AutismCRC

A multistate trial of an early surveillance program for autism within General Practices in Australia

FINAL REPORT

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LA TROBE UNIVERSITY | Olga Tennison Autism Research Centre | UNSW SYDNEY

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Copies of this report can be downloaded from the Autism CRC website **autismcrc.com.au**.

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Autism CRC

Autism CRC is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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1. Executive summary

Introduction

The early detection of developmental conditions such as autism is vital to ensure children can access appropriate and timely evidence-based supports and services. However, many children are not able to access such early supports due to delays in identification. For example, the mean age of diagnosis for Autism Spectrum Disorder (ASD; hereafter, autism) in Australia is 49 months (Bent et al., 2015), despite the ability to detect and diagnose autism from 18- to 24-months (Barbaro & Dissanayake, 2009). The delay in identification of these children requires addressing urgently (Eapen, 2016).

Accordingly, this study aimed to develop a protocol for the accurate early detection of developmental differences including autism in Australia, by synergising and building on existing State and Federal programs. It was proposed that general practitioners (GPs), through their opportunistic contacts with young children, such as the 18-month vaccination or visits for other reasons, could engage parents/caregivers in the developmental monitoring of their toddlers, to identify the early signs of developmental differences such as autism.

The overall objective of the project was to develop and evaluate an approach to early autism detection within a developmental surveillance framework in children aged 18 to 24 months, using opportunistic GP clinic visits in the primary care setting (Barbaro et al., 2021). This project aimed to examine whether, compared to usual practice (surveillance as usual; SaU), an autism surveillance protocol (ASP) pathway would be associated with:

- improved uptake and completion of developmental and autism surveillance;
- increased accuracy in identifying children at 'high likelihood' of an autism diagnosis and related conditions, such as developmental and/or language delay.

Secondary outcomes to be investigated included whether the ASP pathway would increase parental/caregiver engagement, health literacy, and satisfaction in accordance with the National Guideline for the Assessment and Diagnosis of Autism in Australia (National Guideline) and increase GP awareness and utilisation of developmental and autism surveillance tools and resources.

The second part of the study comprised of a qualitative component, which was used to ascertain parental/caregiver participation and experience in the program. The study also

captured stakeholders' (including parents/caregivers and health professionals) perspectives of the barriers and enablers influencing the implementation of the National Guideline.

Method

Within each state (NSW and Victoria), approximately 30 GP clinic 'clusters' were recruited. Children (n=122) aged approximately 18- to 24-months attending participating GP clinics were recruited as part of each cluster. A 'universal developmental surveillance' approach to recruitment was implemented, such that any child between the eligible ages attending an appointment at the clinic for any reason, including for an immunisation, can be recruited to the study.

For the qualitative component of the study, six parents/caregivers of participating children from each site and 12 participating GPs and/or clinic practice nurses (PNs) were recruited from each state with the aim to recruit equally from each study pathway. The study was split into three phases.

Phase 1

GPs and PNs received training on the study procedure and use of the study iPad and weblink, and, for those in the ASP group, the study screening tools and resources.

ASP Pathway

Parents/caregivers who were interested in participating in the study completed the following developmental surveillance instruments: 'Learn The Signs Act Early' (LTSAE); Parents' Evaluation of Developmental Status (PEDS); Quantitative Checklist for Autism in Toddlers-10 item (Q-CHAT-10); and Ages and Stages Questionnaire: Social-Emotional (ASQ:SE). The GP/PN completed the Social Attention and Communication Surveillance-Online (SACS Online) tool with the child during the appointment. An embedded algorithm in the online study platforms scored the responses in the parent/caregiver and clinician tools to identify children who had developmental differences and/or 'high likelihood' of an autism diagnosis.

SaU Pathway

GPs and PNs used a standard template to log the methods and tools used by the GP to assess children's likelihood of an autism diagnosis.

Phase 2

Parents/caregivers of children in both the ASP and SaU pathways who were identified as having a 'high likelihood' of an autism diagnosis by their GP between 18- and 24-months of age were invited by the research team to complete a developmental assessment when the child was aged approximately 24-months. Additionally, a randomly selected 10% of screen negatives from both pathways were also invited to complete this same assessment. The following tools were used as part of the assessment: Autism Diagnostic Observation Schedule-Second Edition (ADOS-2); Autism Diagnostic Interview-Revised (ADI-R); Mullen Scales of Early Learning (MSEL); Vineland Adaptive Behavior Scales, third edition (VABS-3); Sensory Experiences Questionnaire - short form (SEQ). Parents/caregivers also completed a more detailed general and demographic questionnaire in addition to the abovementioned assessments.

Phase 3

Parents/caregivers of all children recruited to both the ASP and SaU pathways of the study completed the preschool version of the Social Responsiveness Scale, Second Edition when their child was approximately 30 months of age. Parents/caregivers of children identified with developmental differences from both arms also completed a semi-structured questionnaire to evaluate the uptake of recommendations, experience of assessment/service use, supports and services received, and parental satisfaction with the health and disability services.

Phase 3a

The worldwide 2019 novel coronavirus (COVID-19) pandemic led to the introduction of stay-at-home 'lockdown' public health orders in Victoria on 24 March 2020 and NSW on 31 March 2020. This led to a significant decrease in the number of people attending face-to-face general practice appointments in both states, but particularly in Victoria due to the longer duration of the lockdowns. Thus, the number of children recruited to the study was greatly reduced. Due to the impacts of the COVID-19 pandemic on the study, from January 2021 the study team placed greater focus on the qualitative component of the study, with analysis of quantitative data already collected conducted, where possible.

GPs and PNs who participated in the study and parents/caregivers of children recruited to the study were invited to participate in a semi-structured interview. The interviews aimed to understand the feasibility of conducting a developmental surveillance program within the

general practice setting; understanding the associated challenges, enablers, and solutions to the process of conducting childhood developmental surveillance; and pathways to early supports and services when a developmental difference is identified.

Summary of findings

This study provided initial evidence for the feasibility and acceptability of the digital screening checks for early identification of developmental differences including early signs of autism. Through the ASP pathway, a greater number of children were identified who had developmental differences and went on to receive a diagnosis of autism in comparison to the SaU pathway. The results of the 'gold standard' assessment of screen negatives and the outcomes of the SRS-2 at 30 months of age indicated that the majority of 'low likelihood' children in the ASP pathway were correctly classified, and thus that the ASP pathway is accurate. Psychometric calculations for the ASP pathway were determined, indicating that the ASP pathway has high sensitivity (100%), specificity (80%), positive predictive value (90.9%), and negative predictive value (100%). It also highlighted the need for developmental surveillance, as opposed to single point in time developmental screening, to ensure all children with developmental differences and/or conditions are identified.

The consensus from the qualitative study with parents/caregivers and GPs was that the tools in the ASP pathway were simple and easy to complete, and as a result they were able to access timely identification and diagnosis for their children where required. The study also highlighted the need for structural changes within general practice, such as further training of service providers and awareness of the community, the importance of child developmental checks and ongoing monitoring in the critical toddler years. Specifically, the need for sufficient time for GPs to complete developmental checks, and a Medicare item for this, was raised by both GPs and parents/caregivers.

The findings from this study suggest that parents/caregivers encounter multiple barriers to accessing early identification of developmental differences including autism, due to long waiting times and major delays in getting their child assessed, with further wait for NDIS support to access early supports and services. This is particularly evident for parents/caregivers from culturally and linguistically diverse backgrounds, who experience added waiting time due to lack of appropriate service providers available in the community.

Strengths and limitations

Some of the findings in relation to barriers and enablers may be related to local issues and the circumstances over the study duration caused by the COVID-19 pandemic. However, the findings sit within the broad international literature on the use of screening tools by health professionals and thus the findings from this study appear to be transferable to other similar settings. Despite the careful planning by the study team, the severe and ongoing impacts of the COVID-19 pandemic on both general practices and families had a devastating impact on the study. Given the challenges experienced by the community, and in particular families with young children during the extensive lockdowns, it is not unexpected that reduced participation would also stem from the parent/caregiver side. We maintained the quality of the study through an awareness of reflexivity and efforts to achieve a high level of interpretive rigour/trustworthiness.

Implications for research and practice

Significant learnings were gained in terms of conducting and adapting a large scale RCT during a pandemic, which, given the ongoing lockdowns due to COVID-19 both in Australia and worldwide, would prove useful for future research. Practical considerations include projects being designed to enable participants to complete questionnaires and other measures remotely or on their own devices when required and ensuring studies can be pivoted to accommodate lockdowns, with such measures built into the study where possible. Alternatively, other methods such as approaching parents/caregivers prior to attending an appointment or 'opt-out' recruitment should be considered.

Key recommendations

- **Increase awareness** and importance of developmental screening and surveillance via education and training about signs of autism (across the lifespan and for all genders), implementing National Guideline recommendations for the autism diagnostic process and effective support mechanism for individuals on the autism spectrum and their families.

- **Wider dissemination of early autism training for GPs** (i.e., SACS-R) and general child development training (i.e., RACGP modules developed for GPs and PNs), along with wider implementation of the National Guideline.

- The Medical Services Advisory committee should include an **MBS item** allowing GPs to book appointments specifically for developmental screening/surveillance.

- Parents/caregivers should be given access to questionnaires **prior to attending** the clinic for the appointment, to ensure sufficient time to complete the questionnaires and enable GPs to have timely access to the results.

- Develop **resources for parents/caregivers** including culturally and linguistically diverse (CALD) communities to inform and educate families on the importance of early developmental monitoring.

- There is a need to **increase the number and capacity of professionals** (including cultural and linguistic diversity) available in the community to undertake autism assessments through the roll out of autism diagnostic training for multidisciplinary child health professionals.

- NDIS process to **include provision for GPs to provide ongoing care, support, and appropriate referrals** to children and parent/caregivers.

Conclusion

This study found that it is feasible for GPs to engage parents/caregiver in developmental monitoring of children with the use of a standardised autism surveillance pathway. The results indicated that both GPs and parents/caregivers were interested in the use of the ASP pathway tested in this study and that this pathway was successful in identifying children who were on the autism spectrum and/or had other developmental conditions. The fulfilment of the recommendations reported here would be of benefit to the implementation of an effective and national program for developmental surveillance of Australian toddlers for the early signs of autism and other developmental conditions.

2. Introduction

The early detection of developmental differences such as autism is vital to ensure children can access appropriate and timely evidence-based supports and services. Children who have undetected developmental conditions early in life are more likely to develop later health, developmental, learning, and behavioural issues, which in turn can have a cumulative effect over the life course.

Current Scenario

Currently, many children are not accessing early support opportunities. In this regard, it is noteworthy that the mean age of diagnosis for Autism Spectrum Disorder (ASD; hereafter, autism) in Australia is 49 months (Bent et al., 2015), which urgently requires addressing (Eapen, 2016) given we can detect and diagnose autism from 18- to 24-months (Barbaro & Dissanayake, 2009). This is in part due to the low uptake of existing developmental surveillance programs, contributing to lack of access and opportunity for early detection, increases in parental stress, as well as flow on effects on delays in access to supports and services.

Rationale for this study

This study aimed to synergise and build on existing State and Federal programs to develop mechanisms for accurate early detection of developmental differences including autism in Australia. It was proposed that the opportunistic contacts that families have with their general practitioner (GP), such as the 18-month vaccination or visits for other reasons, could be used to engage parents/caregivers in developmental monitoring so that early signs of developmental conditions such as autism can be identified. The study also aimed to ascertain the attitudes, barriers, and enablers amongst parents/caregivers and health professionals on access to early detection of autism.

The increasing prevalence of developmental conditions such as autism, first evident in early childhood, can pose significant challenges to the individual, their family, and society if left undetected and unsupported (Australian Institute of Health and Welfare, 2011; Center on the Developing Child at Harvard University, 2010). It is estimated that over 250 million children globally do not reach their developmental potential due to a lack of access to sufficient supports and services (Grantham-McGregor et al., 2007; Walker et al., 2011). In Australia, around one in five children starting their first year of school are ‘developmentally vulnerable’

with delays in one or more domains of development (Australian Early Development Census, 2018). Additionally, despite early signs of autism emerging within the first two years of life for most children (Barbaro & Dissanayake, 2009), the average age of autism diagnosis in Australia is 4.1 years among children under the age of seven years who are accessing services and supports (Bent et al., 2015). Children who have undetected and unsupported developmental conditions early in life are more likely to develop later health issues, including adverse adult mental health outcomes (Kanne et al., 2011; Moore et al., 2017).

There is substantial evidence that providing supports and services early in life can enable children to reach their full potential (Teager et al., 2019). However, significant challenges and inequities remain in detecting children at 'high likelihood' of an autism diagnosis sufficiently early to take advantage of neural plasticity of the developing brain through implementation of comprehensive, multimodal, evidence-based supports and services (Bishop-Fitzpatrick & Kind, 2017). Specifically, early identification and access to optimal early supports and services in the toddler and preschool years for children with early signs of autism is critically important for optimising outcomes. Only 8% of children who received a diagnosis of autism at 2 years of age had co-occurring intellectual disability (ID) when followed up at 9 years, while 24% of those who received the diagnosis between 3- to 5-years of age were found to have co-occurring ID (Clark et al., 2017). Additionally, children who begin school without developmental difficulties or delays will remain on educational trajectories that are enhanced in comparison to children who begin school with unaddressed developmental concerns (Barnes et al., 2016; Brinkman et al., 2013; O'Connor et al., 2020).

Developmental surveillance offers opportunities to identify children with developmental differences reflecting the early signs of autism in a systematic way through health and developmental monitoring, thereby facilitating opportunities for access to early supports and services. Over the past three decades, data have emerged suggesting that developmental conditions beginning in infancy and toddlerhood have the potential to affect key outcomes in the longitudinal trajectory of these children (Heckman & Masterov, 2007; Isaacs, 2007). Similarly, it has been recognised that the earlier services and supports are accessed, the better the outcomes for the child (Galinsky, 2006). There is also increasing evidence to suggest that early detection and support is efficacious, cost-effective, and may be a way of decreasing health inequality, disparities, and breaking the cycles of intergenerational disadvantage (British Medical Association Board of Science, 2013; Center on the Developing Child at Harvard University, 2010; Feinstein, 2003; Pelto et al., 1999). Though some parents have concerns about their child's development from a very early age, children who are diagnosed with autism are identified later than children with general developmental

delay or ID (Oswald et al., 2017). Such delay in diagnosis can also result in increased parental stress and significant delays in initiating early supports and services which, as stated above, can result in less than optimal outcomes over time (Zwaigenbaum et al., 2015).

Whilst advances have been made in developing effective early supports for children on the spectrum, significant barriers exist in accessing such supports and services early within the period of greatest responsiveness (Oberklaid, 2014). There are a few studies that have explored processes for the detection of developmental vulnerability in early life and barriers to accessing early supports and services. One such study is the Watch Me Grow (WMG) program (Eapen et al., 2014), conducted in a birth cohort of two thousand children in Sydney, Australia, in partnership with the New South Wales (NSW) state government health department. The WMG study (Chandra et al., 2016; Eapen et al., 2014; Overs et al., 2017; Woolfenden, Eapen, Axelsson, et al., 2016) revealed that up to 30% of children are identified with developmental concerns by their 18-month 'well-child' check, but only 30-50% of these children attending primary health care (GPs and child and family health nurses) have their developmental surveillance record completed. This is in keeping with the findings from a population health survey in NSW, Australia (Centre for Epidemiology and Research, 2008) that found that only around 66% of children attend 'well-child' checks until around 12 months of age, dropping to 20% between 1 and 4 years of age. Thus, the period from 12 months to 5 years of age is a critical 'silent' period for assessing a range of developmental and behavioural differences, including speech and language difficulties and autism. However, it is to be noted that across Australia there is considerable variability between states in children accessing developmental surveillance (Eapen et al., 2014), which is further influenced by the help-seeking patterns of parents/caregivers from diverse cultural and linguistic backgrounds (Eapen et al., 2017). While NSW has a developmental surveillance attendance rate of 30% at eighteen months (Woolfenden, Eapen, Jalaludin, et al., 2016), attendance is substantially higher in Victoria at 74.2% (Department of Health and Human Services, 2019).

Further, the WMG program found evidence of an 'inverse care law', whereby those at highest likelihood for developmental delay (e.g., children whose mothers were born overseas or with lower maternal education and income levels) were the least likely to access the developmental surveillance program (Chandra et al., 2016; Woolfenden, Eapen, Axelsson, et al., 2016). Qualitative analyses also indicated that facilitators to accessing developmental surveillance for families included proximity to the centre, continuity of care, visits being combined with another recommended service (e.g., immunisation) and language

concordance by the provider (Garg et al., 2018; Scott et al., 2016; Woolfenden, Eapen, Axelsson, et al., 2016). Access to good developmental surveillance programs could lead to better support for families, particularly those who have complex and multiple social risk factors.

The early detection of autism was investigated in Australia using the Social Attention and Communication Surveillance (SACS) tool and its revised version (SACS-R; Barbaro & Dissanayake, 2010; Barbaro & Dissanayake, 2013; Barbaro et al., 2011; Mozolic-Staunton et al., 2020). A training program for universal developmental surveillance of autism was undertaken with maternal and child health nurses and early childhood educators. The program included education on the early behavioural markers for autism and the use of an evidence-based behavioural tool (SACS-R) to monitor approximately 34,000 children aged 8- to 24-months to identify those with a 'high likelihood' of an autism diagnosis. Designed for use during routine developmental surveillance, the SACS-R uses professional observations to monitor the child's development between 11- and 30-months of age using age-appropriate behavioural markers of autism (Barbaro & Dissanayake, 2013). Children identified as having a 'high likelihood' of an autism diagnosis were invited for developmental assessments by the research team, with six-monthly follow-ups and a 'gold standard' diagnostic assessment at 24 months and 3.5 years of age. The SACS-R is currently the most accurate and sensitive tool for the early identification autism and related developmental conditions, such as developmental and/or language delay (psychometrics outlined in 'Methods' section).

Currently there is considerable investment in disability services in Australia, with a new national program available for supporting those with a disability and their carers/families: the National Disability Insurance Scheme (NDIS; Australian Government, 2013). The escalating costs, both financial and otherwise, of developmental conditions and particularly autism has been highlighted by 29% of people entering the NDIS having a diagnosis of ASD (National Disability Insurance Agency, 2019). A significant proportion also have behavioural and emotional challenges, which, if not supported appropriately, can result in a lifetime of significant co-occurring mental health difficulties (Scott et al., 2016). This has led Autism CRC to provide funding support to carry out this study examining the implementation of a universal developmental surveillance program, with a particular focus on autism, in the primary care setting. This study also aimed to develop an integrated care pathway for follow up assessment, diagnostic determination, and referral to appropriate services, including secondary and tertiary services, in collaboration with the local health services as well as NDIS providers in the geographical area. This project will also help to evaluate the implementation of the recently launched National Health and Medical Research Council

(NHMRC)-endorsed National Guideline for the Assessment and Diagnosis of Autism in Australia (National Guideline; Whitehouse et al., 2018). Developed and published by the Autism CRC, with the financial support of the National Disability Insurance Agency (NDIA), the National Guideline aims to create greater consistency in diagnostic practices across Australia.

