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Author:

Eapen, V; Winata, T; Gilbert, M; Nair, R; Khan, F; Lucien, A; Islam, R; Masi, A; Lam-Cassettari, C; ... Liaw, Teng

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BMJ Open Parental experience of an early developmental surveillance programme for autism within Australian general practice: a qualitative study

Valsamma Eapen ^{1,2,3,4}, Teresa Winata,^{1,2,4} Melissa Gilbert,^{3,5} Radhika Nair,^{3,5} Feroza Khan,¹ Abbie Lucien,¹ Raisa Islam,¹ Anne Masi ^{1,3}, Christa Lam-Cassettari ^{1,2}, Antonio Mendoza Diaz,^{1,2,4} Cheryl Dissanayake,^{3,6} Lisa Karlov,^{1,2} Joseph Descallar,^{2,4} John Eastwood,^{4,7} Iqbal Hasan,¹ Bin Jalaludin,^{8,9} Jane Kohlhoff,¹ Siaw-Teng Liaw ¹⁰, Raghu Lingam,¹¹ Natalie Ong,¹² Chun Wah Michael Tam ^{9,13}, Susan Woolfenden,¹¹ Josephine Barbaro ^{3,5}

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For numbered affiliations see end of article.

Correspondence to

Professor Valsamma Eapen;
v.eapen@unsw.edu.au

ABSTRACT

Objectives Implementing support and services early in the life course has been shown to promote positive developmental outcomes for children at high likelihood of developmental conditions including autism. This study examined parents'/caregivers' experiences and perceptions about a digital developmental surveillance pathway for autism, the autism surveillance pathway (ASP), and usual care, the surveillance as usual (SaU) pathway, in the primary healthcare general practice setting.

Design This qualitative study involves using a convenience selection process of the full sample of parents/caregivers that participated in the main programme, 'General Practice Surveillance for Autism', a cluster-randomised controlled trial study. All interviews were audio-recorded, transcribed and coded using NVivo V.12 software. An inductive thematic interpretive approach was adopted and data were analysed thematically.

Participants Twelve parents/caregivers of children with or without a developmental condition/autism (who participated in the main programme) in South Western Sydney and Melbourne were interviewed.

Settings All interviews were completed over the phone.

Results There were seven major themes and 20 subthemes that included positive experiences, such as pre-existing patient–doctor relationships and their perceptions on the importance of knowing and accessing early support/services. Barriers or challenges experienced while using the SaU pathway included long waiting periods, poor communication and lack of action plans, complexity associated with navigating the healthcare system and lack of understanding by general practitioners (GPs). Common suggestions for improvement included greater awareness/education for parents/carers and the availability of accessible resources on child development for parents/caregivers.

Conclusion The findings support the use of digital screening tools for developmental surveillance, including for autism, using opportunistic contacts in the general practice setting.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Interviewees included parents/caregivers from culturally and linguistically diverse backgrounds, recruited as part of a large-scale research study focusing on developmental surveillance in primary healthcare settings in the geographically defined region of Sydney and across greater Melbourne.
- ⇒ The open nature of the interview schedule encouraged parents/caregivers to express a range of positive and negative aspects and experiences, resulting in a rich dataset representing enablers and barriers as well as potential solutions regarding child developmental surveillance and patient-centred care within the general practice setting from the patient perspective.
- ⇒ The emergence of themes and subthemes was analysed according to Braun and Clarke's inductive thematic interpretive approach, a rigorous analytical method of coding which allows multiple coders to agree on multiple domains of primary healthcare practice and policy.
- ⇒ Due to self-selection and convenience selection process, our sample may be biased, as more involved and active parents/caregivers may have chosen to participate in this qualitative study phase.

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INTRODUCTION

The early identification of developmental conditions that emerge in early childhood can facilitate children reaching their full developmental potential.¹ Around one in five Australian children are 'developmentally vulnerable' at the start of primary school,²

**Table 1** Current Australian national and NSW–Victorian models of child development surveillance, screening and diagnosis⁴

Model feature	NSW	Victoria	Australia
Target population—universal	√	√	√
Progressive or proportionate universalism*	√	√	√
Ages for contact	Birth–4 years	Birth–3.5 years	Birth–5 years
Number of contact points	8	10	Not specified
Settings	Home visits and clinics	Home visits and clinics	Home visits and clinics
Healthcare professionals involved			
Primary†	Child and family health nurses, midwives and general practitioners	Child and family health nurses, midwives and general practitioners	Child and family health nurses, midwives and general practitioners
Secondary‡	Paediatricians, social workers, psychologists, speech pathologist and so forth	Paediatricians, social workers, psychologists, speech pathologists and so forth	Paediatricians, social workers, psychologists, speech pathologist and so forth
Physical health monitoring§	√	√	√
Hearing and vision screening¶	√	√	√
Growth monitoring§	√	√	√
Health promotion	√	√	√
Developmental assessment**	√	√	√
Child developmental screening tool	Blue Book (Learn the Signs. Act Early)	Green Book (Parents' Evaluation of Developmental Status)	Based on jurisdiction
Immunisation	√	√	√
Anticipatory guidance	√	√	√
Autism screening	×	×	×
IT used in programme	×	Related website	×

*Each of the comprehensive models sought to include all children (universal reach), although most noted a need for targeted resources for disadvantaged children. Documents varied with respect to the amount of detail regarding the identification, engagement and management of such disadvantaged children, although subpopulations of indigenous/aboriginal families, teenage mothers and children living in poverty were frequently mentioned as being prioritised.

