustrated that socioeconomic disadvantage predicts lower uptake and completion of developmental surveillance. Steps need to be taken to address the child, family, health systems and community risk factors that affect inequity

in access to and use of developmental surveillance in order to ensure that children with developmental difficulties are identified early and have the best chance to achieve better outcomes. In this regard, a model of developmental surveillance within a 'proportionate universalism' framework (integrated universal cover plus targeted services commensurate with needs) that will ensure participation of high-risk population groups who are currently not engaging optimally with health services is critical.

Competing interests

The authors declare that they have no competing interests.

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