Project scope

The overall project scope was to develop a feasible, effective, and national program for developmental surveillance of Australian toddlers for the early signs of autism.

Project objectives

The overall objective of the project was to develop and evaluate a potentially sustainable approach to early autism detection within a developmental surveillance framework, in children aged 18 to 24 months using opportunistic GP clinic visits in the primary care setting (Barbaro et al., 2021). Specifically, this project aimed to examine whether, compared to usual practice (surveillance as usual; SaU), an autism surveillance protocol (ASP) pathway would be associated with:

a) improved uptake and completion of developmental and autism surveillance
b) increased accuracy in identifying children at 'high likelihood' of an autism diagnosis and related conditions, such as developmental and/or language delay.

Secondary outcomes to be investigated included whether the ASP pathway would increase parental/caregiver engagement, health literacy, and satisfaction in accordance with the National Guideline, and increase GP awareness and utilisation of developmental and autism surveillance tools and resources.

With regard to the primary outcomes, we hypothesised that, compared to the SaU pathway:

- The proportion of children completing autism developmental surveillance at the primary health care GP clinic would be increased in the ASP pathway, and
- The proportion of children correctly identified as being at 'high likelihood' of an autism diagnosis, as evidenced by the comprehensive 'gold standard' assessment results, would be increased in the ASP pathway.

A qualitative component of the study was also used to ascertain the parental/caregiver participation and experience in the program when followed up at 30-months of age. The

study also captured stakeholders' (including parents/caregivers and health professionals) perspectives of the barriers and enablers influencing the implementation of the National Guideline. The integrated model of developmental surveillance and referral used in the active arm of the intervention (ASP) will be compared to surveillance as usual (SaU) in terms of uptake of recommendations and service access and satisfaction, thereby informing the development of an integrated developmental surveillance and care pathway in Australia. Thus, this study builds on existing state and national programs to identify barriers and develop mechanisms for accurate early detection of autism in Australia.

3. Research design and methods

Protocol design

The study design is a multi-site, cluster randomised control trial (RCT) comparing a developmental surveillance pathway for autism to usual care, using opportunistic visits to GPs, with a qualitative component implemented (see Figure 1). The units of randomisation were GP clinics across two Australian states, NSW and Victoria, with 30 clinics within each state. Each clinic aimed to recruit approximately 40 children aged between 18- and 24-months, for a total of 2,400 participants.

Using a minimisation randomisation procedure over size of GP clinic (<4 GPs or ≥4) and site (NSW or Victoria), the participating GP clinics within the two sites were allocated to one of two arms (pathways):

1) Surveillance as usual (SaU), representing current practice, or
2) Autism surveillance protocol (ASP), which will implement the 'enhanced developmental surveillance' protocol.

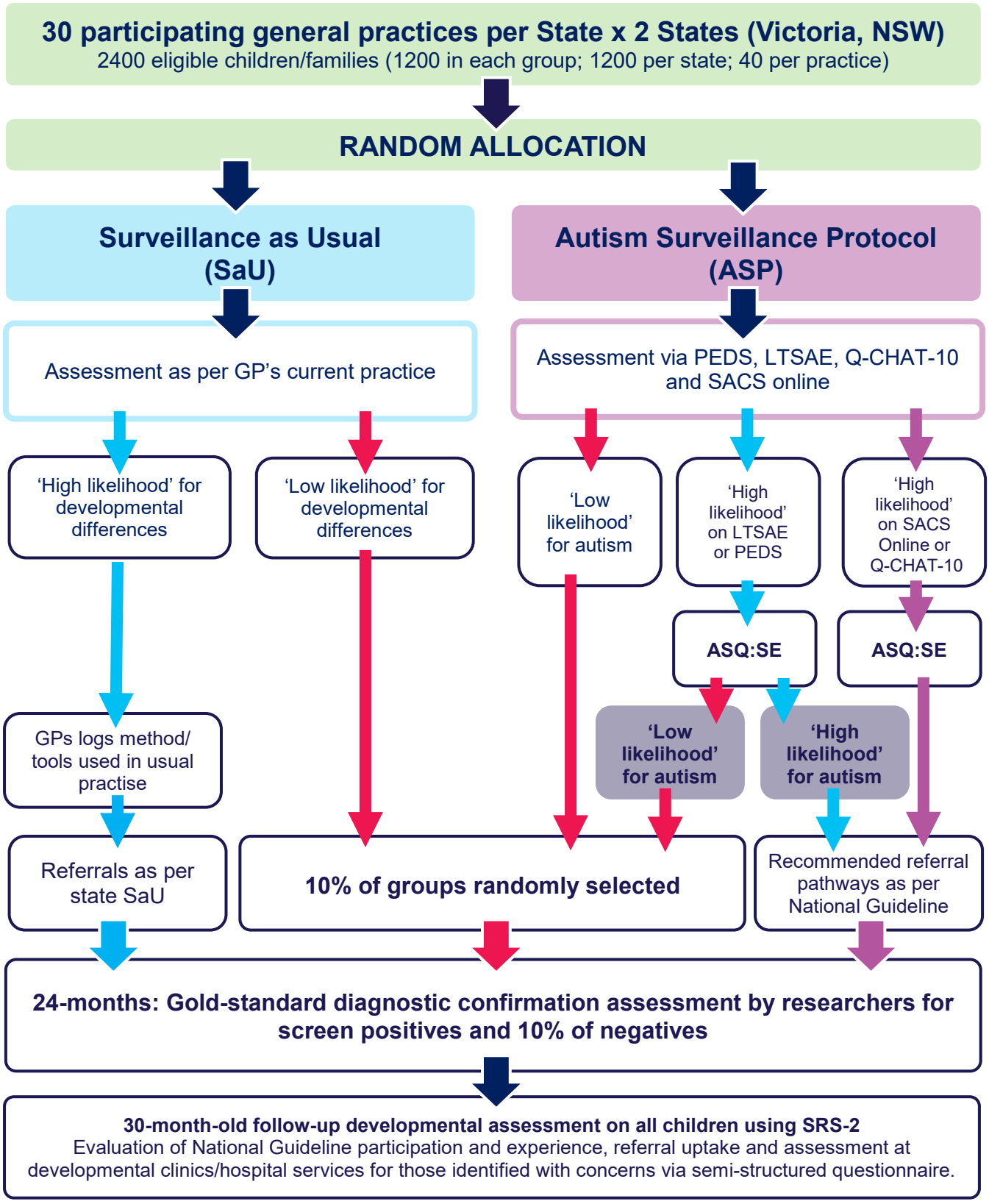
Participants and setting

Within each state (NSW and Victoria), approximately 30 GP clinic 'clusters' were recruited. Children aged approximately 18- to 24-months attending participating GP clinics were then recruited as part of each cluster. GP clinics were recruited through various methods including using Primary Health Networks to distribute study information and direct contact (email, fax, telephone) with prospective clinics. GPs and, in some instances, the clinic practice nurses (PNs) were recruited, with each clinic having at least one GP participating in the study consenting to recruit children. A 'universal developmental surveillance' approach to

recruitment was implemented, such that any child between the eligible ages attending an appointment at the clinic for any reason, including for an immunisation, can be recruited to the study.

For the qualitative component of the study, six parents/caregivers of participating children from each site and 12 participating GPs and/or PNs were recruited from each site with the aim to recruit equally from each study pathway.

Figure 1: Study design



Abbreviations: ASQ:SE Ages and Stages Questionnaire: Social-Emotional; LTSAE, Learn the Signs Act Early; PEDS, Parents' Evaluation of Developmental Status; Q-CHAT-10: Quantitative Checklist for Autism in Toddlers – 10 item; SACS-Online: Social Attention and Communication Surveillance – online; SaU, surveillance as usual; SRS-2: Social Responsiveness Scale, Second edition.

Phase 1 - GP clinic visit

Prior to commencing the study, GPs and PNs received training on the study procedure and use of the study iPad and weblink, and, for those in the ASP group, the study screening tools and resources. Clinic reception staff also received training on the study procedure and participant recruitment and were provided with prompt cards with key information pertaining to the recruitment of children. Potential participants were identified by reception staff when the child presented for their GP appointment, by staff checking the child's age in the patient record. Reception staff offered the child's parent/caregiver information on the study in the form of a study flyer. Clinics also had study posters with the same information on display. Parents/caregivers who were interested in participating in the study were asked to complete the participant information and consent form and demographic questions on the study iPad or via their own mobile device, with those in the ASP group also completing developmental screening questionnaires. Once the parent/caregiver completed the developmental screening questionnaires and submitted the response using the weblink, the GP received the results via email (NSW) or via the integrated Salesforce platform (Victoria) so that this information was available to the GP at the point of care during the consultation.

Table 1 summarises clinical and behavioural measures and assessments for both ASP and SaU pathways. Measures were taken at various points in the trial to allow appropriate comparisons between the groups (see Figure 1 and Table 1). Client-facing documents (participant information sheet, consent form, and screening questionnaires) were translated into Arabic, Chinese (Mandarin), and Vietnamese, which were the most common languages spoken by culturally and linguistically diverse (CALD) families in our study locations and were available as a web-link on the study iPad.

Measures

Autism Surveillance Protocol (ASP) pathway

The parent/caregiver completed developmental surveillance instruments were:

- **'Learn The Signs Act Early' (LTSAE)** developmental checks as recommended by the Centre for Disease Control (Centres for Disease Control and Prevention, n.d.) are used to monitor children's early development in the domains of social and emotional, language/communication, cognitive (learning, thinking, problem-solving), and movement/physical development. These developmental milestone checklists are available for children aged two months to five years, and the checklists for 18- to 23-

months and 24- to 29-months were included in this study. The aim of the LTSAE used by NSW Health as part of the developmental surveillance program is to engage families and encourage parents/caregivers and health service providers to learn/monitor the signs of healthy development.

Table 1: Study tools

<table>
<tr><th>Time Points</th><th>Age in months</th><th>Location</th><th colspan="4">Groups and Tools</th></tr>
<tr><td>1</td><td>18-24</td><td rowspan="5">Waiting room</td><td colspan="2">Autism Surveillance Protocol</td><td colspan="2">Surveillance as Usual</td></tr>
<tr><td rowspan="4"></td><td rowspan="4"></td><td colspan="2">Service data</td><td colspan="2">Service data</td></tr>
<tr><td colspan="2">Consent</td><td colspan="2">Consent</td></tr>
<tr><td colspan="2">Demographics</td><td colspan="2">Demographics</td></tr>
<tr><td colspan="2">LTSAE; PEDS</td><td colspan="2" rowspan="2"></td></tr>
<tr><td colspan="2">Q-CHAT-10</td></tr>
<tr><td rowspan="2">Doctor’s office</td><td colspan="2" rowspan="2">SACS Online
(GP completes)</td><td colspan="2" rowspan="2">Brief online checklist to inform research team of ‘high likelihood’ of autism, type of concern, screening method used, and referrals and recommendation provided</td></tr>
<tr><td>Developmental concerns (any)</td><td>No concerns</td></tr>
<tr><td></td><td></td><td>Waiting room</td><td>ASQ:SE
(option to complete at home)</td><td>-</td><td colspan="2">-</td></tr>
<tr><td></td><td></td><td></td><td>High likelihood of autism</td><td>Low likelihood
10% complete</td><td>High likelihood of autism</td><td>Low likelihood
10% complete</td></tr>
<tr><td>2</td><td>24</td><td>Research site</td><td>Demographics
ADOS-2
ADI-R
MSEL
SEQ
VABS-3</td><td>Demographics
ADOS-2
ADI-R
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ADOS-2
ADI-R
MSEL
SEQ
VABS-3</td></tr>
<tr><td>3</td><td>30</td><td>Online</td><td>SRS-2
Semi-structured questionnaire</td><td>SRS-2
Semi-structured questionnaire</td><td>SRS-2
Semi-structured questionnaire</td><td>SRS-2
Semi-structured questionnaire</td></tr>
</table>

Abbreviations: ADOS-2, Autism Diagnostic Observation Schedule Second Edition; ADI-R, Autism Diagnostic Interview-Revised; ASQ:SE, Ages and Stages Questionnaire: Social-Emotional; LTSAE, Learn the Signs Act Early; MSEL, Mullen Scales of Early Learning; PEDS, Parents’ Evaluation of Developmental Status; Q-CHAT-10: Quantitative Checklist for Autism in Toddlers – 10 item; SACS-Online: Social Attention and Communication Surveillance – online; SEQ: Sensory Experiences Questionnaire - short form; SRS-2: Social Responsiveness Scale, Second edition; VABS-3: Vineland Adaptive Behaviour Scale 3rd Edition.

- **Parents' Evaluation of Developmental Status (PEDS)** is designed for children from birth to eight years of age and consists of 10 questions asking parents/caregivers about concerns they have in domains including global/cognitive, expressive language and articulation, receptive language, fine and gross motor, behaviour, self-help, socialisation, and academic (Glascoe, 2013). It is widely used in Australia and is the first-line developmental surveillance tool used in state-based programs in most states in Australia and internationally. Screening test characteristics are over 70% for sensitivity and specificity for developmental differences.

- **Quantitative Checklist for Autism in Toddlers-10 item (Q-CHAT-10)** is an autism-specific 10-item tool to aid the decision making for primary care professionals about whether to refer a child for a full diagnostic assessment for ASD. The ten most accurate items from the original Quantitative Checklist for Autism in Toddlers (Q-CHAT; Allison et al., 2008) were identified and included in this shortened version. Using a cut-off point of three, the Q-CHAT-10 has sensitivity of 0.91, specificity of 0.89, positive predictive value (PPV) of 0.58, and internal consistency of 0.85, when used in a clinical population; its utility when used in community-based samples has not been reported (Allison et al., 2012).

- **Ages and Stages Questionnaire: Social-Emotional (ASQ:SE)** is a screening tool focusing on the social and emotional behaviour of children aged 6- to 60-months (Squires et al., 2001). This study used the 18- and 24-month questionnaires. Parents are asked a series of questions regarding their child's self-regulation, communication, autonomy, compliance, adaptive functioning, affect, and interaction with people. The ASQ (Squires et al., 1997) and the ASQ:SE have sound psychometric properties and are the recommended developmental surveillance and health monitoring program in all Australian states with the exception of Victoria, where the Brigance Screens (Department of Health, 2013) is used in its place for identification of developmental problems. ASQ:SE has good reliability as a developmental screener globally with Cronbach's alpha of 0.79 for the total score and 0.61 to 0.74 for all the domains indicating acceptable reliability (Kerstjens et al., 2009).

The GP/PN completed the autism developmental surveillance instrument:

- **Social Attention and Communication Surveillance-Online (SACS Online)** is an online version of the SACS-R, which is a professional observational tool intended for use in 11- to 30-month-old children (Barbaro & Dissanayake, 2010; Barbaro & Dissanayake, 2013; Barbaro et al., 2011; Mozolic-Staunton et al., 2020), with the 18-month and 24-month versions used for this study. Originally designed for use by maternal and child health nurses it is also suitable for use by other primary health professionals. The tool consists of five 'key' behavioural items per age group plus additional items, with professionals asked to note whether the child is displaying typical or atypical behaviour for each item. Where a child is noted to have atypical behaviour for three of the five 'key' items, it is recommended that they be referred for further assessment. Study results have indicated that the SACS tool and its revised version have high sensitivity (82-84%), specificity (99-99.8%), PPV for autism (81-83%; and 100% for *any* language/developmental delay or condition), and negative predictive value (99%), making it highly suitable for use in primary- and community-health and early childhood settings (Barbaro & Dissanayake, 2010; Mozolic-Staunton et al., 2020). In the current study, GPs and PNs were provided with access to the training modules and resources in the use of the SACS Online tool via their online study portal, which they completed during their consultations with participating children.

Surveillance as Usual (SaU) pathway

GPs and PNs used a standard template to log the methods and tools used by the GP to assess children's likelihood of an autism diagnosis. This included details such as what developmental differences were raised and by whom, the assessment(s) completed (if any), the reason for the assessment, the GP's findings, and any referrals and/or recommendations made.

Procedures

Autism Surveillance Protocol (ASP) pathway

Parents/caregivers in the ASP pathway completed electronic versions of a participant information and consent form, a brief demographic questionnaire, in addition to the LTSAE, PEDS, and Q-CHAT-10 while in the GP clinic waiting room. In NSW, parents/caregivers used the Watch Me Grow weblink (Kohlhoff et al., in press) to complete the instruments, with

REDCap (NSW) and Salesforce (Victoria) platforms used to manage the completion of these forms and questionnaires. An embedded algorithm in the WMG weblink and Salesforce platforms scored the parent/caregiver responses to identify children with developmental differences and/or 'high likelihood' for autism. This information from the parent/caregiver assessments was either available instantly in the online system (Victoria) or was emailed automatically to the child's GP (NSW). During the consultation, the GP (or PN) also completed the SACS Online assessment, using the Salesforce platform (both NSW and Victoria sites). The ASQ:SE was completed by parents/caregivers of children identified as having any developmental differences or 'high likelihood' of an autism diagnosis following completion of the LTSAE, PEDS, Q-CHAT-10, and/or SACS Online.

Children were determined as having a 'high likelihood' of an autism diagnosis if they are identified as:

a) 'high likelihood' for autism by either the Q-CHAT-10 *or* the SACS Online assessment (regardless of the outcome of the other tools); or
b) 'high likelihood' for developmental issues by LTSAE and/or PEDS *and* ASQ:SE (but were found at 'low likelihood' for autism by Q-CHAT-10 and SACS Online).

Surveillance as Usual (SaU) pathway

Parents/caregivers of children in the SaU arm completed electronic versions of the participant information and consent form and a brief demographic questionnaire. GPs (or PNs) recorded any developmental screening method(s) used during the consultation using the standard template and the child's developmental status (i.e., 'high likelihood' of autism).