†Primary healthcare is provided by general practitioners who serve at the entry level to the health system and, as such, is usually a person's first encounter with the health system. They provide a broad range of activities and services, from health promotion and prevention to treatment and management of acute and chronic conditions.

‡Secondary healthcare relates to a specialist medical practitioner (eg, paediatricians) when patients are referred from a primary care service such as the general practice to the next level in the service system, and this could be in a hospital or a community-based specialist clinic.

§Monitoring enables ongoing tracking of health and developmental problems, as well as linking children with services for further assessment or intervention when concerns are identified.

¶Developmental screening is a test (or a series of tests) performed on a population to systematically examine whether the child is meeting the developmental milestones, with a view of identifying any developmental delay/problems early.

**Developmental assessments are a comprehensive evaluation of a child's physical, intellectual, language, social and emotional development. It is the process of mapping a child's performance compared with children of similar age and aims to highlight what normal developmental parameters are, when and how to assess a child and when to refer for specialist assessment.

IT, information technology; NSW, New South Wales.

but there is evidence that in some jurisdictions (usually rural/remote areas), only 20%–30% of preschool-aged children access recommended developmental surveillance programmes and/or early intervention support.³ Such programmes aim to promote child health and development, and to facilitate early detection and intervention, including monitoring of growth and physical health of children, surveillance of development, and health promotion, including injury prevention and provision of advice to promote child and family well-being.⁴ Children who have a poor start in life are more likely to develop health, developmental, learning and behavioural

issues, which in turn can have a cumulative effect over the course of their life, particularly for adult mental health outcomes, increased inequality in social opportunity, lower labour force participation, and further disadvantage.⁵ Intervening early in the life course achieves better outcomes for children and families, while late intervention is reported to cost \$A15.2 billion annually.⁶ However, there are significant challenges and inequities in early detection of children at developmental risk and access to early evidence-based interventions,⁷ with the average age of diagnosis of autism in Australia estimated to be somewhere between 4 and 6 years of age.⁸ In Australia,

Box 1 General interview guide for parent cohort

Main questions for all parents/caregivers

- ⇒ Can you please tell me about your general experience when attending the GP clinic with your child?
- ⇒ Did the COVID-19 pandemic and lockdowns impact how often you and your child attended appointments with your GP?
- ⇒ Has (child name) had a developmental check before? If so, who did it and why?
- ⇒ Before this appointment with your GP, did you have any concerns about (child name)'s development?
- ⇒ Can you please tell me about your experience of going through the developmental check with your GP?
- ⇒ For parents/caregivers whose child was identified as at risk, we posed an additional question to explore parents' perspectives about what happened next after their child had the developmental screening with their GP.

Additional questions for parents/caregivers in the ASP pathway to obtain views on their experiences by being involved in the study:

- ⇒ From your experience of the developmental checks conducted at the general practice, are there any improvements that could be introduced?
- ⇒ Would you recommend others to have a general practice developmental check for their child? Why/why not?
- ⇒ Do you think developmental checks should be conducted by the GP during their regular appointments? Why/why not?
- ⇒ What are your thoughts and experiences regarding early intervention for children who are identified as having developmental concerns?
- ⇒ Is there anything I have not asked about that you would like to regarding your experience of the child developmental checks at the general practice?

ASP, autism surveillance pathway; GP, general practitioner.

while each state has its own developmental surveillance programme, generally, this is done by Child and Family Health Nurses who complete developmental screening at recommended ages of 6, 12, 24, 36 and 48 months. There have been few studies that have examined the uptake of developmental surveillance programmes^{9 10}; one such programme, the 'Watch Me Grow' (WGM) study found that while up to 30% of children are at developmental risk by their 18-month 'well-child' check, only 30%–50% of these children attending primary healthcare have their developmental surveillance record completed.^{3 11} Further, this study found evidence of an 'inverse care law', where those at highest likelihood of developmental conditions (eg, overseas-born mothers, low educational and income levels) were the least likely to access such programmes.¹² Qualitative analyses from the WGM study revealed key facilitating factors include proximity, continuity of care, dovetailing with another recommended visit (eg, immunisation), as well as parent/caregiver and service provider language concordance.¹³ While there are state and federal developmental surveillance programmes/models (table 1), the uptake is variable especially for children from culturally and linguistically diverse and low-income backgrounds. These children are at higher developmental risk, but the developmental problems/delays go undetected in many prior to starting school, thereby missing

out on early intervention.^{14 15} In this context, a user-friendly digital developmental surveillance programme, the Watch Me Grow-Electronic (WGM-E), was trialled using opportunistic general practitioner (GP) visits with automated reminders for ongoing monitoring and was found to be feasible and acceptable.^{16–18}