Note: Due to COVID-19 restrictions[1] there was a reduction in the number of families attending face-to-face GP appointments. Therefore, from mid-October 2020, the following options were made available for completion of the clinician component (ASP: SACS Online; SaU: as per GP/PN usual practice):

a) 'Face-to-face' – Children attending a face-to-face GP appointment could have the

[1] The worldwide 2019 novel coronavirus (COVID-19) pandemic led to the introduction of stay-at-home 'lockdown' public health orders in Victoria on 24 March 2020 and NSW on 31 March 2020. These orders saw a decrease in the number of people attending face-to-face general practice appointments and an increase in the use of telehealth, particularly in Victoria. While these restrictions were eased in NSW on 1 May 2020 and in Victoria on 26 May 2020, there have since been several instances of varying levels of restrictions being reinstated in both states.

clinician component completed during their appointment

b) 'Mixed' – Children attending a face-to-face GP appointment could have the clinician component completed via a telehealth appointment following their face-to-face appointment

c) 'Telehealth': children attending a telehealth GP appointment could have the component completed during this appointment.

GPs in the ASP arm (NSW and VIC) were trained to administer SACS assessments via telehealth. In Victoria, parents were also emailed questionnaires once the GP entered their details in Salesforce, allowing parents to complete questionnaires from their home devices.

Phase 2 – 24-month assessment protocol

Measures

The following measures were used as part of the 'gold standard' assessment by the research team of children found to have a 'high likelihood' of an autism diagnosis and the 10% of negative screens:

- Autism traits:
    - **Autism Diagnostic Observation Schedule-Second Edition** (ADOS-2; Lord, 2012) will be used to confirm a diagnosis of autism. The ADOS-2 is a semi-structured, standardised diagnostic observational assessment of social interaction, communication, play, and imaginative use of material for individuals suspected of being on the autism spectrum. The ADOS-2 module administered by the trained researcher is determined by the child's age and expressive language ability. The Toddler Module is for children aged between 12- and 30-months and was therefore administered in this study (Esler et al., 2015; Luyster et al., 2009).

    - **Autism Diagnostic Interview-Revised** (ADI-R; Lord et al., 1994) is a diagnostic, semi-structured, extended parental/caregiver interview including 93 items assessing reciprocal social interaction, communication, play, and repetitive, restricted, and sensory behaviours and interests. Test-retest and inter-rater agreement (intra-class correlations ≥ .92), and discriminant validity between autistic and non-autistic individuals for each of the domains are all

excellent (Lord et al., 1994).

- Developmental skills:
    - **Mullen Scales of Early Learning** (MSEL; Mullen, 1995) is a standardised measure of non-verbal and verbal development in children from birth through to 68 months of age. The MSEL consist of five subscales: gross motor, fine motor, visual reception, receptive language, and expressive language. For each domain, raw scores and corresponding age equivalence scores are recorded. The gross motor scale will not be utilized in this study. The MSEL has excellent test-retest and inter-scorer reliability for children aged ≤ 24 months ($r \geq .82$; Mullen, 1995).

- Child behaviour:
    - **Vineland Adaptive Behavior Scales, third edition** (VABS-3; Sparrow et al., 2016), a parent/caregiver completed questionnaire, was used to assess adaptive/functional skill development. It provides a measure of adaptive behaviour in four broad domains of communication, daily living skills, socialisation, and motor skills. The VABS-3 has sound psychometric properties with internal consistency of 0.90 to 0.98, test-retest reliability of 0.80 to 0.92 and inter-rater reliability of 0.79 (Hill et al., 2017).

    - **Sensory Experiences Questionnaire - short form** (SEQ; Baranek et al., 2006) is a parent/caregiver completed questionnaire with good internal consistency ($\alpha = 0.80$; Baranek et al., 2006) and excellent test-retest reliability (intra-class correlation = 0.92; Little et al., 2011).

Procedure

Parents/caregivers of children in both the ASP and SaU pathways who were identified as having a 'high likelihood' of an autism diagnosis by their GP between 18- and 24-months of age were invited by the research team to complete a developmental assessment when the child was aged approximately 24-months. Additionally, a randomly selected 10% of screen negatives from both pathways were also invited to complete this same assessment. The assessments were undertaken by trained researchers who have achieved research-reliable coding on the ADOS-2 and ADI-R, as well as having trained on the other included measures. Parents/caregivers also completed a more detailed general and demographic questionnaire in addition to the abovementioned assessments. The ADOS-2 and ADI-R

scores, together with the developmental assessment and clinical judgement were used to determine whether the child meets a Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) diagnosis of ASD. Assessments were completed by the research team at the University campuses or community centres.

Note: Where COVID-19 restrictions or parental/caregiver concerns prevented administration of the face-to-face child measures (ADOS, MSEL, and SEQ) at 24 months, only the parent/caregiver measures were administered remotely (via phone/Zoom for ADI-R and online/mail for the VABS-3). When COVID-19 restrictions were eased sufficiently to allow completion of face-to-face assessments, families who were only able to complete the parent/caregiver measures remotely were then invited to complete the child measures.

Phase 3 – 30-month assessment protocol

Parents/caregivers of all children recruited to both the ASP and SaU pathways of the study completed the preschool version of the Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012; Duku et al., 2013) when their child was approximately 30 months of age. The SRS-2 is an autism screening tool that asks parents/caregivers to rate their child's traits of autism, as seen in a naturalistic setting, on a quantitative scale. The total score provides an indication of the extent of social differences. The SRS-2 has good internal consistency ($\alpha = .93$) and good test-retest reliability in pre-schoolers (intra-class correlation = 0.74; Duku et al., 2013; Pine et al., 2006).

Parents/caregivers of children identified with a developmental condition from both arms also completed a semi-structured questionnaire to evaluate the uptake of recommendations, experience of assessment/service use, disability supports and services received, and parental satisfaction with the health and disability services. This was to facilitate comparison between those in the ASP arm who received the assessments and recommendations using the National Guideline and those in the SaU pathway who received routine care.

Phase 3a: Methodology as of January 2021

Due to the impacts of the COVID-19 pandemic on the study, from January 2021 the study team placed greater focus on the qualitative component, with analysis of quantitative data already collected conducted, where possible. Child recruitment to the study ceased as of 23 April 2021, with any further 24- and 30-month assessments due to be completed still fulfilled. Additional questions (including qualitative and quantitative items) regarding parent/caregiver experiences with having their child monitored as part of the study were added to the 30-

month assessment for all participants who had not yet completed the 30-month assessment. The amended qualitative component of the study is described below.

GPs and PNs who participated in the study and parents/caregivers of children recruited to the study were invited to participate in a semi-structured interview. The interviews aimed to understanding the feasibility of conducting a developmental surveillance program within the general practice setting; understanding the associated challenges, enablers, and solutions to the process of conducting childhood developmental surveillance; and pathways to early supports and services access when a developmental concern is identified.

A total of 22 GPs (12 in Victoria, 10 in NSW) and 12 parents/caregivers (6 each in NSW and Victoria), evenly spread between the study arms, participated in this qualitative evaluation study. Note that while PNs were invited to participate in the interview, none were recruited. Each interview took approximately 30 minutes, with interview data analysed and coded using a grounded theory of inductive thematic approach (Braun & Clarke, 2006) via NVivo 12 software (QSR International, 2020). Rather than generating or building upon existing theoretical directions, the focus of this approach meant that data was examined afresh to consider and develop possibilities elided by the dominant theoretical paradigm. Three researchers coded the data independently, with inter-rater reliability of 95.1% and 90.7% for parents/caregivers' data and general practitioners' data, respectively, with reliability calculated based on methods reported by McAlister et al. (June, 2017).

Interview schedules

Parents/caregivers

The interviews comprised of questions/prompts posed to parents/caregivers of children in the SaU and ASP pathways about:

1) accessing child developmental screening through GPs,
2) their general views on child developmental checks, and
3) 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 tools and procedures relating to the study.

See for the general parent/caregiver interview questions and prompts/follow-up questions.

Table 2. General interview questions and prompts for parent cohort

Main questions for parents/caregivers	Prompt or follow-up questions
Can you please tell me about your general experience when attending the GP practice with your child?	Do you usually see the same GP? Has your GP built a relationship with you and your child? What are some of the reasons why your child sees your GP? Do you prefer telehealth appointments for your child as opposed to visiting the GP clinic? Why?
Did the COVID-19 pandemic and lockdowns impact how often you and your child attended appointments with your GP?	Did you use telehealth appointments?
Has [child name] had a developmental check before? If so, who did it and why?	How old was [child name] when they had this check? What was the outcome of the check?
Before this appointment with your GP, did you have any concerns about [child name]'s development?	N/A
Can you please tell me about your experience of going through the developmental check with your GP?	Did the GP explain the process and what they were screening for? What did the GP do during the developmental check? How long did the developmental check take? What did the GP say after completing the check? How did you feel after [child name]'s developmental check?
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.	What was the developmental concern identified? Were you given any referral information or resources? What were the next steps? How much follow up was there from your GP in this process? Did this meet your needs? Were there any barriers that got in your way at this time? Have you applied to the NDIS ECEI for [child name]? What services have been accessed by [child name] since the developmental check by the GP that identified concerns?
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 GP practice, are there any improvements that could be introduced?	What did the GP do well? What could be done differently? What advice do you have for GPs doing these checks with young children? Do you think your GP is well equipped to carry out this screening?
Would you recommend others to have a GP developmental check for their child? Why/why not?	N/A

Main questions for parents/caregivers	Prompt or follow-up questions
Do you think developmental checks should be conducted by GP during their regular appointments? Why/ Why not?	N/A
What are your thoughts and experiences regarding early intervention for children who are identified as having developmental concerns?	N/A
Is there anything I have not asked about that you would like to regarding your experience of the child developmental checks at the GP practice?	N/A

General practitioner/ Practice nurses

The main interview outcomes of GP/PN interviews from both study arms were to:

1) identify perceptions, barriers and solutions for GPs when conducting childhood developmental surveillance within the General Practice setting
2) identify practice systems that need to be put in place so that these childhood developmental surveillance activities can be widely adopted in general practice
3) investigate how practitioners perceive their role in providing ongoing care for children with developmental conditions or disabilities.

For GPs in the ASP pathway, additional questions/prompts regarding their experiences with the study tools and procedure were also included. See Table 3 for GP interview questions/prompts.

Table 3. Main interview questions and prompts for GP cohort

Main questions for GPs	Prompt or follow-up questions
Describe your experience of conducting childhood developmental screening/surveillance (DS) in your practice.	Can you give me an example or some examples when you have screened the child and tell me how that worked out? When do you conduct this screening? When are you more likely to conduct screening? Is this something you do routinely, if not why? How do you conduct this screening? E.g., what tools do you use, how much time, other factors, etc. How do you work with the Practice Nurse (PN) or other staff at your practice when conducting DS? How do you work with other health practitioners such as Child and Family Health Nurses (CFHNs), speech pathologists, Paediatricians when conducting DS and how accessible are they?

Main questions for GPs	Prompt or follow-up questions
	How do you see your role in conducting DS?
Describe what other factors may assist you to conduct DS in your practice?	Is there anything practical or structural support that you require to conduct DS in your current practice? Can you suggest what is needed to help GPs/PNs to implement/adopt DS routinely in general practice?
What barriers did the COVID pandemic and associated changes pose on conducting DS at your practice? **Were there any specific enablers that you found helpful in conducting DS?**	Can you give me an example of what made it difficult to conduct DS that was specifically linked to the pandemic? How about any changes linked to the pandemic that made it easier for you to conduct DS (e.g. access to Medicare billing for telehealth)?
Describe your experience in managing children whom you (or their parents) identified as having a specific developmental concern.	Can you give me an example and describe how you went with this child and who was involved? Do you conduct further assessment in your current practice? Do you conduct this assessment yourself and if not why? And if you refer, to whom or what service? How do you work with other staff (e.g., PNs) within your practice or with other health professionals outside your practice in these situations?
How do you perceive your role in Early Intervention (EI) for child developmental issues? ***FYI The National Disability Insurance Scheme (NDIS) has made available early childhood early intervention (ECEI) services for children aged under seven years of age with a developmental delay or disability.***	Is there anything practical or structural that you require to implement EI in your current practice? Can you suggest what is needed to help GPs or PNs to implement/adopt EI routinely in general practice?
Overall, can you describe your role (GP or PN) in providing ongoing care for CWDD within your practice? In particular, we are interested in how you see the extent of your involvement after the children are referred to other services e.g., specialist paediatric or others.	What is currently your experience with CWDD who attend these services? Can you please give an example of this? Is there anything practical or structural within your practice currently that can assist you in providing child developmental surveillance and ongoing care for children with developmental concerns? How would you like to be involved in the care of children with developmental conditions such as autism? Can you suggest what is needed to help GPs (and PNs) to play an ongoing role in the care of children with developmental conditions in general practice?
Additional questions for GPs in the ASP pathway to obtain views on their experiences with the study tools and procedures.	
Can you describe your experience of participating in the ASP subgroup of this study?	N/A
Were there any issues; what suggestions do you have to address this to resolve this?	N/A

Main questions for GPs	Prompt or follow-up questions
What were your experiences like with completing the SACS Online assessment with children?	Were there any particular barriers or enablers for completing the SACS Online assessment?
What were your experiences like with the parent/caregiver questionnaires – the Q-CHAT-10, 'Learn the Signs. Act Early', and the PEDS?	Did you notice any positive or negatives for parents in completing these questionnaires? Were there any particular barriers or enablers for *yourself* relating to these tools?
What are your thoughts on using these clinician and parent-completed tools in the future for conducting childhood developmental screening?	N/A
Anything else to add?	N/A

Note: DS, developmental screening/surveillance; GP, general practitioner; PN, practice nurse.

Data management

Data was stored and managed at both sites using two applications – REDCap (Research Electronic Data CAPture; Harris et al., 2019; Harris et al., 2009) and Salesforce (Manna, 2018).

REDCap is a secure, web-based software platform designed to support data capture for research studies, providing: 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. REDCap servers are located within Australia, thereby ensuring participant data is governed by Australian laws.

Salesforce is a highly secure cloud-based software application designed to store and manage customer data. Salesforce is compliant with GDPR and Australian Data Privacy laws. It uses industry-accepted encryption products to protect customer data and communications during transmissions between La Trobe University network and the Covered Services, including through Transport Layer Encryption (TLS) leveraging at least 2048-bit RSA server certificates and 128-bit symmetric encryption keys.

Access to the data was restricted to members of the study team, with different levels of access for different members. If families requested to complete questionnaires by hard copy, then copies of the questionnaires were sent to the family, with item level responses and summary and total scores entered in REDCap/Salesforce by the research team.

Data generated at the NSW site was managed using REDCap and data generated at VIC site was managed using Salesforce. Data generated from ASQ-SE is stored within the ASQ platform and extracted only for the purposes of analysis. Access to this data is restricted to certain members of the team.

Reports and other information (such as GP consent forms, etc.) are stored in a local secure research drive with restricted access to the clinicians and members of the research team.

4. Results

Phase 1

A total of 122 children were recruited to the study, with 82 in the ASP pathway and 40 in the SaU pathway. Slightly more males were recruited in both pathways, with 58.5% (*n* = 48) in ASP and 60.0% (*n* = 24) in SaU, with a mean age of ~20 months (ASP: 20.1 months; SaU: 19.6 months). While similar proportions of children in both pathways were born full term (ASP: *n* = 75, 91.5%; SaU: *n* = 37, 92.5%), double the proportion of children in the SaU pathway were born via IVF (ASP: *n* = 4, 4.9%; SaU: *n* = 4, 10.0%).

Most children were born in Australia (ASP: *n* = 78, 98.7%; SaU: *n* = 36, 97.3%) and while most spoke only English at home, more children in the SaU pathway did so (ASP: *n* = 59, 72.0%; SaU: *n* = 36, 90.0%). Around half of the children were reported to have Australian ethnicity (ASP: *n* = 42, 51.2%; SaU: *n* = 20; 50.0%), with 15.9% (*n* = 13) of ASP children and 15.0% (*n* = 6) of SaU children reported to have mixed ethnicity. A greater proportion of children in the SaU pathway were Aboriginal (*n* = 2, 5.0%) in comparison to the ASP pathway (*n* = 1; 1.2%). Table 4 displays the demographic details for the children recruited to the study.

Table 4: Child demographics

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 26	*n* = 15	*n* =56	*n* = 25	*n* = 82	*n* = 40
Gender, *n* (%)						
Female	12 (46.2)	6 (40.0)	22 (39.3)	10 (40.0)	34 (41.5)	16 (40.0)
Male	14 (53.8)	9 (60.0)	34 (60.7)	15 (60.0)	48 (58.5)	24 (60.0)
Age in months, mean (*SD*)	21.4 (2.3)	20.5 (2.2)	19.5 (2.1)	19.1 (1.2)	20.1 (2.4)	19.6 (1.8)
Born full term, *n* (%)	24 (92.3)	14 (93.3)	51 (91.1)	23 (92.0)	75 (91.5)	37 (92.5)
Born via IVF, *n* (%)	1 (4.5)	1 (9.1)	3 (5.6)	3 (12.5)	4 (4.9)	4 (10.0)
Country of birth, *n* (%)						
Australia	23 (100)	11 (91.7)	55 (98.2)	25 (100)	78 (98.7)	36 (97.3)
Singapore	-	1 (8.3)	-	-	-	1 (2.70)
Vietnam	-	-	1 (1.8)	-	1 (1.3)	-
Main language spoken at home, *n* (%)						
English only	25 (96.2)	13 (86.7)	34 (60.7)	23 (92.0)	59 (72.0)	36 (90.0)
English and Spanish equally	-	1 (6.3)	-	-	-	1 (2.5)
English and Khmer equally	-	-	1 (1.8)	-	1 (1.2)	-
English and Vietnamese equally	-	-	1 (1.8)	-	1 (1.2)	-
Cantonese	-	-	1 (1.8)	-	1 (1.2)	-
Croatian	-	-	1 (1.8)	-	1 (1.2)	-
Greek	-	-	1 (1.8)	-	1 (1.2)	-
Gujarati	1 (3.8)	-	-	-	1 (1.2)	-
Khmer	-	-	1 (1.8)	-	1 (1.2)	-
Spanish	-	1 (6.7)	5 (8.9)	-	5 (6.1)	1 (2.5)
Urdu	-	-	1 (1.8)	-	1 (1.2)	-
Vietnamese	-	-	10 (17.9)	-	10 (12.2)	-
Ethnicity, *n* (%)[a]						
Australian	22 (100.0)	6 (54.5)	20 (35.7)	14 (56.0)	42 (51.2)	20 (50.0)
Aboriginal	-	-	1 (1.8)	2 (8.0)	1 (1.2)	2 (5.0)
Torres Strait Islander	-	-	-	-	-	-
Arabic	-	-	2 (3.6)	-	2 (2.44)	-
'Asian'	1 (4.5)	-	-	-	1 (1.22)	-
Akan	-	1 (9.1)	-	-	-	1 (2.5)

	Victoria		NSW		Total	
Burmese	-	1 (9.1)	-	-	-	1 (2.5)
Chilean	-	-	1 (1.8)	-	1 (1.22)	-
Chinese	-	1 (9.1)	1 (1.8)	-	1 (1.22)	1 (2.5)
Colombian	-	1 (9.1)	-	-	-	1 (2.5)
Indian	-	-	1 (1.8)	-	1 (1.22)	-
Irish	-	-	-	1 (4.0)	-	1 (2.5)
Italian	-	1 (9.1)	-	-	-	1 (2.5)
Mongolian	-	1 (9.1)	-	-	-	1 (2.5)
Pakistan	-	-	1 (1.8)	-	1 (1.22)	-
Peruvian	-	-	2 (3.8)	-	2 (2.44)	-
Polish	-	-	-	1 (4.0)	-	1 (2.5)
Russian	-	1 (9.1)	-	-	-	1 (2.5)
Serbian	-	1 (9.1)	-	-	-	1 (2.5)
'South American'	-	-	1 (1.8)	-	1 (1.22)	-
Spanish	-	-	1 (1.8)	-	1 (1.22)	-
Vietnamese	-	-	13 (23.2)	1 (4.0)	12 (14.6)	1 (2.5)
Not specified	-	-	-	1 (4.0)	-	1 (2.5)
Do not wish to answer	-	-	-	1 (4.0)	-	1 (2.5)
Mixed ethnicities	1 (4.5)	2 (18.2)	12 (21.4)	4 (16.0)	13 (15.9)	6 (15.0)

Notes: ASP, Autism Surveillance Protocol; IVF, Invitro fertilisation; SaU, Surveillance as Usual. Data was not provided for all participants, where this has occurred valid percentages are presented.
[a] Parents/caregivers were able to choose multiple options, thus percentages do not add to 100.