There is also a discordance between early identification of developmental and behavioural conditions and the engagement of families to participate in early intervention pathways.^{13 19} This means parents/caregivers may not always receive the relevant support about their child's early intervention needs/care plan even though early diagnosis has been detected, due to several factors such as a lack of services availability and referrals, high costs, unwillingness to participate due to cultural/language barriers and/or other factors.^{13 19} Furthermore, there is considerable investment in disability services in Australia, with state and national programmes available for supporting children with developmental conditions, including the National Disability Insurance Scheme (NDIS).²⁰ However, significant challenges remain in terms of establishing a unified approach to early detection of children at high likelihood of developmental conditions in the community, and in the implementation of evidence-based assessments and care pathways using an integrated stepped-care approach. This highlights the need for a universal system that has the reach and scalability to address the current inequity by providing access to early identification and care pathways at the right place and at the right time. It has the potential to reduce adverse impact on life trajectories from personal, family, economic and societal perspectives. In this regard, the escalating impact of developmental conditions, particularly autism, has been highlighted by the fact that 31% NDIS participants have a primary diagnosis of autism, with annual support package costs estimated to be \$4.9 billion.²¹

Using a qualitative research methodology, this current study aimed to explore the general experiences and perspectives of parents or caregivers who participated in the 'General Practice Surveillance for Autism' programme²² within the primary healthcare setting. We ascertained key barriers and enablers, as well as the acceptability and feasibility of the digital developmental surveillance and referral used in the intervention (autism surveillance pathway (ASP)) arm of the trial, including the uptake of recommendations, service access and satisfaction, through the eyes of parents/caregivers. The following findings are expected to inform the development of an integrated early child development surveillance and care pathway in the Australian primary healthcare setting.

METHODS

Study context

The original programme is a cluster, multistate randomised controlled trial of an early universal surveillance programme for developmental conditions, with a particular focus on autism, that was conducted in 53 GP clinics across New South Wales (NSW) and Victoria.²² The clinics were allocated randomly to either the intervention

Table 2 Demographic characteristics of interviewed participants and their child's any identified developmental concerns

Demographic feature	Total (n=12)	ASP group (n=7)	SaU group (n=5)
Parent's/caregiver's age* (years)			
21–30	3	3	0
31–40	8	3	5
41–50	0	0	0
51–60	0	0	0
61–70	1	1	0
Parent's/caregiver's sex			
Male	1	1	0
Female	11	6	5
State residency			
NSW	6	3	3
Victoria	6	4	2
Parent's/caregiver's ethnicity			
Australian	6	4	2
Other			
Chinese	1	0	1
Cambodian	1	1	0
Vietnamese	2	1	1
Indian	1	1	0
Ghana	1	0	1
Relationship to the child			
Mother	11	6	5
Father	1	1	0
Child's sex			
Male	8	4	4
Female	4	3	1
Child's developmental concerns identified during study programme participation†			
No concern	6	3	3
Concern(s) (such as delayed language, speech, etc)	6	4	2

*Age is at of interview data collection on 30 June 2021.
†Child's developmental concerns are identified when the child is approximately 24 months old.
ASP, autism surveillance pathway; SaU, surveillance as usual.

group, the ASP, or the control group, the surveillance as usual (SaU) pathway.

Treatment group (ASP)

While in the clinic waiting room, parents/caregivers were asked to complete an online demographic questionnaire and several additional developmental screening measures:

- ▶ Learn the Signs. Act Early (LTSAE) for NSW participants.²³ It is a Centers for Disease Control and Prevention (CDC)-related milestone checklist to help parents track their child's development.
- ▶ Parents' Evaluation of Developmental Status for Victorian participants.²⁴

- ▶ Quantitative Checklist for Autism in Toddlers both jurisdictions.^{25 26}

During the consultation, the GP then administered the online version of the Social Attention and Communication Surveillance (SACS Online) tool²⁷ to determine whether the child had a 'high' or 'low likelihood' of being autistic. When children were screened positive for concerns on any of the aforementioned screening tools, parents/caregivers were guided to complete a secondary assessment, the Ages and Stages Questionnaire–Social Emotional Scale.²⁸

Control group (SaU)

Parents/caregivers of children only complete the demographic questionnaire. General practitioners then used their own standard template/tools to log their results and assess children to be at high likelihood for autism.

Children in both groups who were identified as having a 'high likelihood' of having autism were referred to the study team for a 'gold standard' diagnostic assessment for autism and other developmental disorders. Further details on the study methodology, measures and processes can be found in our main study protocol.²²

Participant recruitment and interviews

All families who participated in the original study were eligible to participate in the interview. Through convenience sampling, a quarter (n=22) out of the full sample of parents/caregivers (n=88) who took part in the original study²² were selected and invited to participate in a semistructured interview, either via a follow-up email or phone call. Based on their participation of the main trial programme, the 22 families provided informal, general/detailed feedback and comments to the research team about the programme and were relatively available and approachable to discuss further about the research. Of the 22 families who have been invited, only 12 responded and were willing to be interviewed in the end. According to Saunders *et al*'s qualitative research theory,²⁹ we halted the interviews as data saturation was reached (ie, majority of the participants had provided similar responses to the questions regarding enablers as well as barriers and potential solutions to accessing developmental checks within the primary care setting and no additional themes were emerging) following 12 interviews. The interviews were conducted via phone and comprised questions regarding accessing child developmental screening (recommended by the State Health Department) through GPs, parents/caregivers' views on child developmental checks and any specific impacts relating to the COVID-19 pandemic. Parents/caregivers of children in the ASP pathway were also asked questions specifically relating to their experiences of the additional tools and procedures relating to the study (box 1; see online supplemental table 1 for a full interview guide). The participant interviews were conducted from 1 May to 26 June 2021. Interview sessions lasted approximately 30 min each. All interviews were

Table 3 Overview of themes and subthemes

Code	Theme	Subtheme	
		ASP research pathway	SaU pathway
1	Overlapping enablers for both pathways		
1.1		Patient–GP mutual trust and relationship	
1.2		Awareness about child developmental concerns	
1.3		Importance of early intervention provision	
1.4		Telehealth adoption	
2	ASP pathway-specific enablers		
2.1		Ease of screening system	
2.2		Access to timely diagnosis	
3	Overlapping barrier for both pathways		
3.1		COVID-19 lockdowns and restrictions	
4	SaU pathway-specific barriers		
4.1			Long waiting times
4.2			Lack of clear action plan
4.3			General practitioners' unclear communication and explanation
4.4			Complex health service navigation
4.5			Seeking GP validation
5	ASP pathway-specific barrier		
5.1		Technical issues with digital system	
6	Overlapping recommendations for both pathways		
6.1		Need for education about child development	
6.2		Need for reliable services in GP clinics	
6.3		Need for further research and training for GPs	
6.4		Lengthening GP consultations	
6.5		Need for community awareness	
7	SaU pathway-specific recommendations		
7.1			Need for mandatory standardised screening
7.2			Need for educational resources and guides

ASP, autism surveillance pathway; GP, general practitioner; SaU, surveillance as usual.

audio-recorded, transcribed and coded using NVivo V.12 software.³⁰

Our interview was able to distinguish between support for surveillance versus screening based on the wording/terms and examples that were used in this study programme. ‘Surveillance’ refers to ongoing monitoring through the reminders sent to the family to take the developmental checks again; whereas ‘screening’ refers to the one-off initial developmental check done at the GP clinic. We also explained and clarified the difference between these two terms at the beginning of each participant

interview, or whenever questions relating to support for screening and surveillance were asked as part of the interview, which was captured in the transcripts/recordings.

Data analysis

Each of the interview transcripts was analysed thematically, providing an opportunity for comparison between transcripts and for identifying common themes and subthemes of individual experiences and perceptions regarding the feasibility of conducting a developmental surveillance programme within the GP setting. Thematic analysis was undertaken to develop key themes relating to participants’ experiences and perceptions; this was done through inductive coding in NVivo V.12.³¹ Data from parents in the ASP and SaU arms were coded and organised separately to allow themes to emerge as it applies to each context and then compared across the two arms. Transcribed interviews were coded by two main researchers (TW and MG). Several interviews were randomly selected and coded by secondary reviewers (FK and AL) and themes were compared. As these researchers were also members of the study team, three transcripts were also reviewed and coded by an external reviewer (RI). Any disagreements were resolved through multiple discussions and consensus reached on themes and subthemes. The study has been reported in line with the Standards for Reporting Qualitative Research (online supplemental table 2).³²

Patient and public involvement

No patient and public involvement was declared.

RESULTS

Demographic characteristics of the 12 interviewed participants and their child’s identified developmental concerns (if any) are featured in [table 2](#). The ASP and SaU participants were relatively similar in composition; there were no differences in demographics, diversity and/or child-specific variables between these two groups.

The study interviews generated seven major themes and 20 subthemes across the two study groups. [Table 3](#) provides a list of the themes and subthemes that have emerged from the data; [online supplemental table 3](#) shows additional supporting quotes from participants. [Figure 1](#) illustrates the barriers, enablers and suggestions for improvements made by participants in each of the study arms/pathways regarding developmental surveillance programmes as currently implemented through community GPs and the benefits of an integrated ASP pathway that may be relevant to primary healthcare settings.

Theme 1: overlapping enablers for both pathways

1.1 Patient–general practitioner mutual trust and relationship

Parents/caregivers affirmed that a patient–doctor relationship grounded by mutual trust was a facilitating factor