Most parents/caregivers who consented in the general practice clinic for their child to participate in the study and completed the questionnaire(s) were female (ASP: *n* = 60, 73.2%; SaU: *n* = 37, 92.5%) and the child's mother (ASP: *n* = 60, 73.2%; SaU: *n* = 36, 90.0%), though this was to a greater extent in the SaU pathway than the ASP. While most parents/caregivers were born in Australia, there was a higher proportion in the SaU pathway (*n* = 32, 80.0%) compared to the ASP pathway (*n* = 56, 68.3%). Note that in order to reduce the length of time needed to complete the questionnaires in the clinic, brief demographic information was collected only on the parent/caregiver who completed the consent form and questionnaire(s) at the GP appointment. The demographics for parent/caregiver of children recruited to the study is contained in Table 5.

Table 5: Demographics of parent/caregiver who completed study consent and questionnaire(s)

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 26	*n* = 15	*n* = 56	*n* = 25	*n* = 82	*n* = 40
Gender, *n* (%)						
Female	21 (80.8)	14 (93.3)	39 (68.4)	23 (92)	60 (73.2)	37 (92.5)
Male	4 (15.4)	1 (6.7)	17 (30.4)	2 (8)	21 (25.6)	3 (7.5)
Other	-	-	-	-	-	-
Age in years, mean (*SD*)	33.2 (5.2)	37.38 (3.99)	35.2 (6.8)	35.57 (6.46)	34.7 (6.4)	36.1 (5.9)
Relationship to child, *n* (%)						
Mother	22 (84.6)	13 (86.7)	38 (67.9)	23 (92)	60 (73.2)	36 (90.0)
Father	4 (15.4)	2 (113.3)	17 (30.4)	1 (4)	21 (25.6)	3 (7.5)
Grandmother	-	-	-	1 (4)	-	1 (2.5)
Carer	-	-	1 (1.8)	-	1 (1.2)	-
Country of birth, *n* (%)						
Australia	23 (88.5)	12 (80.0)	33 (58.9)	20 (80)	56 (68.3)	32 (80.0)
Cambodia	-	-	2(3.6)	-	2 (2.4)	-
Chile	-	-	1 (1.8)	-	1 (1.2)	-
Colombia	-	1 (6.7)	-	-	-	1 (2.5)
France	-	-	-	1 (4)	-	1 (2.5)
Ghana	-	1 (6.7)	-	-	-	1 (2.5)
Hong Kong	-	1 (6.7)	-	-	-	1 (2.5)
India	1 (3.8)	-	-	-	1 (1.2)	-
Indonesia	1 (3.8)	-	-	-	1 (1.2)	-
Iran	-	-	1 (1.8)	-	1 (1.2)	-
Ireland	-	-	-	1 (4)	-	1 (2.5)
Korea	1 (3.8)	-	-	-	1 (1.2)	-
Lebanon	-	-	1 (1.8)	-	1 (1.2)	-
Malaysia	-	-	1 (1.8)	-	1 (1.2)	-
Mauritius	-	-	1 (1.8)	-	1 (1.2)	-
Pakistan	-	-	1 (1.8)	-	1 (1.2)	-
Peru	-	-	2 (3.6)	-	2 (2.4)	-
Poland	-	-	-	1 (4)	-	1 (2.5)
Scotland	-	-	1 (1.8)	-	1 (1.2)	-

	Victoria		NSW		Total	
Switzerland	-	-	-	1 (4)	-	1 (2.5)
Taiwan	-	-	1 (1.8)	-	1 (1.2)	-
Timor	-	-	1 (1.8)	-	1 (1.2)	-
Uruguay	-	-	1 (1.8)	-	1 (1.2)	-
Vietnam	-	-	9 (16.1)	1 (4)	9 (11.0)	1 (2.5)

Notes: ASP, Autism Surveillance Pathway; IVF, Invitro fertilisation; SaU, Surveillance as Usual. Data was not provided for all participants, where this has occurred valid percentages are presented.

[a] Parents/caregivers were able to choose multiple options, thus percentages do not add to 100.

Overall, 81.7% (*n* = 67) of children in the ASP group had the SACS Online assessment completed by their GP/PN. Most parents/caregivers completed the PEDS (*n* = 75, 91.5%), Q-CHAT-10 (*n* = 75, 91.5%), and LTSAE (*n* = 76, 92.7%). State differences were noted in the tool results. For the SACS Online, 3 children (6.5%) in NSW had a 'high likelihood' of an autism diagnosis result, with none in Victoria. This is expected given that there were only 26 children recruited in the ASP pathway in Victoria and we would not have expected any to be identified as having developmental differences indicative of high likelihood of an autism diagnosis. Similarly, there were no children in Victoria with 'some concerns' on Q-CHAT-10, compared to 18.5% (*n* = 10) in NSW. Three children (13.0%) in Victoria were identified with 'some concerns' with LTSAE, with 23 (43.4%) identified in NSW. Of the children whose parents/caregivers were invited to complete the ASQ:SE, only one did so in Victoria and 33 in NSW. The completion of tools in the ASP pathway by GPs/PNs and parents/caregivers is displayed in Table 6.

Table 6: Autism Surveillance Protocol Pathway tool usage and outcomes.

	Victoria *n* = 26	NSW *n* = 56	Total *n* = 82
GP/PN completed tool			
SACS assessment completed, *n* (%)	21 (80.7)	46 (82.1)	67 (81.7)
SACS results, *n* (% of completed)			
'Low likelihood'	21 (100.0)	43 (93.5)	64 (95.5)
'High likelihood'	-	3 (6.5)	3 (4.5)
Parent/caregiver completed tools			
PEDS completed, *n* (%)	20 (76.9)	55 (98.2)	75 (91.5)
Q-CHAT-10 completed, *n* (%)	21 (80.8)	54 (96.4)	75 (91.5)
Q-CHAT-10 results, *n* (% of completed)			
'No concerns'	21 (100.0)	44 (81.5)	65 (86.7)
'Some concerns'	-	10 (18.5)	10 (13.3)
LTSAE completed, *n* (%)	23 (88.5)	53 (94.6)	76 (92.7)

	Victoria *n* = 26	NSW *n* = 56	Total *n* = 82
LTSAE results, *n* (% of completed)			
'No concerns'	20 (87.0)	30 (56.6)	50 (65.8)
'Some concerns'	3 (13.0)	23 (43.4)	26 (34.2)
ASQ:SE completed, *n* (%)	1 (3.8)	33 (58.9)	34 (41.5)
ASQ:SE results, *n* (% of completed)			
'Below cut-off'	1 (100)	19 (57.56	20 (57.1)
'Monitoring'	-	4 (12.1)	4 (11.8)
'Above cut-off'	-	10 (30.3)	10 (29.4)

Notes: ASQ:SE, Ages and Stages Questionnaire: Social-Emotional; GP, general practitioner; LTSAE, Learn the Signs. Act Early; PEDS, Parents' Evaluation of Developmental Status; PN, practice nurse; Q-CHAT-10, Quantitative Checklist for Autism in Toddlers-10 item; SACS, Social Attention and Communication Surveillance. Data was not provided for all participants, where this has occurred valid percentages are presented.

Phase 2

Overall, 18 children were referred for a 24-month assessment from the ASP pathway (NSW: *n* = 18; VIC: *n* = 0) and 5 children from the SaU pathway (NSW: *n* = 2; VIC: *n* = 3). Of these, 2 children (both from SaU pathway) in Victoria completed the assessment and in NSW, 17 in ASP and 1 in SaU completed the assessment. Of the 17 participants in NSW in the ASP pathway, two children could not attend the face-to-face assessments. In terms of screen negatives, 5 children in NSW and 1 child in Victoria (all ASP) were contacted to complete the 24-month assessment. In NSW four children completed the full assessment and one completed a partial assessment (due to the lockdown); no children in Victoria completed the assessment.

Of the 17 children from the ASP pathway and 3 children from the SaU pathway who completed the 24-month assessment by the research team, most were male (ASP: *n* = 12, 70.6%; SaU: *n* = 2, 66.7%). Mean age at assessment was 26.5 months (*SD* = 1.8) in the ASP pathway and 26.8 months (*SD* = 0.8) in the SaU pathway. Most children were born full term (ASP: *n* = 16, 94.1%; SaU: *n* = 3, 100%) and none were born via IVF. Almost all children were born in Australia (ASP: *n* = 16, 94.1%; SaU: *n* = 3, 100%) with only English spoken at home for over half of children (ASP: *n* = 8, 47.1%; SaU: *n* = 2, 66.7%).

In terms of diagnostic outcomes for the ASP pathway, 3 children (25%) displayed signs of autism with language delay; 3 (25%) were on the autism spectrum with global developmental delay; 4 (33.3%) had language delay; and 1 child (7.7%) had no concerns –

this child was flagged at 'high likelihood' on PEDS plus ASQ:SE only, and not on any of the autism specific tools. A full 'gold standard' assessment was not able to be completed for 1 (8.3%) child in the ASP pathway due to COVID-19 lockdowns, as the components that require face-to-face assessment could not be completed; thus, no diagnostic outcome was available for this child. Two (66.7%) of the 3 children in the SaU pathway who completed a 24-month assessment by the research team were diagnosed with autism, with the remaining 1 (33.3%) child displaying signs of autism with language delay. The four screen negative children in the NSW ASP pathway who completed a 24-month assessment by the research team were found to have no concerns. An additional screen negative child from the NSW ASP pathway was unable to complete the 24 month assessment by the research team due to COVID-19 lockdowns, thus no diagnostic outcome was available for this child.

Table 7. Outcomes and demographics for children who completed a 24-month child assessment by the research team

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 0	*n* = 2	*n* = 17	*n* = 1	*n* = 17	*n* = 3
High likelihood, *n* (%)	-	2 (100.0)	12 (70.59)	1 (100.0)	12 (70.6)	3 (100.0)
Diagnostic outcome						
No concerns	-	-	1 (7.7)	-	1 (7.7)	-
ASD	-	2 (100.0)	-	-	-	2 (66.7)
Possible ASD + LD	-	-	3 (25)	1 (100.0)	3 (25)	1 (33.3)
ASD + GDD	-	-	3 (25)	-	3 (25)	-
LD	-	-	4 (33.33)	-	4 (33.33)	-
Incomplete assessment[a]	-	-	1(8.33)		1 (8.33)	
Screen negatives, *n* (%)	-	-	5 (29.41)	-	5 (29.41)	-
Diagnostic outcome						
No concerns	-	-	4 (80)	-	4 (80)	-
Incomplete assessment[a]	-	-	1 (20)	-	1 (20)	-
Gender, *n* (%)						
Female	-	1 (50.0)	5 (29.4)	-	5 (29.4)	1 (33.3)
Male	-	1 (50.0)	12 (70.6)	1 (100)	12 (70.6)	2 (66.7)
Age in months, mean (*SD*)	-	26.8 (1.1)	26.5 (1.8)	26.76 (-)[b]	26.5 (1.8)	26.8 (0.8)
Born full term, *n* (%)	-	2 (100.0)	16 (94.1)	1 (100)	16 (94.1)	3 (100.0)

	Victoria		NSW		Total	
	ASP *n* = 0	SaU *n* = 2	ASP *n* = 17	SaU *n* = 1	ASP *n* = 17	SaU *n* = 3
Born via IVF, *n* (%)	-	-	-	-	-	-
Country of birth, *n* (%)						
Australia	-	2 (100.0)	16 (94.1)	1 (100)	16 (94.1)	3 (100.0)
Vietnam	-	-	1 (5.9)	-	1 (5.9)	
Main language spoken at home, *n* (%)						
English only	-	2 (100)	8 (47.1)	-	8 (47.1)	2 (66.7)
English and 'other'	-	-	2 (11.8)	-	2 (11.8)	-
Croatian	-	-	1 (5.9)	-	1 (5.9)	-
Spanish	-	-	3 (17.7)	-	3 (17.7)	-
Vietnamese	-	-	3 (17.7)	-	3 (17.7)	-
Ethnic background, *n* (%)[c]						
Australian	-	1 (50.0)	4 (23.5)	-	4 (23.5)	1 (33.3)
Aboriginal	-	-	-	-	-	-
Torres Strait Islander	-	-	-	-	-	-
Chilean	-	-	1 (5.9)	-	1 (5.9)	-
Peruvian	-	-	1 (5.9)	-	1 (5.9)	-
Polish	-	-	-	1 (100)	-	1 (33.3)
South American	-	-	1 (5.9)	-	1 (5.9)	-
Vietnamese	-	-	3 (17.7)	-	3 (17.7)	-
Multiple ethnicity, *n* (%)	-	-	7 (41.2)	-	7 (41.2)	-
Child lives with, *n* (%)						
Both parents	-	-	14 (87.5)	1 (100)	14 (82.4)	1 (33.3)
Primary caregiver only	-	1 (50.0)	1 (6.3)	-	1 (5.9)	1 (33.3)
Do not wish to answer	-	1 (50.0)	-	-	2 (11.8)	1 (33.3)
Sibling with ASD, *n* (%)	-	-	1 (5.9)	-	1 (5.9)	-

Notes: ASD; autism spectrum disorder; ASP, Autism Surveillance Protocol; GDD, global developmental delay; IVF, Invitro fertilisation; LD, language delay; SaU, Surveillance as Usual. Data was not provided for all participants, where this has occurred valid percentages are presented.

[a] Due to the COVID-19 pandemic lockdowns, a full 'gold standard' assessment was not able to be completed for some children, as face-to-face assessments could not be completed.

[b] Due to only one participant in this group, SD was not able to be calculated.

[c] Parents/caregivers were able to choose multiple options, thus percentages do not add to 100.

Demographics for the mothers of children who underwent a 24-month assessment showed that the mean age was 34.3 years (*SD* = 3.6) for ASP and 33.6 years (*SD* = 0.6) for SaU. One-third were born in Australia (ASP: *n* = 5, 33.3%; SaU: *n* = 1, 33.3%), with varied ethnicities. While no mothers in the SaU pathway required an interpreter, almost a quarter in the ASP pathway (*n* = 4, 23.5%) did. In the ASP pathway, most mothers had completed a University degree (*n* = 9, 52.9%) and worked part-time (*n* = 6, 35.3%). In terms of occupation/profession, three (17.6%) mothers worked in administration and another three (17.6%) mothers held professional roles, with four (23.5%) mothers denoting 'other'. Education and employment was more varied in the SaU pathway, with an even spread between mothers completing some secondary education, TAFE, and a university degree (all *n* = 1, 33.3%), and also in terms of employment, with one (33.3%) mother working part-time, one (33.3%) mother retired/pensioner, and one mother not wishing to answer. No mothers in the SaU pathway wished to disclose their usual occupation/profession.

Due to the small number of participants in the SaU group and the frequent use of the "do not wish to answer" response or simply not providing a response regarding demographics of fathers in this group, only demographics for fathers in the ASP pathway will be discussed here. Fathers' mean age was 41.8 years (*SD* = 10.1) for the ASP pathway. A third of fathers in ASP were born in Australia (*n* = 6, 35.3%), with the most common ethnicities reported being Vietnamese at 29.4% (*n* = 5) and Australian at 23.5% (*n* = 4). Close to a third of fathers had completed a University degree (*n* = 5, 29.4%), 23.5% (*n* = 4) worked in a professional role, and most (*n* = 13, 76.5%) worked full-time.

Table 8. Demographics for parents/caregivers of children who completed a 24-month child assessment by the research team

	Victoria		NSW		Total	
	ASP *n* = 0	SaU *n* = 2	ASP *n* = 17	SaU *n* = 1	ASP *n* = 17	SaU *n* = 3
Mother						
Age in years, mean (*SD*)	-	34.16 (-)[a]	34.3 (3.6)	33.25 (-)[a]	34.3 (3.6)	33.7 (0.6)
Country of birth, *n* (%)						
Australia	-	1 (50)	5 (33.3)	-	5 (33.3)	1 (33.3)
Columbia	-	-	1 (6.7)	-	1 (6.7)	-
Croatia	-	-	1 (6.7)	-	1 (6.7)	-
Hong Kong	-	-	1 (6.7)	-	1 (6.7)	-

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 0	*n* = 2	*n* = 17	*n* = 1	*n* = 17	*n* = 3
Peru	-	-	1 (6.7)	-	1 (6.7)	-
Poland	-	-	-	1 (100)	-	1 (33.3)
Timor	-	-	1 (6.7)	-	1 (6.7)	-
Vietnam	-	-	3 (17.6)	-	3 (17.6)	-
New Zealand	-	1 (50)	-	-	-	-
Other	-	-	2 (13.3)	-	2 (13.3)	-
No response	-	1 (50)	-	-	-	1 (33.3)
Ethnic background, *n* (%)						
Australian	-	1 (50)	2 (13.3)	-	2 (13.3)	1 (33.3)
Aboriginal	-	-	-	-	-	-
Torres Strait Islander	-	-	-	-	-	-
Cambodian	-	-	1 (6.7)	-	1 (6.7)	-
Chinese	-	-	2 (13.3)	-	2 (13.3)	-
Croatian	-	-	1 (6.7)	-	1 (6.7)	-
Greek	-	-	1 (6.7)	-	1 (6.7)	-
Peruvian	-	-	1 (6.7)	-	1 (6.7)	-
Polish	-	-	-	1 (100)	-	1 (33.3)
South American	-	-	1 (6.7)	-	1 (6.7)	-
Vietnam	-	-	5(29.4)	-	5(29.4)	-
Other	-	-	1 (6.7)	-	1 (6.7)	-
Do not wish to answer	-	1 (50)	-	-	-	1 (33.3)
Needs interpreter, *n* (%)	-	-	4 (23.5)	-	4 (23.5)	-
Education, *n* (%)						
Some secondary education	-	1 (50)	1 (6.7)	-	1 (6.7)	1 (33.3)
Completed Secondary education	-	-	3 (17.6)	-	3 (17.6)	-
TAFE	-	1 (50)	1 (6.7)	-	1 (6.7)	1 (33.3)
University	-	-	9 (52.9)	1 (100)	9 (52.9)	1 (33.3)
Usual occupation/profession, *n* (%)						
Administration	-	-	3 (17.6)	-	3 (17.6)	-

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 0	*n* = 2	*n* = 17	*n* = 1	*n* = 17	*n* = 3
Labourer	-	-	1 (6.7)	-	1 (6.7)	-
Professional	-	-	3 (17.6)	-	3 (17.6)	-
Technician	-	-	1 (6.7)	-	1 (6.7)	-
Other	-	-	4 (23.5)	-	4 (23.5)	-
Do not wish to answer	-	2 (100)	-	-	-	2 (66.7)
Current employment status, *n* (%)						
Working full time	-	-	3 (17.6)	-	3 (17.6)	-
Working part time	-	-	6 (35.3)	1 (100)	6 (35.3)	1 (33.3)
Home care	-	-	4 (23.5)	-	4 (23.5)	-
Maternity leave	-	-	1 (6.7)	-	1 (6.7)	-
Retired/ Pensioner	-	1 (50)	-	-	-	1 (33.3)
Student	-	-	1 (6.7)	-	1 (6.7)	-
Do not wish to answer	-	1 (50)	-	-	-	1 (33.3)
Father						
Age at assessment in years, mean (*SD*)	-	-	41.8 (10.1)	33.4 (-)[a]	41.8 (10.1)	33.4 (-)[a]
Country of birth, *n* (%)						
Australia	-	-	6 (35.3)	-	6 (35.3)	-
Malaysia	-	-	1 (6.7)	-	1 (6.7)	-
Peru	-	-	1 (6.7)	-	1 (6.7)	-
Poland	-	-	-	1 (100)	-	1 (33.3)
Scotland	-	-	1 (6.7)	-	1 (6.7)	-
Uruguay	-	-	1 (6.7)	-	1 (6.7)	-
Vietnam	-	-	3 (17.6)	-	3 (17.6)	-
No response	-	2 (100)	-	-	-	2 (66.7)
Ethnic background, *n* (%)						
Australian	-	-	4 (23.5)	-	4 (23.5)	-
Aboriginal	-	-	-	-	-	-
Torres Strait Islander	-	-	-	-	-	-

	Victoria		NSW		Total	
	ASP *n* = 0	SaU *n* = 2	ASP *n* = 17	SaU *n* = 1	ASP *n* = 17	SaU *n* = 3
Chinese	-	-	1 (6.7)	-	1 (6.7)	-
Greek	-	-	1 (6.7)	-	1 (6.7)	-
Peruvian	-	-	1 (6.7)	-	1 (6.7)	-
Polish	-	-	-	1 (100)	-	1 (33.3)
South American	-	-	1 (6.7)	-	1 (6.7)	-
Vietnamese	-	-	5 (29.4)	-	5 (29.4)	-
Multiple ethnicity	-	-	1 (6.7)	-	1 (6.7)	-
Do not wish to answer	-	2 (100)	-	-	-	2 (66.7)
Needs interpreter, *n* (%)	-	-	-	-	-	-
Education, *n* (%)						
Completed Primary education	-	-	1 (6.7)	-	1 (6.7)	-
Some Secondary education	-	-	1 (6.7)	-	1 (6.7)	-
Completed Secondary education	-	-	1 (6.7)	-	1 (6.7)	-
Trade certificate	-	-	2 (13.3)	-	2 (13.3)	-
TAFE	-	-	4 (23.5)	-	4 (23.5)	-
University	-	-	5 (29.4)	1 (100)	5 (29.4)	1 (33.3)
Do not wish to answer	-	2 (100)	-	-	-	2 (66.7)
Usual occupation/profession, *n* (%)						
Manager	-	-	-	1 (100)	-	1 (33.3)
Professional	-	-	4 (23.5)	-	4 (23.5)	-
Technician	-	-	3 (17.6)	-	3 (17.6)	-
Community/ Personal Social Worker	-	-	1 (6.7)	-	1 (6.7)	-
Clerical/ Administrative Worker	-	-	1 (6.7)	-	1 (6.7)	-
Machinery Operator/Driver	-	-	1 (6.7)	-	1 (6.7)	-

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 0	*n* = 2	*n* = 17	*n* = 1	*n* = 17	*n* = 3
Other	-	-	3 (17.6)	-	3 (17.6)	-
Do not wish to answer	-	2 (100.0)	-	-	-	2 (66.7)
Current employment status, *n* (%)						
Working full time	-	-	13 (76.5)	1 (100)	13 (76.5)	1 (33.3)
Working part time	-	-	-	-	-	-
Unemployed	-	-	1 (6.7)	-	1 (6.7)	-
Do not wish to answer	-	2 (100)	-	-	-	1 (33.3)
Not specified	-	-	-	-	-	-

Notes: ASP, Autism Surveillance Protocol; SaU, Surveillance as Usual; TAFE, Technical and Further Education. Data was not provided for all participants, where this has occurred valid percentages are presented.

[a] Response provided by only one parent, thus SD not able to be calculated.

[b] Parents/caregivers were able to choose multiple options, thus percentages may not add to 100.

Psychometric properties of the ASP pathway

Based on the reference standard (diagnostic outcome) and screening test results, children were assigned to one of the four cells labeled A through D in Table 9, depending on their likelihood of being on the autism spectrum or not based on the 24-month gold standard assessments, and whether the screening tests yielded a positive result ('high likelihood' for autism) or a negative result ('low likelihood' for autism). We have only included the number of children who completed the full assessments as part of these calculations, with only results from the NSW ASP pathway included as no children were identified as having a 'high likelihood' of an autism diagnosis in Victoria. This is expected given that there were only 26 children recruited in the ASP pathway in Victoria and we would not have expected any to be identified as having developmental differences indicative of high likelihood of an autism diagnosis.

Table 9. Sensitivity, specificity, and positive and negative predictive values on the NSW ASP pathway data

Diagnostic outcome					
		Likely to be on the spectrum	**Likely to NOT be on the spectrum**	**Total**	
Screening status	**Positive ('high likelihood' for autism)**	A = 10	B = 1	11	*Positive predictive value*
	Negative ('low likelihood' for autism)	C = 0	D = 4	4	*Negative predictive value*
	Total	10	5	15	
		Sensitivity	*Specificity*		

What are referred to as sensitivity, specificity, and predictive values can then be calculated from the numbers of people in each of the four cells, and, if expressed as percentages, are based on the following formulas:

Sensitivity = [a/(a+c)]×100 = 10/10 x 100 = 100%

Specificity = [d/(b+d)]×100 = 4/5 x 100 = 80%

Positive predictive value (PPV) = [a/(a+b)]×100 = 10/11 x 100 = 90.9%

Negative predictive value (NPV) = [d/(c+d)]×100 = 4/4 x 100 = 100%

Interpretation of sensitivity and specificity, respectively:

- If a child is likely to be on the autism spectrum, there is a 100% probability that the screening test will be positive.
- If a child is likely to not be on the autism spectrum, there is an 80% probability that the screening test will be negative.

Interpretation of predictive values:

- If a child screens positive, there is a 90.9% probability that the child may be on the spectrum.
- If a child screens negative, there is a 100% probability that the child may not be on the spectrum.

In caution, please refer to the diagnostic outcome in Table 7. Three children were diagnosed with autism, 3 had a possible autism diagnosis, 4 language delay, one did not have any concern, and one could not complete the full assessment. Due to the varying diagnostic results, we cannot infer whether a child either is, or is not, on the spectrum. Hence, we have listed 'Likely to be on the spectrum' or 'Likely to NOT be on the spectrum' in Table 9.

Phase 3

A total of 16 parents/caregivers completed the SRS-2 Preschool when their child was approximately 30 months of age (see Table 10). For children with 'low likelihood' for autism, 5 (6.1%) children in the ASP pathway and 8 (20.0%) in the SaU pathway completed the SRS-2; for children with 'high likelihood' for autism, 2 (2.4%) in the ASP pathway and 1 (2.5%) in the SaU pathway completed the SRS-2. One of the children who was identified as 'high likelihood' in the ASP pathway received a score in the 'mild' range, with the others' score in the 'within expected limits' range. The child in the SaU arm who was identified as 'high likelihood' also scored in the 'within expected limits' range on the SRS-2. Of the children identified as 'low likelihood', most (ASP: *n* = 4, 80.0%; SaU: *n* = 6, 75.0%) received a score of 'within expected limits'. Three children, one (20%) in the ASP pathway and two (25%) in the SaU pathway, received scores in the 'mild' range.

Despite the semi-structured questionnaires being sent to all parents/caregivers of children who were identified as 'high likelihood' (ASP: *n* = 17; SaU: *n* = 3), only two parents/caregivers (both from NSW) in the ASP pathway and none in the SaU pathway completed these. Similarly, the questions on parent/caregiver experience of the developmental assessment were sent to all parents/caregivers who had not yet completed the 30-month questionnaires (ASP: *n* = 16; SaU: *n* = 5); however, only two parents/caregivers in the ASP pathway and one in the SaU pathway (all from Victoria) completed these items. Due to the very small number of responses to these items, these were not analysed.

Table 10. Completion of SRS-2 Preschool at 30 months of age

	Victoria		NSW		Total	
	ASP	SaU	ASP	SaU	ASP	SaU
	n = 26	*n* = 15	*n* =56	*n* = 25	*n* = 82	*n* = 40
Low likelihood						
SRS-2 Preschool completed, *n* (%)	5 (17.9)	1 (6.7)	-	7 (28.0)	5 (6.1)	8 (20.0)
SRS-2 Preschool result, *n* (%)						
Within expected limits	4 (80.0)	-	-	6 (85.7)	4 (80.0)	6 (75.0)
Mild range	1 (20.0)	1 (100.0)	-	1 (14.3)	1 (20.0)	2 (25.0)
Moderate range	-	-	-	-	-	-
Severe range	-	-	-	-	-	-
High likelihood						
SRS-2 Preschool completed, *n* (%)	-	1 (6.7)	2 (3.6)	-	2 (2.4)	1 (2.5)
SRS-2 Preschool result, *n* (%)						
Within expected limits	-	1 (100.0)	1 (50.0)	-	1 (50.0)	1 (100.0)
Mild range	-	-	1 (50.0)	-	1 (50.0)	-
Moderate range	-	-	-	-	-	-
Severe range	-	-	-	-	-	-

Notes: ASP, Autism Surveillance Protocol; SaU, Surveillance as Usual; SRS-2, Social Responsiveness Scale-Second Edition.
Data was not provided for all participants, where this has occurred valid percentages are presented.

Phase 3a – Qualitative analysis

Parent/caregiver perspectives

The 'obstacles or barriers', 'facilitators or enablers', and 'suggested improvements' served as the three main themes from the parent/caregiver qualitative data, each of which are displayed in Table 11. Parents/caregivers experienced more obstacles with the current developmental surveillance pathway provided in GP practices in the SaU pathway compared to the ASP pathway (refer to Figure 2). There were eight subthemes under 'barriers or obstacles' (six in the SaU pathway; one in the ASP pathway; and one in both pathways).

For the SaU pathway notably, they were:

a) ‘long waiting times to access NDIS support package, paediatric care and/or allied health support’
b) ‘lack of clear action plan provided to parents/caregivers’
c) ‘unclear explanation about child’s developmental condition causing a delay in diagnosis’
d) ‘health service navigation is complex for families’
e) ‘having to see multiple GPs due to GP unavailability’
f) ‘lack of GPs’ empathy towards parents/caregivers’.

One subtheme that emerged in the ASP pathway was ‘technical issues with the digital screening questionnaires’; and one subtheme from both pathways was ‘COVID-19 lockdowns caused problems accessing GPs, specialists, allied health support’.

Although challenges were encountered by parents/caregivers regarding the current child developmental screening through general practice, they also expressed some positive experiences when dealing with the current system and due to participating in this study. There were a total of six subthemes (two in the ASP pathway and four in both pathways) under the ‘enablers or facilitators’ theme. Subthemes appearing in both pathways were:

a) ‘parents/caregivers feel the importance of early support and service provision for their child’
b) ‘parents/caregivers were made aware of any developmental concerns for their child’,
c) ‘mutual trust and relationship between parents/caregivers and GPs led to following GP’s advice and directions’
d) ‘parents/caregivers accepted and adapted rapidly to telehealth consultations’.

The subthemes that emerged only in the ASP pathway were: ‘the screening checks and system were easy and simple to complete’ and ‘parents/caregivers were able to access timely diagnosis due to timely assessments’.

Other than revealing barriers and enablers of the current practice and research programs, our parent/caregiver cohort also offered several suggestions that they think may improve future child developmental surveillance systems. There are seven subthemes under ‘suggested improvements’ expressed by parents/caregivers (two in the SaU pathway and five in both pathways). Subthemes in the SaU pathway were: ‘standardised developmental

screening needs to be made mandatory (not when it is convenient or opportunistic)' and 'the need to have quick-reference educational resources or guides for parents/caregivers'. Subthemes that emerged in both pathways were:

a) 'duration of GP consultations needs to be longer'
b) 'the need for parents/caregivers to be educated about child developmental milestones and conditions (especially autism)'
c) 'the need for a child-friendly environment and reliable technical services in GP waiting rooms'
d) 'the need for further research, training, and education regarding child developmental screening for GPs'
e) 'the need for community awareness of child developmental screening and research studies'.

Figure 2. Comparisons of barriers, enablers, and suggestive improvements from parent/caregiver perspectives between current GP developmental pathway and ASP research pathway

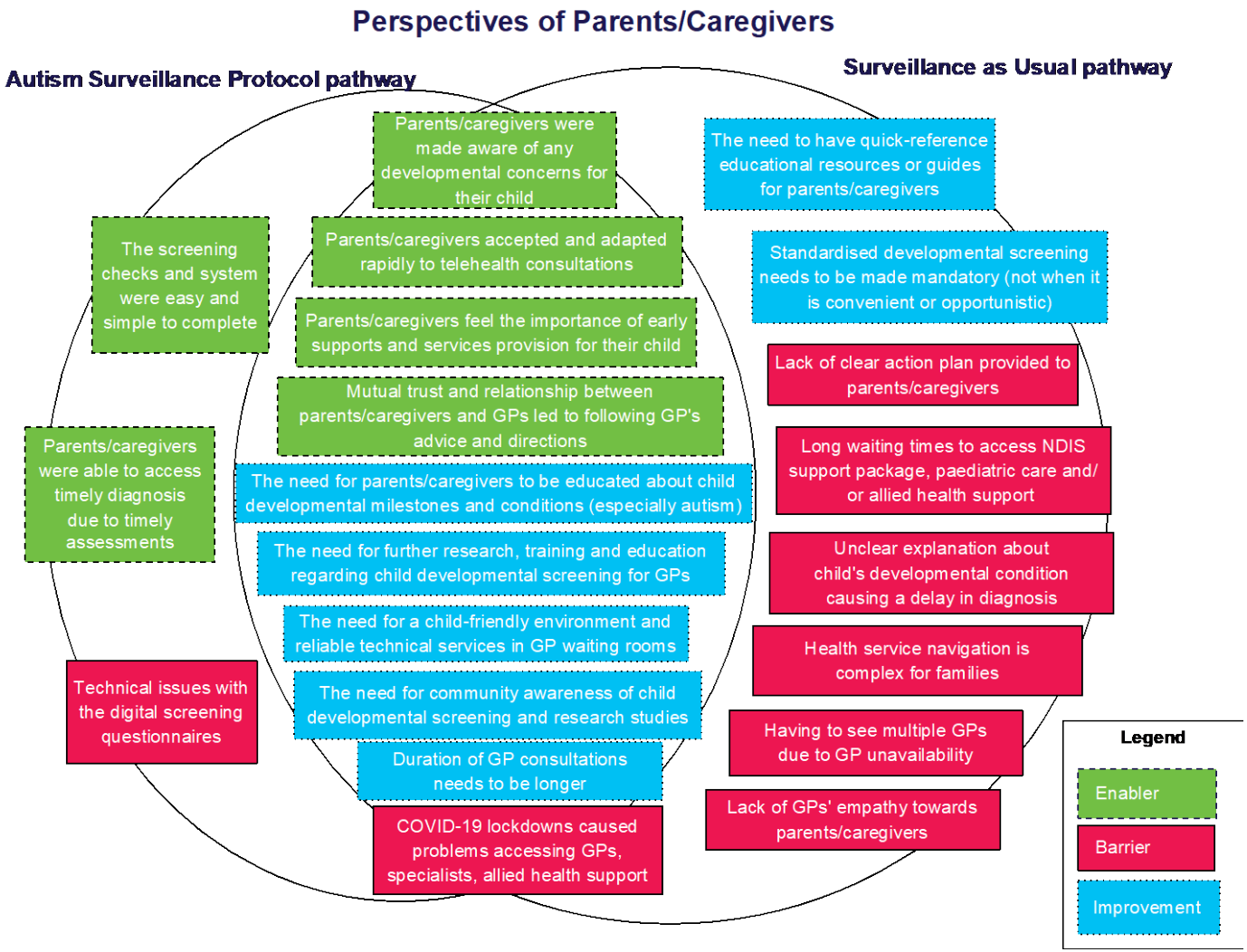

Table 11. Themes, subthemes, and reference quotes of parents/caregivers' perspectives