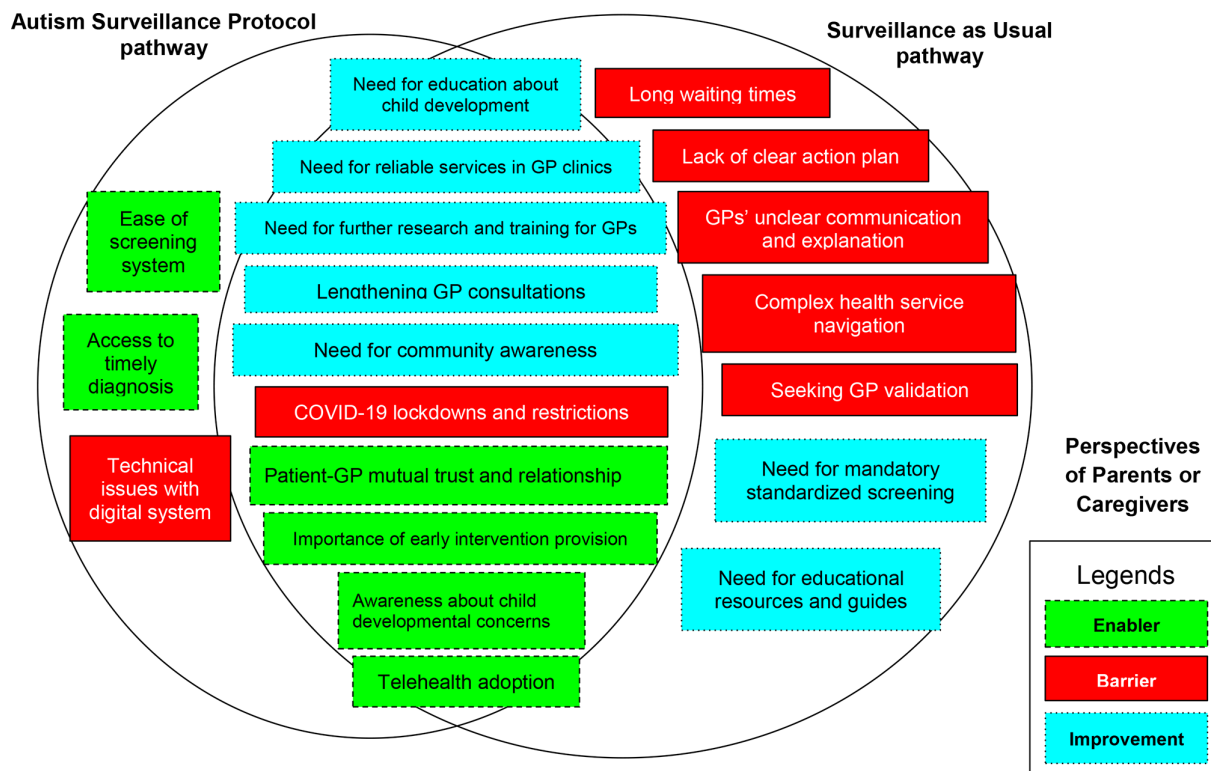


Figure 1 Comparison of barriers, enablers and suggested improvements from parent/caregiver perspectives across current GP developmental (surveillance as usual) and autism surveillance pathway research pathways. GP, general practitioner.

in parents/caregivers following their GP's advice and directions.

I did (antenatal) shared care, so he saw me throughout all three of the pregnancies with the girls. So he's kind of known them since before they were conceived. (P03, Victoria)

1.2 Awareness about child developmental concerns

Before participating in this programme, the majority of participants were not aware of what developmental issues their child may have or what to look for. After participating in this study programme, all parents/caregivers appreciated when GPs discussed the screening results regarding their child's health and well-being, and any areas of parental/caregiver concerns with them.

We went through all the answers, and talked about, you know, some of them we just flew through because there was no concern there but a couple of them there was some concern. (P08, NSW)

Such discussions held during opportunistic contacts appeared to help them highlight the importance of undertaking child developmental checks so that parents'/caregivers' knowledge about developmental milestones could be enhanced and thereby increase their engagement with ongoing developmental monitoring.

1.3 Importance of early intervention provision

Early support and services for developmental issues were highlighted as critical by the parents/caregivers. Majority

of the participants were in agreement that the programme clarified the benefit of early detection and intervention for any/future child developmental concerns.

Definitely we have to intervene early, 100% getting any extra help, is very beneficial ... For me I think just doing everything early is really important. (P12, NSW)

1.4 Telehealth adoption

The rapid switch to and acceptance of patient–doctor consultation from face-to-face to telehealth due to the COVID-19 pandemic was also affirmed by parents/caregivers. They were able to discuss any health concerns about themselves and/or child(ren) with their GPs. Just as in the following case example, it appears that it would be highly feasible to use digital developmental screening tools remotely and then discuss any concerns in a follow-up GP consultation.

Yes (to telehealth) for minor [child developmental] issues, and if it's for something more serious, that we are unsure of ourselves, then we do like the GP to have a look at them but telehealth generally we have no issues for majority of it [developmental concerns]. (P12, NSW)

Theme 2: ASP pathway-specific enablers

2.1 Ease of screening system

Participants felt that the online screening tool of an early developmental surveillance programme was user-friendly

and straightforward for parents/caregivers with young children.

It was relatively straightforward, it wasn't particularly complicated, it was not very complicated. (P03, Victoria)

2.2 Access to timely diagnosis

One facilitating factor emphasised by majority of the parents/caregivers (n=10) was that they were made aware of the need for diagnosis and assessments in a timely fashion.

She just wrote up the referral for the developmental paediatrician. And also did the referral for the study at La Trobe so she could be assessed. (P04, Victoria)

Theme 3: overlapping barrier for both pathways

3.1 COVID-19 lockdowns and restrictions

The greatest obstacle encountered during the study was the restrictions/lockdowns as a result of the COVID-19 pandemic. This made it harder for participants to access or use allocated/referred support and services.

So it was then that we were able to kind of look at therapy but because of the COVID-19 we didn't start the therapy early because of that COVID-19. So it took some time before he started the therapy. (P02, Victoria)

Theme 4: SaU pathway-specific barriers

4.1 Long waiting times

The majority of participants experienced lengthy waiting period to access government-supported healthcare services for their children, such as an NDIS support package, paediatric assessment, or allied health support.