Theme	Subtheme	Pathway	Example of reference quotes
	Long waiting times to access NDIS support package, paediatric care and/ or allied health support		No, we haven't, still haven't managed to have that appointment. It is 12 month waitlist. (P04, Victoria) It was a long waiting time that, six months that my son was at, then at two years old and then he was two and a half before he started seeing anyone or someone. (P11, NSW)
	Lack of clear action plan provided to parents/caregivers		It was not them to pick that up. I was, it was my concern. So I visit more than twice to the GP. And then it was when … only when I say, 'I believe there is something wrong with my son', then they say it, they actually start referring me to see someone else. (P11, NSW) 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 a family doctor and then that family doctor finally referred to the speech therapy and OT places. (P07, NSW)
	Unclear explanation about child's developmental condition causing a delay in diagnosis		I found GPs were reluctant to mention some things that were quite obviously wrong. He clearly had some social problems, he didn't want to make eye contact, things that I hadn't noticed as a mother, because he was my first child I didn't realise he wasn't normal… that this isn't right, you know, maybe we need to get him checked. But looking back, I can't see how other GPs wouldn't have noticed that. Maybe they didn't, you know, it's hard to talk about … it's hard to tell someone that their child isn't developing normally. They could be more forthcoming with that information and more direct. (P08, NSW) Oh, on my part. I think I didn't have an idea about autism. Oh, I don't know if there is a program through the pregnancy programs. But if there could be more information out there. Yeah. You would at least have an idea. But then they also couldn't tell me this might be why my son behaves like that. It was kind of strange to me (P02, Victoria) There's very little information for someone who's a new mum. … It wasn't 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)
	Health service navigation is complex for families		I've kind of pushed with like, his paediatrician and like I got into NDIS now. So, I'm trying to like push with all them and the speech place, like to try and get him diagnosed and stuff because I'm concerned and they're kind of not seeing what I'm saying. (P06, Victoria) I told her how I've been trying to get the assessment and it being so hard (P02, Victoria)

Theme	Subtheme	Pathway	Example of reference quotes
	Having to see multiple GPs due to GP unavailability		We see a couple of GPs. One is for the skin eczema, skin doctor. We do have a general GP when she is sick and for the vaccination. At the moment she's very busy. So when we make appointments for running nose, a flu, we just make the appointment with the next available doctor. (P10, NSW) Me and my husband attended a couple of GP 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)
	Lack of GPs' empathy towards parents/caregivers		Yeah, it can be really, really emotional stage when someone says that something is not right with your child. Also, I think, I would say whether you go to see maternal health [nurse] or even your GP, 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)
	Technical issues with the digital screening questionnaires*	ASP pathway	The questions on the iPad I guess they might have a little bit repetitive, when you're filling in that online that gets laborious, when you don't have a proper keyboard, you know what I mean. So you're typing on the screen and it's hard to be thorough. I did try it because I noticed that the survey was for 18 months or onwards. I did try I think [name of child] seventeen and a half months and I thought oh I'll register him because it'll take a couple of weeks before anyone can get back to me. So I went through the whole registration process, answered all the questions and then right at the end of the questionnaire, asked me for his birthday and then they said I couldn't submit the answers because he's not 18 months. That was just disappointing. I mean that was just a pain in the butt. I had to come back two weeks later and do it again. For the sake of two weeks. Well, then, yeah it did take a couple of weeks for someone to get back to me so perhaps if the date had been like the birthday entry had been at the start of the questionnaire if you are gonna to be really strict about it, or otherwise a lot more leeway with birthdays. (P08, NSW) The only thing that we did with the iPad. We did, and then it didn't apply. 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)
	COVID-19 lockdowns caused problems accessing GPs, specialists, allied health support	Both pathways	I took her to the hospital emergency, also twice or may be once as she had the cold symptoms so couldn't take her, and she's always got a cold. So yeah, I couldn't go to the doctors. (P04, Victoria) So it was then that we were able to kind of look at therapy but because of the COVID we didn't start the therapy early because of that COVID. So it took some time before he started the therapy. (P02, Victoria) I haven't really done a lot of appointments with the doctor, I think due to COVID. (P05, Victoria) One of the main bottlenecks were pretty much Coronavirus, as it happened within that timeframe. So that's one of the reasons that limit us to visit places as they are closed or shut down. We were not able to see like

Theme	Subtheme	Pathway	Example of reference quotes
			specialists out there. They were not able to see more clients at one given day, or they will just limit how many people they can see in a day that that also makes the waiting time longer. (P11, NSW)
Enablers or facilitators	The screening checks and system were easy and simple to complete	ASP pathway	It was relatively straightforward, it wasn't particularly complicated, it was not very complicated. (P03, Victoria) I think that's been pretty thorough. I'm thankful to have had the process and didn't have to pay for it. I know it was part of the study, but you know I come to support you. To get my oldest son, like screened and assessed and we had to do it privately. So this was really good. (P08, NSW)
	Parents/caregivers were able to access timely diagnosis due to timely assessments		She asked why they thought it and I told her that. No, she wasn't giving any eye contact and stuff. But yeah, 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)
	Mutual trust and relationship between parents/caregivers and GPs led to following GP's advice and directions	Both pathways	That GP was so helpful. Yeah, we still see that GP. So helpful. (P02, Victoria) Yes. When it comes to Dr. [name], as I said, he has known me since I was a teenager. He knows my mum, he knows my sisters and my sisters have an extensive asthmatic history. And so he kind of … it's good knowing that he knows a lot about us. So he's also an obstetrics doctor. So he was my doctor throughout… I did 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)
	Parents/caregivers were made aware of any developmental concerns for their child		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. And then kind of summarised at the end of that, but yes, there's some points of concern. But not overmuch, apart from 'wait, maybe 12 months and see how he's going. So yeah, the GP was quite thorough. (P08, NSW)
	Parents/caregivers feel the importance of early support and service provision for their child		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) Because I think if it's missed out in early childhood like a mate of mine, it can't be rectified. Like certain things in childhood that they have to develop in order to get to the next stage of development. If they miss a stage of development, then it delays the next stage. Then they become adults and can't develop and you know it can lead in to their development towards adulthood. (P10, NSW) It helps them fit in from a younger age and helps them to get along in life, you know, they don't miss those first five years of not learning what is in their personal world or development and get some skills. (P08, NSW)

Theme	Subtheme	Pathway	Example of reference quotes
	Parents/caregivers accepted and adapted rapidly to telehealth consultations		He [the GP] wants to actually have a look and check my child's skin, so when the virus was around he [suggested] using a teleconference, and then nurse would take a picture of the skin and then we send it to him and we used telehealth fine. (P10, NSW) If given a choice, if it is a mild check-up or anything else, I just need to confirm with my GP, I'll definitely go through the telehealth telephone. (P01, Victoria) Yes, for minor issues, and if it's for something more serious, that we are unsure of ourselves, then yeah we do like the GP to have a look at them but if it's, yeah, telehealth generally we have no issues for majority of it. (P12, NSW)
Suggested improvements	Standardised developmental screening needs to be made mandatory (not when it is convenient or opportunistic)	SaU pathway	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) Definitely. … they should just have a little chat today and say, you know, how's it going? Is there any concerns you have, you know, what, what is the, you know, and do like a developmental checklist with them, and then the doctor could explain to them, we're going to, you know, focus on these aspects. These behaviours. Yeah, looking out for this kind of thing. (P05, Victoria)
	The need to have quick-reference educational resources or guides for parents/caregivers		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. She's a new mum. Checklist can be just a five starting bullet point is the new mum, that's your, your son or daughter on this development, like kind of make new moms, new parents out there, be more aware of what a development chart looks like and what, what they can do or can't do for your child. (P11, NSW)
	The need for parents/caregivers to be educated about child developmental milestones and conditions (especially autism)	Both pathways	I didn't have an idea about autism. Oh, I don't know if there is a program through the pregnancy, kind of highlight some of the things, you know, not [that] you're expecting your child to be like this. But if there could be more information out there. You have at least an idea. You have an idea, but I think those. You do not have an idea. (P02, Victoria) 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)
	Duration of GP consultations needs to be longer		It always has been very quick. I just felt that there is too much happening. (P12, NSW) I do feel like sometimes they do rush a lot of things. I mean maybe we can maybe like, I don't know, especially when it comes to a child development or whether it's just concerning for parents, but maybe they can extend on how long they, they don't really have a time limit, but I almost feel like they rush quite a bit

Theme	Subtheme	Pathway	Example of reference quotes
			because there's other patients that, that is lining up to get this wanting to see the GPs. Well, to my honest opinion is to kind of allocate a little bit more time for each patient. (P11, NSW) And then they're very busy, … They are really busy they just go through everything fast. (P09, NSW)
	The need for child-friendly environment and reliable technical services in GP waiting rooms		The questions on the iPad I guess they might be a little bit repetitive, when you're filling in that online that gets laborious, when you don't have a proper keyboard, you know what I mean. (P08, NSW) 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 because in doctor clinic because these checks are done in the typical GP room where there are not, it's obviously not a child friendly environment to play, and for them to be themselves so it's very hard for a GP to really detect everything when a child is uncomfortable or unaware of. (P12, NSW)
	The need for further research, training and education around child developmental screening for GPs		Maybe they need some training. Like specialised training because I don't know if they do a lot of developmental training when they're doing their courses. (P10, NSW)
	The need for community awareness of child developmental screening and research studies		To kind of have a better way of raising awareness for mums and new parents out there when it comes to child development, whether that's something, they can add an extra page to the blue book … 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) Not everyone is aware until you actually like myself. I didn't, I was not aware that my child was underdeveloped until like a later time. And because I don't take my child out there a lot. GP has a better understanding of because they see kids or whether it's kids or patients, other patients. So they would know a rough idea of what age they should be developed at a certain that should be like a 12 or 24 months … We don't know what stage, they should be at. So making us aware of where our kids development should be at [a] certain stage, should be more out there and should be made open, like, I don't know, make some sort of some announcement. (P11, NSW)

* Issues with the digital parent/caregiver questionnaires were only raised for NSW.

General Practitioners' perspectives

Three major overarching categories emerged from the GP qualitative interview data: 'barriers or difficulties' relating to utilising the current developmental screening practices versus using the ASP digital tools for developmental surveillance programs, 'enablers or benefits' related to using or incorporating these tools for assessment of children, and 'suggested improvements' in relation to using these tools for future child developmental surveillance programs, as displayed in Table 12. The themes and subthemes are shown in Figure 3. There are 12 subthemes (five in the SaU pathway; three in the ASP pathway; and four in both pathways) which emerged within the 'barriers or difficulties' theme, namely:

a) 'COVID-19 lockdowns impacting participant recruitment'
b) 'parent/caregivers' lack of understanding of developmental screening/milestones'
c) 'need for simplified and clearer parent/caregiver information'
d) 'language and cultural barriers within the CALD population'
e) 'family financial and socioeconomic circumstances often prevent them obtaining the relevant services for their child'
f) 'lack of paediatric and/or allied health professionals to refer to'
g) 'long waiting time for specialist appointments'
h) 'parents/caregivers' denial of (potential or actual) diagnosis of their child'
i) 'health service navigation is complex'
j) 'more time needed to complete developmental screening'
k) 'study age criteria too narrow'
l) 'technical implementation issues'.

The 'enablers or benefits' theme presented seven subthemes (one in the SaU pathway; two in the ASP pathway; and four in both pathways):

a) 'importance of early diagnosis, supports, and services'
b) 'mutual trust and good relationships between GPs and parents/caregivers'
c) 'using concrete, standardised screening tools'
d) 'reliable and rapid communication between GPs and specialists/allied health professionals'
e) 'having the SACS Online assessment and resources as part of the research screening tools'
f) 'interest in conducting developmental screening with parents/caregivers'

g) ‘interest in supporting and participating in research that would contribute towards further training and education’.

The GPs also provided several suggestions (a total of seven subthemes under the ‘suggested improvements’ theme – one in each pathway, and five in both pathways) on how the current practice and the research could be implemented for the future, namely:

a) ‘need for recognition of and support for GPs’ role in developmental screening and ongoing care for children with developmental concerns’
b) ‘the need for funding to conduct ongoing developmental screening’
c) ‘a comprehensive, streamlined process for developmental screening’
d) ‘the need for further training and education for GPs on child developmental screening’
e) ‘the need for digital developmental screening’
f) ‘the need for a quick-reference educational guide for parents/caregivers’
g) ‘in-clinic research support to liaise/administer the study to allow a consistent, streamlined process’.

Figure 3. Comparisons of barriers, enablers and suggestive improvements out of general practitioners' perspectives between current GP developmental pathway and ASP research pathway

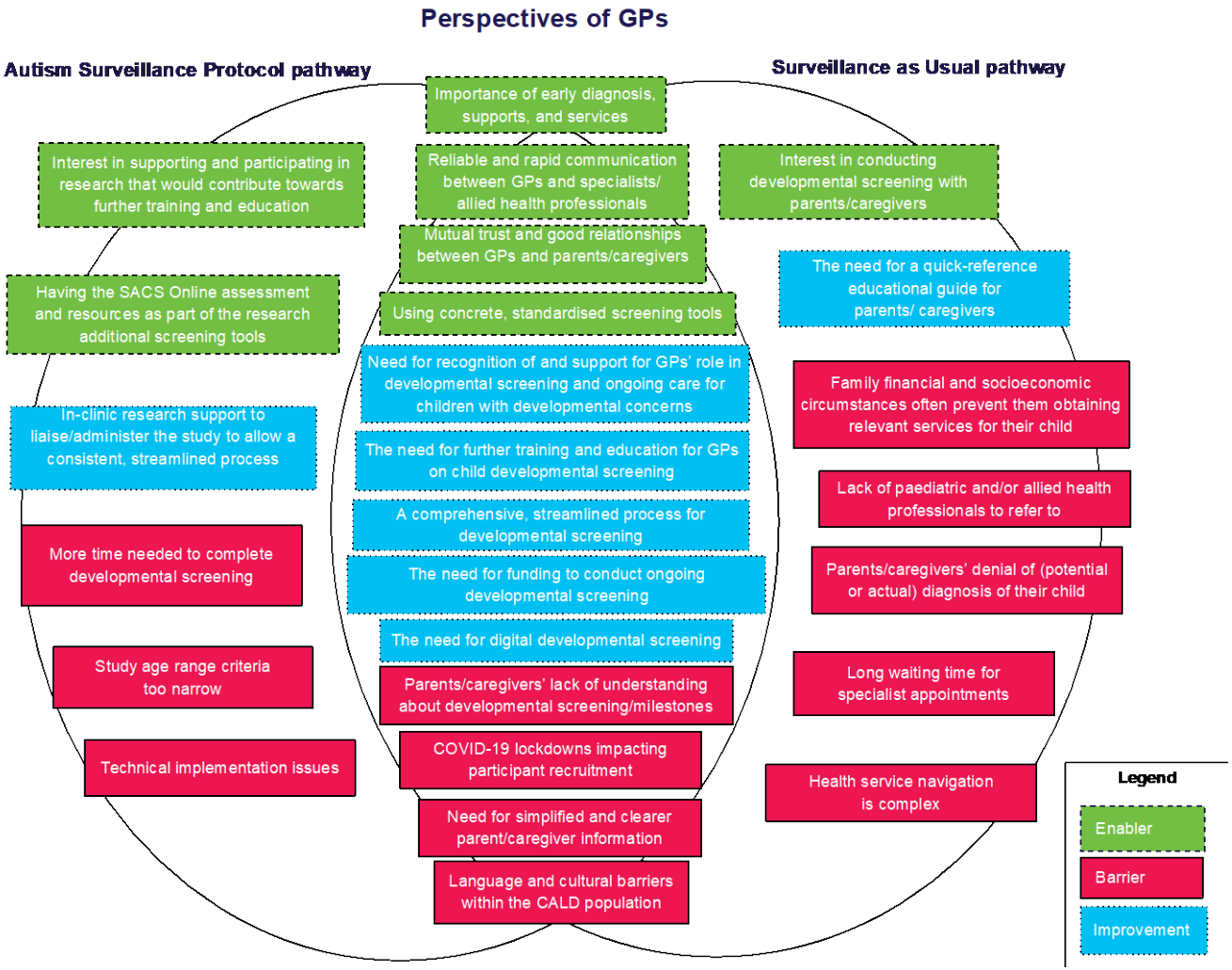

Table 12. Themes, subthemes and reference quotes of general practitioners' perspectives

Theme	Subtheme	Pathway	Example of reference quotes
Barriers or difficulties	Family financial and socioeconomic circumstances often prevent them obtaining relevant services for their child	SaU pathway	[The current] Medicare rebate for these cases is not sufficient enough. If they qualify for NDIS now, even with limited funding I think that helps a lot with access to treatment. So I think with the introduction of NDIS, I think a lot of my patients can afford to actually see the providers now. Previously, dating back three or four years ago, a lot of the times they won't seek treatment because of financial barriers. (G05, NSW) Finance, very very important. To get the NDIS approved they need a very comprehensive psychologist …psychiatric or paediatrician plus as follow up review. And until it wasn't approved, they won't get any funds. So they are really are … most of them are really under the pressure to get finance. I will do the care plan as well because they can use the care plan to see the different allied health, only five sessions a year which is really nothing. (G40, Victoria) We have more healthcare card holders. And I know this because I get regular government type things, you know, where they tell you you're doing this, you've got such and such a population. And these are the number of people who are on health care card holders. And we are consistently higher than others for healthcare card holders. Bear in mind also that in terms of where the high birth rates were now, this is a few years old, but I think number one, birth rate is high at [suburb]. And the middle class is in [suburb]. And more around this area as well for the refugees the Asian community, the Korean community in [suburb]. There's quite a few kids around here and they're not necessarily the best resource for kids though. This area is gentrifying. And in fact the poor are getting squeezed out by the middle class. So maybe life will get better in the future. There'll be more services available because those with money generally have better infrastructures. But at the present time, no, there's a problem for getting services. (G27, NSW)
	Lack of paediatric and/or allied health professionals to refer to		Behavioural problems or learning difficulties is a bit more of a minefield, because to get into the paediatricians who specialize in that sort of area, often has long waits. And there isn't anybody specifically in this area, or there might be one paediatrician in [suburb] that we use, but a lot of the others are over at [suburb] or city, [suburb], I mean, not geographically close is what I'm saying. And more of an issue for them to get to. (G16, NSW) Parents have to travel half to one hour to go and see someone because they couldn't get in near here. (G35, Victoria)
	Long waiting time for specialist appointments		If they're waiting for public health or paediatrician, sorry. Well, yeah. Paediatrician, OT, whatever speech pathologist. Yeah. By the time they get there, it's been nine months. (G27, NSW)