No, we haven't, still haven't managed to have that appointment. It is [a] 12 month waitlist. (P04, Victoria)

4.2 Lack of clear action plan

Another obstacle experienced by parents/caregivers was the minimal guidance and interpretation regarding their child's paediatric healthcare plan offered to them by their general practitioners.

One day I went to the GP first and I asked the GP to refer her to some places, but then the GP was taking too long. So, I went to [another] doctor and then that doctor finally referred [her] to the speech therapy and OT places. (P07, NSW)

4.3 General practitioner's unclear communication and explanation

This subtheme is linked to the previous subtheme regarding delays and impeded access to diagnosis of developmental conditions. As one participant relayed her experience with unclear guidance:

There's very little information for someone who's a new mum ... It wasn't a direct, I don't know how to say, the information wasn't direct 'here's what you should do. And here's what you should look into.' There were lots of information to throw at me and I had nowhere ... I had no understanding of where to start. (P11, NSW)

A few parents/caregivers felt there was a lack of understanding from the general practitioner about their child's condition(s), including inadequate proper communication and explanation with patients.

Especially with respect to GP, I'm pretty sure they can... they can be more ... seem ... show some empathy towards that whole situation and try to, you know, explain it in a better way. (P01, Victoria)

4.4 Complex health service navigation

Parents/caregivers of young children faced numerous challenges navigating the healthcare system, including how to access paediatric services, getting developmental assessments and so forth.

I told her how I've been trying to get the assessment and it being so hard. (P02, Victoria)

4.5 Seeking general practitioner validation

Some participants experienced frustration regarding their GP's lack of availability to see them on time, which resulted in cascading issues with regard to keeping up with their child's healthcare action plan after needing to see multiple GPs.

Me and my husband attended a couple of GPs with [name of child] because we haven't felt like we needed. I mean, we haven't felt like we had a good GP each time. Yeah. And then we had to go to get a second opinion. (P09, NSW)

Theme 5: ASP pathway-specific barrier

5.1 Technical issues with the digital system

Several parents from Sydney encountered *technical* problems when accessing the digital questionnaires. Although this was rectified early in the study, the flow of screening completion was impacted for some of the early participants.

There was technical issues we've been sort of made to go back and do it again, went back and did it again. And then there was more technical issues going on the other end, we went back and did the third time. Then I have got done then. (P10, NSW)

Theme 6: overlapping recommendations for both pathways

6.1 Need for education about child development

There was general lack of knowledge and awareness among parents/caregivers about child developmental milestones and the need for ongoing developmental



monitoring by completing the developmental checks at the recommended ages and stages. Participants felt that education around these topics would be very beneficial.

I think the more information you give parents, like it makes them feel more informed and more knowledgeable on how they can assist their children's, like learning and development. (P05, Victoria)

6.2 Need for reliable services in GP clinics

A few participants emphasised the need to have readily available wireless internet access in order to complete digital developmental screening tools using their mobile devices. The need for a child-friendly environment for children is significant to enable parents/caregivers to complete such tasks while their children can be left within the vicinity.

Maybe make the place a little bit more kid friendly. I guess having some toys around, you know that could help with them and engaging them a little bit more like just things like that while we parents complete the online surveys... (P12, NSW)

6.3 Need for further research and training for general practitioners

Some parents/caregivers felt that their GPs lacked paediatric knowledge. They highlighted the need for further education and training for all GPs in order to keep up with new information and issues on children's health and development. Research in this area was also felt as important as part of GP medical education/training.

Maybe they need some training. Like specialised training because ... they [should] do a lot of developmental training when they're doing their courses. (P10, NSW)

6.4 Lengthening general practitioner consultations

A key policy issue raised is related to the duration of GP consultations. Several participants felt that the time allocated was insufficient to have a coherent and effective patient–doctor consultation, which may have hindered proper developmental screening and discussion for their children.

It always has been very quick. I just felt that there is too much happening. (P12, NSW)

6.5 Need for community awareness

Community awareness about child developmental surveillance and screening were considered essential by some parents/caregivers. It was thought that these things would increase levels of knowledge and improve attitudes towards child development and the need for children to receive regular developmental screening as part of their health, well-being, and growth.

“To kind of have a better way of raising awareness for mums and new parents out there when it comes to

child development, ... It could be something they do when, when we do go and get our baby check, there's more awareness out. There could be a bigger poster out.” (P11, NSW)

Theme 7: SaU pathway-specific recommendations

7.1 Need for mandatory standardised screening

Parents/caregivers stressed the importance of conducting developmental screening with every single child that visits the GP clinic. They urged that this needed to be done at each major age milestone (eg, 12, 18, and 24 months), not when it is convenient or opportunistic.

“Have a check list and make it mandatory. Maybe have it so that everyone has to complete this thing. If they fall behind with this checklist, get them help sooner.” (P11, NSW)

7.2 Need for educational resources and guides

Family reference guides or resources about child development were considered by parents/caregivers as not only beneficial for their children but also to increase their own level of awareness and knowledge in this area.

I feel like there should be kind of some structure out there, whether if it's someone who's a new mum, they could have a checklist where they can go through. (P11, NSW)

DISCUSSION

Multiple factors influencing parents/caregivers' use of general developmental and autism surveillance tools within primary healthcare services emerged from this qualitative study. While participants in both the ASP and SaU identified common enablers and barriers and made similar suggestions for improvement, participants in the current surveillance setting (SaU) identified more barriers.