Theme	Subtheme	Pathway	Example of reference quotes
			I certainly know, there's some types of allied health interventions that are almost inaccessible for children, because the waiting list is so long that, you know, my joke is by the time they access it, it's not much use if they've become adults. (G33, Victoria)
	Parents/caregivers' denial of (potential or actual) diagnosis of their child		So sometimes it can be the parents that will delay the diagnosis because they don't want to accept. In fact, even now poor mum was extremely stressed because the child's not having OT care, speech development. The father is still in denial too. So we've got a lot of that social issues because the father refuses to see their child may have some sort of autism, autism, and so is refusing to accept [name of child]'s care. (G26, NSW) Parents, especially coming from the other countries, they really don't like me saying that their child, maybe is on the spectrum. And so they do try to deny and say maybe I'm thinking that because they are bilingual and because the child is shy. (G40, Victoria)
	Health service navigation is complex		I think the other problem is the, the lack of knowledge about available resources in the community which is very large and I always struggled to know not only the funding systems available, if there are concerns for children and parents, but also where to access them, because you could almost treat the same issue in five different ways, depending on your background and experience and local resources. So, you know, some will go down the specialist pathway, some will go by the Allied Health pathway, some would go through other structured programs. And again, it comes down to me making a guess, or having past experience in terms of what, what pathway I'm going to choose at the same time with the parents, I think, which may not be necessarily the best outcome, because some, some, some ways of treating it, I'm sure are better than others. But again, that might be an access thing as well. (G33, Victoria) I can go forever with this. The GP is often pretty undervalued. Like it's pretty easy because you meant to have this holistic approach to kids with developmental concerns or potential diagnosis, but it really happens like you've got this fragmentation of care. Like you have paediatrician says, I'll go to the OT for that. OT will say “oh, that's a speech problem go to the speechie”. And then you often get parents who are a bit overwhelmed with the whole process. Like everyone deals with their specific thing, but no one often takes a step back and looks at everything. (G23, NSW)
	More time needed to complete developmental screening		And then when they come in having the time to not only ask them the questions again, but having to go online, remembering my log on details, which is really bad having issues all the time with that. And then doing that second part of the survey. So it just all boils down to time. And sometimes I find that because we're so busy, I don't actually have time to fill out that second part of the survey. (G24, NSW)

Theme	Subtheme	Pathway	Example of reference quotes
		ASP pathway	Some of the drawbacks to any sort of research at this particular time, especially if you try and do an 18 months session, they were sort of asking us to do the computer data was it's a very busy, busy time because 18 months vaccinations are like 12 months, essentially it's three vaccines... So that is already a barrier because we doctors are a hundred percent making sure that the vaccines are given correctly, that documentation is done correctly. So it's a very stressful time for a GP. (G26, NSW) I didn't realise that was going to take up so much time at the beginning. I thought it was just part of my routine 18 months consult. But in fact during that secondary screening [SACS] actually takes these 15 or 20 more minutes that I hadn't counted on and it's not in my appointment book either. So they come in for the 18 month check and they get booked with the nurse as well for the vaccinations, but then I've got to find another 15 or 20 minutes to do that screening as well, which I think would have been nice to, to know that that was the time commitment. And then we could I don't know, explain to the parents, maybe when they book, this is what we're going to do. So there was a little bit of that lack of coordination perhaps with our front desk staff and admin and our bookings that we made it a little bit clunky. (G22, NSW) I think it was more time consuming than realised at the outset. So it took, whilst it might just be, you know, a 10 minute thing, once you've read everything, the reading of everything, talk for the parent on saying yes to a lot of time, so they had to read and digest and consent and all of that. And then once they got through that stage, at other part might have been quick, but it wasn't a quick do this, while we vaccinate your child… (G34, Victoria)
	Study age range criteria too narrow		And we had a lot of kids who were like, six months, 12 months, 13 months, 14 months, but they weren't actually falling into that age group that you all were looking at. So they weren't able to participate and get screens by the study. (G39, Victoria)
	Technical implementation issues*		It was a bit clunky at the beginning that it was hard to you know, they're meant to fill out the questionnaire and then we get an email back straight away with the result, but sometimes they didn't come back. On another days, they did fix it up. So now it's coming back, but sometimes it doesn't come back immediately. And so there's a kind of gap in between, see one or two other patients, and then they come back in and then to do that secondary screening. (G22, NSW) Once the patient managed to do whatever they did on their iPad, when I came in and then saw them and I was meant to report by completing the next segment, which was my segment, didn't always work. (G27, NSW)
	COVID-19 lockdowns impacting participant recruitment	Both pathways	Everything about COVID it has, it's more difficult. It's more time consuming. Even the phone calls by the time that you actually get them online. It's not always a convenient time ... I'm here sometimes till 7, 8, 9 pm doing the phone calls. Then there is the need to do whatever it is they need to do. I get it to, will you

Theme	Subtheme	Pathway	Example of reference quotes
			pick it up? Am I mailing emailing, faxing? It's actually been more time consuming than when they were here and they left right. With everything being done that was required to be done. (G27, NSW) So for about five, five or six months there, we, we couldn't conduct a proper exam, you know, even on our regular patients, because they were scared to come in. Even immunisations were postponed. Even regular immunisations were being postponed at that time. And it was locked down. And so most of it is phone. And, you know, there's only so much you can do on the phone. Yeah. So I think COVID would have substantially delayed a lot of a lot of those prep years kids, you know, they were at home. Yeah, pretty much all of last year. So it's really now things would be identified. (G42, Victoria) Because of COVID all of their speech programs, all of them are closed. And they are not coming into GP practice as well, because they don't want themselves or their children catch a COVID as well. Definitely. A big barrier. (G40, Victoria) I did have trouble getting them to get their consent forms looked at and signed up. Because partly with the whole COVID lockdown, the clinic wasn't running as it normally is, people sitting in the waiting room, they only come in the minute you've starting your consult, and so on. So that didn't help. (G35, Victoria)
	Need for simplified and clearer parent/caregiver information		Caretaking facilities would be helpful sometimes. In this area it's white, it's basically everybody speaks English. I've got maybe, no, I don't know of any young families where the patient, the parents don't speak good English. Even the older ones, the oldies, usually bring in a younger member of the family who translates. We don't have any problems with needing translators here. And that's just a geographic thing. I think it would be a whole lot more difficult to do the assessment if English wasn't the primary language. (G16, NSW) The parents, the little bit uneducated one, they've found [it a] little bit hard to understand. But once explained, they were okay. (G41, Victoria) … one example comes to mind where a family misunderstood and thought that they had to go in for a two to three hour assessment, which they've obviously misread that, that obviously occurs, if there's an issue and after 2 years they get the assessment, but there was there just it wasn't clear. And for them, at least for this particular family. And so there was it was very much “Oh, no, I'm not doing that. I don't have time for that.” And so I think, again, it comes back to time, a lot of time was required on both our part to explain things, and on the parents part to actually read all the information (G34, Victoria)

Theme	Subtheme	Pathway	Example of reference quotes
	Parents/caregivers' lack of understanding about developmental screening/ milestones		I guess, if we put like blurbs about what's the developmental stage of the kids, like in a poster, and then the parents could read it while they're in the waiting room, that might be helpful, basically, because, you know, like I said, if the parents have a two year old, six months, so it'd be great if I just put it there while they're waiting in the waiting room waiting to be vaccinated. And that would be another thing. (G06, NSW) And the parents, many parents will attribute one end of the spectrum or the other, they live their life to believe that their kid's absolutely normal and perfect, or they're overly worried and overly anxious, and overly analysing anything as a sign of something. And for both ends of that spectrum, slightly different approaches, and concerns. But teaching skills, social communication and social interactions and teaching strategies on behaviour is definitely worthwhile.(G43, Victoria)
	Language and cultural barriers within the CALD population		We have predominantly Middle Eastern, but we do have a lot of Asians and South American backgrounds and a lot of refugees. So sometimes, it may be a bit difficult to screen, because I don't speak another language. So sometimes bit difficult to identify children with autism. Sometimes parents can't voice their concerns as well. So sometimes there might be an issue like that. Also, you know, if the kids speak two different languages. A lot of parents sometimes put the speech delays into being that they're speaking two languages and they might not identify that as a problem. (G05, NSW) Sometimes it's hard to talk to them if they don't speak the language. Most of my clients are Caucasians. And, you know, people who were born here, even if they're non-English speaking, background at home, they have two languages. And it's hard for me to think about people who have two or three languages in a household. And you're assessing them for speech. Because, you know, you're asking them how many words are they saying? … And how do you accommodate that, because this one [*points to checklist*] shows up for Caucasian background where it's just one language, one family, and we're multicultural. So the speech is a big deal. (G06, NSW)
Enablers or benefits	Interest in conducting developmental screening with parents/caregivers	Both Pathways	So in general I think when the children come for their routine check-ups, so the six week check-up, and then they come for the four months, six months, 12 months, 18 months. So I usually take a bit of time there to ask the mum how they are going. And so I have a little chart on my wall, one of those standard developmental screening charts to remind me of what kind of milestones they should be achieving at each at each level. (G22, NSW) Usually will take place at all of the immunisations, most of the time. So that would be six weeks, six months, 12 months and 18 months, and then we'll do another one around the three and a half to four year mark, that's a standard. That is just literally questions to the parent, based on what should be there. The kid's current developmental status, usually followed in the blue book. (G19, NSW)

Theme	Subtheme	Pathway	Example of reference quotes
			We try and do a quick developmental screening and issues of concern. Well, we particularly do it when it's a 12 month appointment. And again, at eighteen months, when they come in for the 18 month immunisations or when they attend the GP clinic, not the immunisation clinic, most of us then also re-evaluate them as to whether there are any suspicious features or specific concerns (G43, Victoria) So usually from … I do several of the screens. One is on the six weeks old, one is on the four month old, one is on the six month, one is on the twelve [months], one is on the 18 [months], one is on the 2 [years]. So on each of them, I usually check the milestone in all comprehensive, not only on the physical, also on the mental. So check for the … if they have the proper eye contact, about the language, about the comprehensive spectrum that I have as a chart. So to check if they are both developmental, mental developmental, milestone is okay. And physical milestone is okay, based on their age. (G40, Victoria)
	Reliable and rapid communication between GPs and specialists/allied health professionals		The great advantage we have these days is that we communicate very quickly. With specialists like paediatricians through social media. Many of the younger paediatricians are very quick to respond. So, I can actually put in a brief report about the patient"… "I have child with...a four-year-old who is not doing such and such. What do you think?" And they're very quick to provide advice, which are usually within a few hours. (G04, NSW) I think around our area is fine. Allied health/specialists quite accessible, no matter your demographic (G44, Victoria)
	Having the SACS Online assessment and resources as part of the research screening tool	ASP pathway	I think it's been a really good eye opener of things to look out for. I think you're going to find that it actually ends up being the criteria you're looking at, I think [this tool] is going to be very helpful for people. And I think it's something that I'm more aware of, and will be keeping in the back of my mind when I'm seeing young kids, as a way of having a better understanding [of] who's at risk, because I do think that you are going to find you get good results from this when you get your results in. … as I say, just that it's made, improve my awareness and hopefully my ability to pick things up a bit earlier as well. (G35, Victoria) When I had your software package, I would use the prompts that you have, which will allow us to specify and that will also allow me to get some clarity on this situation… The tools were excellent. (G37, Victoria) It was good training for me, because I got to pick up on a lot more characteristics of autistic kids that I wouldn't have before. (G34, NSW) It's a reasonable tool. I just think it needs to be now sort out in a way that we can encourage more doctors to use again. (G43, Victoria)

Theme	Subtheme	Pathway	Example of reference quotes
			I found that I keep emphasising the resource. I just found that so useful. Sure, and I think, you know, you can read about things. But those short videos were so helpful to really see what it is we're looking for, as I say, you can read about things, but it's just not the same as seeing something, very well done, very concise, easy to access, and I think all GP should have access to that sort of learning tool. (GP34, Victoria)
	Interest in supporting and participating in research that would contribute towards further training and education		So, when I have seen you do [the] research project, I really felt that it's uh very good that somebody is thinking to train and understand how to pick up developmental issues by the age of two [years], so it is a very, very important thing. So, in medical school, I mean postgraduate GP training, of course in paediatrics training that will do all the training but in GP training, it needs to be included how to pick up, early pick up of [a] developmental issue. (G41, Victoria) So, [for] the GP to be more involved, there needs to be more education and possibly need to start at a, you know, at a fellowship level. Before doctors are fully qualified. And look, maybe it's already happening there, maybe with younger GPs but some sort of education around that. It wasn't particularly well done when I went through, but that's now a while ago, so whether it's happening better now. But yeah, and awareness, I suppose. (G36, Victoria) I'm a very strong advocate in education for our medical students and also for GPs' need to pass the fellowship exams. So, what I'd like, if it could be put in a syllabus about the RACGP syllabus for paediatrics, a standard approach to looking at milestones and giving us a little bit more education, I've trained as a GP back in the nineties, we didn't have that. Now we have the diploma of paediatrics, but not all doctors are going to do it. I don't think I need to do it, but it'd be lovely if we could have updates on paediatrics milestones and maybe then put it in a way for young doctors coming through as part of the syllabus, paediatric milestones. I think that would be great, you know, if the research was done and then that way, we could then have a standard thing and then it will prompt me as a supervisor to make sure that my registrar is competent in those things. (G26, NSW)
	Mutual trust and good relationships between GPs and parents/caregivers	Both pathways	Parents that who are coming and seeing me during the pregnancy and after birth, and I am raising my concern, they are very welcome. I found that they've more patience because it looks like that they really have a more trust, rather than then wanting for the second opinion, either way or not. (G40, Victoria) Luckily, most of us have great relationships with our patients. So, we get to encourage them to be a key part of that process. And touch base regularly. Yeah, that's important, it's … I mean, we're blessed with that. (G43, Victoria)

Theme	Subtheme	Pathway	Example of reference quotes
			I think I've been looking after them for eight years, eight or nine years now. Three children have autism in their family. And so, I've seen them grow up. We've developed a trust with the children. (G23, NSW) I think as GPs we are pretty privileged that we get to grasp a broader understanding of family dynamics. Like you might see the other people in the family, you know, that mum or dad might have their own issues and that's why they can come and access as much therapy and intervention. (G23, NSW)
	Using concrete, standardised screening tools		I usually take a bit of time there to ask the mum how they are going. And so I have a little chart on my wall, one of those standard developmental screening charts to remind me of what kind of milestones they should be achieving at each, at each level. (G22, NSW) I think I would love for you all to sort of have these programs on a regular basis, so that we could utilise these programs and the ability to get quickly in and, thereby, sort of implement the strategies early, having a structure like what your setup is very good. And I think it will be pretty useful for all general practice. (G45, Victoria) So, in general, because we do that as part of a standard check-up anyway, so each time a child comes in for these checks we just ask a set of general questions in terms of their development. So, their motor skills, their social skills, their language and speech development, that sort of stuff. So, I think in terms of this study, it fits in perfectly with this study anyway. So, there's, there's nothing extra that we have to do except for the survey that they have to answer outside. (G24, NSW)
	Importance of early diagnosis, supports, and services		I think it's very important, our role's very important, because we need to start early, so that early intervention is good, because if it's delayed, then time is lost. And then it's harder to implement things when they're older. So it's always good to try and implement as early as possible. (G45, Victoria) Our role is to be able to be screeners in the community. And we are also information providers, we are points of reference for hearing parents who are concerned or teachers. So, I think that we're central to the actual general practice usually. (G37, Victoria) I also like your program. The child got huge benefit. This is why that I'm saying, how much the intervention earlier, the more benefits. He started everything, was so quicker for him. He got his NDIS so quick, and everything was very good. And I think this will also benefit GPs (G40, Victoria)
Suggested improvements	The need for a quick-reference educational guide for parents/ caregivers	SaU pathway	If it's a parental anxiety, some of the parenting resources can be useful, just so they can get an appreciation of what sort of normal development is and what the timeframe is. And I think that's more of an issue for parents where it might be their first child, and it's like, well, you know, are things on track, is it

Theme	Subtheme	Pathway	Example of reference quotes
			something we need to be worried about and, you know, sometimes getting another source other than me to confirm what I'm saying can be sort of reassuring in that sort of context. (G33, Victoria)
	In-clinic research support to liaise/administer the study to allow a consistent, streamlined process	ASP pathway	If we had someone with a, with an iPad who could actually go and screen in the waiting room, that might be an option utilising these opportunities during those immunisation periods to screen those patients when they come in, it could. Also having sort of like a navigator person in the waiting room, absolutely. Anything to help take the burden off the doctors and the nurses would be ideal. (G32, NSW)
	A comprehensive, streamlined process for developmental screening	Both pathways	Well, identifying and putting them into the right streamline are very important things that should happen to a child which is best not to fall under my responsibility, but I'm the facilitator, to some extent, of referrals. (G27, NSW) They get given the iPad straight away, or they get given a QR code and they can do it on their own phone. Perhaps that'd be even better than passing a company iPad around and do it on their own phone. And then we get the results by the time they finished the check with the nurse immunisations and we can discuss this results with them. And then if there's a pathway that says, do this next, or recall the patient in two months, or we will contact the patient. I think that'd be a great, a great tool for us. (G22, NSW)
	The need for further training and education for GPs on child developmental screening		I'm a very strong advocate in education for our medical students and also for GPs' need to pass the fellowship exams. Yeah. So what I'd like, if it could be put in a syllabus about RACGP syllabus for paediatrics, a standard approach to looking at milestones and giving us a little bit more education. I've trained as a GP back in the '90s, we didn't have that. Now we have the diploma of paediatrics, but not all doctors are going to do it. Yeah. I don't think I need to do it, but it'd be lovely if we could have updates on paediatrics milestones and maybe then put it in a way for young doctors coming through as part of the syllabus, paediatric milestones. I think that would be great, you know, if the research was done and then that way we could then have a standard thing and then it will prompt me as a supervisor to make sure that my registrar is competent in those things. (G26, NSW) I think, I would just have to admit that I lack the skills, I feel I lack the skills. I couldn't tell a parent how to improve speech or, you know, it's just not something that I'm trained in and have any exposure to, really… I would pretty much refer and support, but to specifically provide some instruction on, I'd hesitate, because I haven't had the training … with the unacceptable delays in time, and crucial time that, you know, we could be doing something, if we were upskilled and we're able to assist and put people in the right direction of what they can do while they're waiting. Absolutely. (G34, Victoria)

Theme	Subtheme	Pathway	Example of reference quotes
	The need for digital developmental screening		I think this is great, because it means that the patients can fill it out in the waiting room, they can come in with the information, sometimes it helps them to focus their ideas, because sometimes they've just had a bad day with the child or things be a bit hectic, and they don't focus on what the problems are. … But I think this sort of screening program where you've got a, an app or a way that the parent can put the information in, means that it's all written down for the GP. And it becomes much clearer. (G16, NSW) I think the computer and everything online is great now because people can actually visualise it in front of them. So, I actually use the computer and online services quite a lot during my consultations… So, in terms of developmental screening, it's, I find it really useful when there's … I show parents, they, you know, there's a table with the age and then you know, the milestones and that sort of stuff. (G24, NSW)
	The need for funding to conduct ongoing developmental screening		So if you had provision to have a Medicare item number for a say a health assessment type thing in which you could do for a developmental assessment, that would make a massive difference, because you [would] train your nurses up. And yeah, just makes it more feasible in [the] general practice model. (G36, Victoria) Time is very crucial… If we can convince [the government] that [we] need an [Medicare] item number, [that] probably will encourage the GP to do the development [screening] during the immunisation, or another appointment for this, if there is item number. So the benefit of having [an] item number is that GPs are not asked for that or told that they are over servicing. So over servicing is a big, big issue. To some degree, Medicare may say that we are billing too much. So, if that item number that can trace back what was the issue. The use [of] the time and claim the money. So, if the people pays privately, I can tell you many GP will do developmental assessment in their regular practice. A problem is the people don't want to pay GPs. (G41, Victoria), I think if you give any GPs a Medicare item to bill then that would capture a majority of actually doing something. (G44, Victoria) I think if it was earmarked as this is what this appointment's for, that, that would work. And I guess an [Medicare] item number would perhaps encourage doctors to participate, and but also for parents to understand that this is just what you do when this child reaches this age. It's just another thing that needs to be done. (G34, Victoria) If it could be a standalone, Medicare rebatable appointment to do it, then that would make it far more doable. To be honest, general practice, for the most part, is extremely time poor. And doing too many over too long a period would be difficult without some kind of way of slotting it in as an appointment or whatever. (G35, Victoria)

Theme	Subtheme	Pathway	Example of reference quotes
			… with general practice is that if you give [a] financial incentive to any kind of tool like that, you're always gonna have a great uptake. (G44, Victoria)
	Need for recognition of and support for GPs' role in developmental screening and ongoing care for children with developmental concerns	Both Pathways	One of the things that absolutely annoys me about the NDIS, is the exclusion of GPs, in general, from lots of the process, even though we are often the ones who have recommended that we go for an NDIS application, for some reason, we're often peripheral. While in fact, in helping parents understand how to ask for funding that's associated with goals for positive change, and we are in a position to understand what may help. (G43, Victoria) I don't think GPs can help much at the moment unless I see it in a different form, NDIS early developmental intervention. We don't have the expertise or the time, or the probably … definitely don't have the funding, so I don't think you're going to get any motivation to see GPs in this sphere. (G44, Victoria) I think it's important for GPs to be involved in that process. In terms of referrals. So, I mean, general practice with anyone is that, you know, was supposed to be the sort of that center point that is that, so that, you know, everything is communicated through the GP. So that everything centralised, and there's one person who knows what's going on, across whoever's involved in my management of that patient. The tricky thing being is that you see a lot of kids with developmental concerns that don't make the diagnosis. And your hands are a little bit tied on how much I mean, you can, help from a general practice perspective. (G36, Victoria)

Overall summary comparisons

Parents/caregivers and GPs offered some differing and similar views towards child developmental surveillance programs. There were more barriers presented by both parents/caregivers and GPs in the SaU pathway; in particular, parents/caregivers were concerned with the way child developmental surveillance is currently being conducted via general practice (i.e., SaU), and some of their anecdotal experiences were affirmed and felt by GPs. GPs in both pathways noted language and cultural barriers were evident for CALD parents/caregivers. Parents/caregivers in the SaU pathway also encountered multiple challenges when accessing specific paediatric care or allied health services due to long waiting time (waitlist) in receiving assessments and the consequent delay in receiving NDIS support, which often led to a major delay in getting their children the necessary early services and supports. This in turn usually causes a huge stress not only for the families but also for the GPs as the pressure falls on them to provide ongoing support and monitoring during the waiting period (i.e., by the time the child gets diagnosed, the condition has already cascaded or worsened as the child has aged).

Furthermore, the COVID-19 pandemic restrictions also led to changes in the way health professionals in both pathways conduct their practices, such as moving from face-to-face to predominantly telehealth consultation. Although the switch to telehealth consultations meant that GPs would have more time to do other tasks (since telehealth practice means that GPs do not have to physically move patients in and out from the waiting room and would stay in their consultation room with their device – such as a laptop, computer, or telephone), the reliance on technology to conduct an online consultation often created a barrier for GPs in receiving the full information or picture of their patients. For example, the use of online videoconferencing such as Zoom made it harder for GPs, as parents/caregivers preferred to complete the consultation without the child(ren) present, which made it difficult for GPs to understand the child's condition and meant they could not conduct developmental screening. This was confirmed by some of the parents/caregivers and GPs in both pathways. Parents/caregivers in the SaU pathway were concerned by the lack of clear communication and the explanations provided by GPs about their child's developmental condition, even though GPs adapted themselves very rapidly with the pandemic situation. It is apparent from the parent/caregiver and GP interviews in both pathways that trust and rapport between health professionals and patients are vital in working together towards supporting the child.

Participation in research was perceived positively by parents/caregivers in both pathways, with inconsistencies for GPs. Parents/caregivers enjoyed being a part of the research study and contributing towards a 'higher cause'; for example, digital screening checks were simple and easy

to complete, and as a result they were able to access timely identification and diagnosis of their child by participating in the research. Some state-based differences noted for GPs. In NSW, this was predominantly caused by the COVID-19 pandemic, which meant the research team were not able to visit the practices or address technical issues in a timely way. Since the research trial was ceased earlier than expected, it was not possible to fully implement the education and training component and the feedback loop and support for parents/caregivers to access services once concerns were identified as were all adversely impacted. This view was not shared by the GPs in Victoria, with most reporting they enjoyed being part of the research and felt remorseful that they could not recruit children into the study due to the long and stringent lockdowns in Victoria.

GPs in NSW also reported technical difficulties that were not reported by GPs in Victoria. For instance, most NSW GPs in the ASP pathway could not access the surveys that parents/caregivers had completed as the reception staff were required to print an email containing these results and pass it on to the GP; hence, the implementation flow of the digital tools between parents/caregivers and GPs in NSW did not work smoothly. GPs in Victoria did not face these same technical issues, as the parent/caregiver questionnaires and SACS Online tool were integrated into a single online system, allowing GPs to access the results from the parent/caregiver questionnaires instantaneously. Nonetheless, it is important to note that rather than using study iPads, switching to parents/caregivers completing the questionnaires on their own device (accessing the questionnaires via link or QR code) would in future solve this issue by making it easier for families to complete the questionnaires, on their own device rather than using the clinic iPad. Further, providing the link to families prior to attending the clinic for the consultation could also streamline the process. This would enable parents/caregivers to use a larger device (e.g., laptop, computer) if preferred and would ensure sufficient time to complete the questionnaires prior to seeing the GP.

Time was the biggest factor mentioned by GPs in both pathways for clinics to fully participate, as reception staff found it difficult to explain the study in their limited capacity, indicating that an ‘opt-out’ approach may be preferable for future studies (i.e., all children undergo developmental monitoring, unless otherwise specified). Additionally, GPs in the ASP pathway found it difficult to conduct developmental screening in their 15 minute consultations, in addition to the reason the appointments were booked (e.g., for immunisations or other specific concerns). GPs expressed the need to either book longer appointments (which may not be financially viable for all families especially, if the clinics are privately billed) or have a Medicare Benefits Schedule (MBS) item number so that they can conduct development screenings. The need for staff coordination and navigation support is therefore significant to allow a proper implementation of this digital

developmental surveillance program. Most GPs in the ASP pathway indicated that the training and resources provided were highly beneficial as it helped them to understand the early signs of autism and they felt more confident while referring parents/caregivers to specialist services. They also expressed the need for ongoing access to an autism screening tool for clinicians. Parents/caregivers and GPs in both pathways also attested the need for further training and education around child developmental checks for clinicians and the wider community, without which they felt inadequate to conduct development screening.

5. Findings

This study provided initial evidence for the feasibility and acceptability of the digital screening checks for early identification of developmental difficulties including early signs of autism. Through the ASP pathway, a greater number of children were identified who had developmental differences and autism in comparison to the SaU pathway. The results of the 'gold standard' assessment of screen negatives and the outcomes of the SRS-2 at 30 months of age indicated that the majority of 'low likelihood' children in the ASP pathway were correctly classified, and thus that the ASP pathway is accurate. The psychometric analysis of the ASP pathway also found that it has high sensitivity, specificity, NPV, and PPV, indicating that the ASP pathway is accurate in identifying children who will go on to have an autism diagnosis. It also highlighted the need for developmental surveillance, as opposed to single point in time developmental screening, in order to ensure all children with developmental differences or concerns are identified.

The consensus from the qualitative study with parents/caregivers and GPs was that the tools in the ASP pathway were simple and easy to complete, and as a result they were able to access timely identification and diagnosis for their children where required. They also indicated that it helped build their confidence and knowledge in identifying the early signs of autism. However, some parents/caregivers were not able to complete all required questionnaires while waiting for the appointment, with access to these prior to the appointment suggested. The study also highlighted the need for structural changes within general practice, such as further training of service providers and awareness of the community, the importance of child developmental checks and ongoing monitoring in the critical toddler years. Specifically, the need for sufficient time for GPs to complete developmental checks, and a Medicare item for this, was raised by both GPs and parents/caregivers.

The findings from this study suggest that parents/caregivers encounter multiple barriers to accessing early identification of developmental difficulties including autism, due to long waiting

times and major delays in getting their child assessed, with further wait for NDIS support to access early supports and services. This is particularly evident for parents from culturally and linguistically diverse backgrounds, who experience added waiting time due to lack of appropriate service providers available in the community. The resulting parental stress is also shared by the GPs, as the GPs provide families with ongoing support during the waiting period, but they are not adequately resourced or have the necessary training to do so.

6. Strengths and limitations

This is a study in a defined geographical region of NSW (South West Sydney) and Victoria (metropolitan Melbourne) and some of the findings in relation to barriers and enablers may be related to local issues and the circumstances over the study duration caused by the COVID-19 pandemic. However, the findings sit within the broad international literature on the challenges in the use of screening tools, within a developmental surveillance framework, by health professionals and thus the findings from this study appear to be transferable to other similar settings.

Despite the careful planning by the study team for the roll-out of the research and flexible attempts to maintain the study during unprecedented events, the severe and ongoing impacts of the COVID-19 pandemic on both general practices and families had a devastating impact on the study. There were practices who had completed the research training but could not commence the study or recruit any/many participants due to the COVID-19 pandemic restrictions and lockdowns, which may have led to a skewed sample in terms of GPs' responses towards the research study set-up. Furthermore, given the challenges experienced by the community, and in particular families with young children during the extensive lockdowns, it is not unexpected that reduced participation would also stem from the parent/caregiver side.

Another limitation of the study is that the cultural background of the health professionals and parents/caregivers and how these impact on their perceptions on the use of screening tools was not explored specifically. Nonetheless, the study was able to gain valuable perspectives of GPs and parents/caregivers regarding barriers, enablers, and suggested improvements for current developmental screening through community general practices and the ASP pathway research setup, which may likely be relevant to other settings.

We maintained the quality of the study through an awareness of reflexivity and efforts to achieve a high level of interpretive rigour/trustworthiness. For the qualitative data, 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, with an acceptable inter-rater reliability for interview data with parents/caregivers and GPs. The other strengths included access to a semi-structured interview guide with a highly diverse study population, and a relatively large cohort of participating health professionals and parents/caregivers from both states and study arms.

7. Implications for research and practice

As noted above, significant learnings were gained in terms of conducting and adapting a large scale RCT during a pandemic, which, given the ongoing lockdowns due to COVID-19 both in Australia and worldwide, would prove useful for future research. Practical considerations include projects being designed to enable participants to complete questionnaires and other measures remotely or on their own devices when required and ensuring studies can be pivoted to account for lockdowns, with such measures built into the study where possible. Additionally, parent/caregiver-facing materials such as information and consent forms need to be simple and brief, to facilitate a better understanding of the study requirements for studies based in busy environments such as general practice. Alternatively, other methods such as approaching parents/caregivers prior to attending an appointment or 'opt-out' recruitment should be considered.

A summary of the process for autism surveillance based on the best practice recommendations as outlined in the National Guideline has been developed (see Appendix A) and distributed to all GPs who participated in this study. This could be developed further for wider dissemination through the Royal Australian College of General Practitioners (RACGP) and the Australian College of Rural and Remote Medicine (ACRRM), as well as the Australian Nurse Practitioners Association (ANPA). This autism surveillance process could also be presented to relevant Federal and State Government health agencies to propose unifying the processes for early identification of autism across Australia as part of the wider implementation of the National Guideline.

8. Key recommendations

Based on the outcomes and learnings from this study, the key recommendations are as follows:

- **Increase awareness** and importance of developmental screening/surveillance among GPs. This should focus on providing GPs with education and training about the signs of autism (across the lifespan and for all genders), implementing National Guideline recommendations for the autism diagnostic process and effective support mechanism for

individuals on the autism spectrum and their families.

- **Wider dissemination of early autism training for GPs** (i.e., SACS) and general child development training (i.e., RACGP modules developed for GPs and PNs), along with wider implementation of the National Guideline, can help increase the capacity of the GPs and PNs to support children and families.

- The Medical Services Advisory committee should include an **MBS item** allowing GPs to book appointments specifically for developmental screening/surveillance, as most GPs expressed 'insufficient time' within a typical appointment as a constraint to the regular and consistent use of developmental screening/surveillance.

- Parents/caregivers should be given access to parent/caregiver completed tools **prior to attending** the clinic for the appointment, to ensure sufficient time to complete the questionnaires and enable GPs to have timely access to the results.

- Develop **resources for parents/caregivers** including CALD communities to inform and educate families on the importance of early developmental monitoring.

- There is a need to **increase the number and capacity of professionals** (including cultural and linguistic diversity) available in the community to undertake autism assessments through the roll out of autism diagnostic training for multidisciplinary child health professionals.

- NDIS process to **include provision for GPs to provide ongoing care, support, and appropriate referrals** to children and parent/caregivers.

9. Conclusion

Early identification and access to early supports and services for children on the spectrum and/or with other developmental conditions can significantly assist them to reach their potential and improve long-term wellbeing of children and their families. This study found that it is feasible for GPs to engage parents/caregiver in developmental monitoring of children with the use of a standardised autism surveillance pathway. Both parents/caregivers and GPs showed support for

such a program, citing the importance of early identification of developmental conditions as well as the important role GPs play in the support of families.

The study also found that there is an urgent need to improve GPs' abilities and confidence in early identification of autism and providing care for autistic children and their families. To undertake developmental surveillance and early detection of autism, all GPs require up-to-date training on the early signs of autism and general child development. They also require training on how to raise concerns and support children on the spectrum and their families, along with access to accurate and easy to access evidence-based early autism identification tools. Time and financial constraints are other factors that impede the implementation of developmental monitoring in general practice, which can be overcome through the creation of MBS items specifically for child developmental surveillance. This would enable GPs to book children for a separate, specific child developmental surveillance consultation, therefore providing appropriate time and consideration for the consultation, as well as providing access for parents/caregivers who do not have the resources for a privately paid consultation.

In addition to this, both GPs and parents/caregivers noted the importance of the availability of resources available to the community, such as the promotion of child developmental monitoring, and access for such resources for CALD communities. Increased access to professionals for the diagnosis and support of children on the spectrum was also highlighted.

In conclusion, this study supports the use of early autism and developmental surveillance using standardised parent/caregiver and clinician tools in the general practice setting. The results indicated that both GPs and parents/caregivers were interested in the use of the ASP pathway tested in this study and that this pathway was successful in identifying children who were on the spectrum and/or had other developmental conditions. The fulfilment of the recommendations reported here would be of benefit to the implementation of an effective and national program for developmental surveillance of Australian toddlers for the early signs of autism and other developmental conditions.

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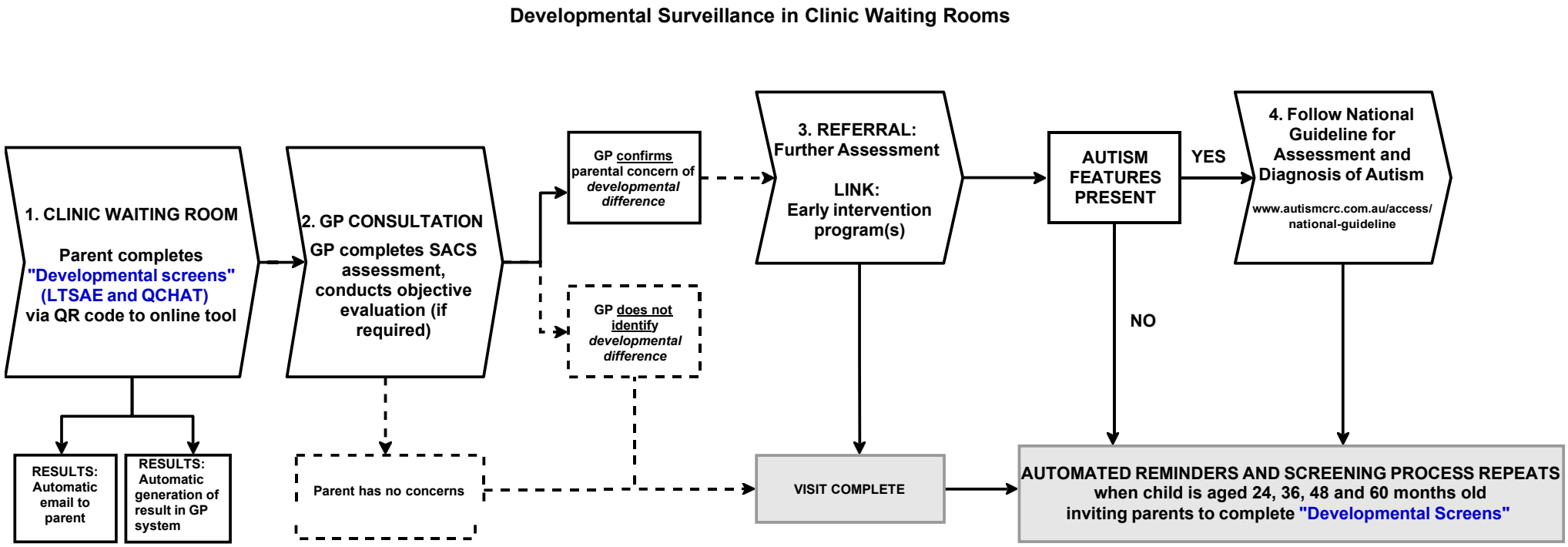
Appendix A

Developmental Surveillance Flow-Chart



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Our values

Inclusion

Working together with those with the lived experience of autism in all we do

Innovation

New solutions for long term challenges

Evidence

Guided by evidence-based research and peer review

Independence

Maintaining autonomy and integrity

Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone

Australian Government
Department of Industry, Science, Energy and Resources

AusIndustry
Cooperative Research Centres Program