Most families in the study had positive attitudes and experiences with their GPs, including the ability to trust, have open and honest conversations, and being made aware of important information regarding their child's health, which would all lead to greater awareness and confidence, and thereby improving their overall healthcare experience and well-being. This was indeed affirmed by several previous studies, which had shown that building trust and rapport in doctor–patient relationships through open communication, patient engagement and shared decision-making mitigates patients' feelings of anxiety and vulnerability, thus improving their overall healthcare experience.^{33 34}

Results also suggested that the implementation of digital screening tools in primary health services has the added benefit of parents/caregivers having access to developmental checks at the point of care and being referred for further assessments as needed. Some families were unaware of the need to have their child's development

assessed frequently through child and family health checks.^{12 13 15} This could be addressed via the implementation of the ASP pathway as in this study, where parents/caregivers are engaged to complete the developmental surveillance programme during opportunistic GP visits with opportunities for ongoing monitoring. In NSW, a similar project, the WMG-E, has been implemented to engage parents/caregivers using opportunistic contacts to complete developmental checks digitally and thereafter sends automated reminders for parents to retake the developmental checks at the next recommended ages and stages (6, 12, 18, 24, 36, 48 and 60 months), thereby providing opportunity for ongoing developmental monitoring.^{16 17} The Victorian Maternal and Child Health service provides universal access to all Victorian children for 10 'key age and stage' assessments (after-birth home visit; visits of 2, 4 and 8 weeks; visits of 4, 8, 12 and 18 months; and visits of 2 and 3.5 years).³⁵ These assessments include ongoing monitoring of child development (including the online SACS assessment),³⁶ as well as child and parental/caregiver health and well-being.³⁷ Research involving other health conditions such as adolescent health risk behaviours, depression and anxiety, eating disorder and drugs/alcohol have also shown similar findings on the need for and benefits of implementing digital screening and support checks.^{38–41} Thus, further evaluation of the implementation and scale-up of digital monitoring programmes for developmental conditions, including autism, is warranted.

For families who participated in this study, a major issue was the effects of COVID-19 pandemic restrictions/lock-downs during the study period, which often prevented families from having in-person consultation with their GPs, leading to a reduction in the frequency of consultation and checks. This has been indeed confirmed in many healthcare services, with one systematic review reporting a decrease of healthcare use by one-third during the pandemic and with greater reduction in consultations among people with less urgent/severe illness.⁴² The finding from this review that reduction in service contact often tended to be greater for milder or less severe forms of illness is in keeping with our finding that most families did not engage in developmental checks for their children during the pandemic as they considered this to be of low priority. Additionally, the impact of not being able to have face-to-face appointments was reported to make it difficult for them to express their genuine concerns and access physical assessments/therapies. Further, a qualitative study found that the doctor–patient relationship was most important for telehealth services to be effective, with similar views expressed by some parents in our study.⁴³

Several contextual barriers were also identified, such as long waiting periods for services and support, unclear health information and action plans/goals, and complex health system navigation. It is critical that such issues of referral and care pathways are addressed for improving the overall experience and outcomes of developmental surveillance programmes. It has been found that patient

experience, and in particular, confidence in the care provider and perceived quality of care, is negatively correlated with longer wait times.⁴⁴ Negative patient experience has also been linked to poor health communication during patient–doctor consultations, particularly in the context of healthcare system complexity.^{45 46}

Another barrier identified by some participants in the SaU arm was the lack of understanding and responsiveness of some GPs when they raise concerns about their child's development, resulting in feelings of frustration and not being valued. Such gaps between expectations and actual experiences have been reported in other studies which have linked negative patient experience/well-being to poor communication or connectedness between patients and doctors, inability to trust and time pressure.^{47–49} It would appear that, by providing a framework for parents to raise concerns and for GPs to provide appropriate assessments and referrals for children's developmental needs as done in the ASP pathway will help address this issue.

Implications for health policy and practice

This study suggests that there is a need for parents/caregivers to be educated about child developmental conditions, including autism. According to families, there is a need for community awareness about such topics, as well as further training and education regarding paediatrics/child developmental screening for GPs. While educational resources for parents/caregivers to learn about child development and guidelines for professionals exist,^{50 51} there is a need to increase the awareness and to implement the resources and guidelines in a systematic way using routine contacts during key age periods in the primary care settings.

The current national government-run Medicare programme funds Australian primary healthcare services by reimbursing GPs set consultations fees using a convoluted system of Medicare Benefits Schedule (MBS) item numbers, which also sets the duration of the consultation and the types of services which can be delivered.⁵² Patients are either bulk-billed (ie, fully reimbursed by Medicare) or privately billed (ie, consultation fee set by the GPs incurring an out-of-pocket cost, with a partial reimbursement by Medicare) for their healthcare services.⁵³ Our study findings indicate that there is a need for an MBS schedule review to consider increasing the duration of GP consultations for parents/caregivers to discuss potential developmental concerns at key ages and stages. This could be complemented by the introduction of MBS item numbers for separate, dedicated sessions specific for child development screening by GPs especially when concerns are identified using routine contacts.

Furthermore, there is also a need to train and upskill practice staff such as practice nurses who can play a critical role for facilitating developmental checks alongside vaccination or other recommended checks, such as dental and visual check-ups. It is also important to provide child-friendly environments and other support



(eg, administrative staff/receptionist) in the GP waiting rooms so that parents/caregivers are able to complete digital developmental screening checks uninterrupted and in a timely manner.

Strengths and limitations

This is a qualitative study in a defined geographical region of NSW and Victoria during the COVID-19 pandemic; accordingly, some findings may be related to local issues and the circumstances caused by the pandemic. In this regard, the technical difficulties experienced by some families in NSW was linked to a system compatibility issue. However, the overall findings are in accordance with the broad international literature about identifying and managing developmental conditions in primary care and on the related challenges experienced by parents/caregivers patients as well as by health professionals including regarding the use of child developmental screening tools.^{13 19 54 55} Another limitation of the study is that the cultural background of the parents/caregivers, and the ways in which this impacts their perceptions on the use of screening tools specifically, was unable to be explored. As motivation bias may be introduced due to the fact that convenience sampling was also used in the selection/recruitment process, our findings are qualitatively transferable because they do not have to be statistically representative of the greater population of interest. We also acknowledge that the themes and subthemes described here primarily relate to the barriers and enablers of access to developmental surveillance, but we did not conduct enough interviews to reach saturation in terms of ascertaining the varied experiences of service recommendations and referral pathways following identification of concerns.

We maintained the quality of the study through an awareness of reflexivity and efforts to achieve a high level of interpretive trustworthiness and rigour. This was achieved through feedback from colleagues, checking data analysis with other team members and coding of the analysis by a researcher independent of the data collection. Further, the main strength of this study is that the voice of our parent/caregiver cohort is heard and facilitated by the culturally sensitive approach of the researchers in the data collection process.

CONCLUSION

This qualitative study has provided critical insights into the enablers, barriers and potential solutions to engaging parents/caregivers in developmental screening including for autism during opportunistic contacts in the primary care setting. The study has also highlighted the need to improve awareness among parents and in the general community about the importance of developmental surveillance and ways to engage parents with appropriate resources. In this regard, our findings suggest that attention needs to be given to cultural sensitivity and linguistic needs by adapting relevant developmental resources.

It is also important to attend to the training needs of GPs on how to raise concerns with parents/caregivers and support children with developmental needs and their families. The participants also raised the need for increased access to allied health professionals for the diagnosis and support of children being on the autism spectrum. Efforts are also needed to promote the implementation of systematic processes and access to accurate and easy to use evidence-based early identification tools, such as those used in this research programme.²² Health professional time as well as financial and logistical constraints are other factors that impede the implementation of developmental monitoring in GP, which can be overcome through the inclusion of commonwealth MBS items specifically for child developmental surveillance. Facilitating parent engagement alongside supporting primary care physicians who often have a trusting and ongoing relationship with the family to conduct developmental checks at the point of care can significantly increase opportunities for early identification of children with developmental conditions including autism.

Author affiliations

¹Faculty of Medicine, Discipline of Psychiatry and Mental Health, UNSW, Sydney, New South Wales, Australia

²Academic Unit of Infant, Child and Adolescent Psychiatry, South Western Sydney Local Health District, Liverpool, New South Wales, Australia

³Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria, Australia

⁴Ingham Institute for Applied Medical Research, Liverpool, New South Wales, Australia

⁵Cooperative Research Centre for Living with Autism, The University of Queensland, Saint Lucia, Queensland, Australia

⁶Cooperative Research Centre for Living with Autism (Autism CRC), The University of Queensland, Saint Lucia, Queensland, Australia

⁷Faculty of Medicine and Health, School of Medicine, The University of Sydney, Sydney, New South Wales, Australia

⁸Centre for Research, Evidence Management and Surveillance, South Western Sydney Local Health District, Liverpool, New South Wales, Australia

⁹Faculty of Medicine, School of Population Health, UNSW, Sydney, New South Wales, Australia

¹⁰School of Public Health and Community Medicine, UNSW, Sydney, New South Wales, Australia

¹¹Population Child Health Research Group, Faculty of Medicine, School of Women's and Children's Health, UNSW, Sydney, New South Wales, Australia

¹²Children's Hospital Westmead Clinical School, The University of Sydney, Sydney, New South Wales, Australia

¹³Primary and Integrated Care Unit, South Western Sydney Local Health District, Liverpool, New South Wales, Australia

Twitter Christa Lam-Cassettari @DrChristaLC, Siaw-Teng Liaw @EIAstee, Chun Wah Michael Tam @vitalis and Josephine Barbaro @drjbarbaro

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ORCID iDs

Valsamma Eapen <http://orcid.org/0000-0001-6296-8306>

Anne Masi <http://orcid.org/0000-0002-3135-6961>

Christa Lam-Cassetari <http://orcid.org/0000-0001-6167-551X>

Siaw-Teng Liaw <http://orcid.org/0000-0001-5989-3614>

Chun Wah Michael Tam <http://orcid.org/0000-0001-8645-4756>

Josephine Barbaro <http://orcid.org/0000-0001-7359-0097>

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