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Abstract

Timely autism spectrum disorder (ASD) diagnosis is critical to access early intervention. The objectives of this thesis were to 1) conduct a systematic review of ASD diagnosis guidance documents; 2) conduct a policy scan of Canadian and UK policies for ASD diagnosis; 3) describe Canadian ASD diagnostic practices through a national survey of paediatricians; and 4) identify determinants of wait times for ASD diagnosis. The systematic review and policy scan showed varying recommendations for ASD diagnosis. The 91 survey respondents described divergent ASD diagnostic assessment practices. Duration of the assessment was a determinant of wait time for the first visit of the assessment and total wait time. The mean adjusted wait time from referral to communication of the diagnosis was 254 days (95% confidence interval 214, 302). ASD diagnostic guidance and practices vary widely. Efficient assessment practices are a key element of reducing wait times and facilitating access to intervention.
Acknowledgments

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I would like to thank my patients and their families. You inspire me every day to try to make the world a better place for people with ASD.

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<tr>
<td>AACAP</td>
<td>American Academy of Child and Adolescent Psychiatrists</td>
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<tr>
<td>AAN</td>
<td>American Academy of Neurology</td>
</tr>
<tr>
<td>AAP</td>
<td>American Academy of Pediatrics</td>
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<tr>
<td>ABA</td>
<td>applied behavioural analysis</td>
</tr>
<tr>
<td>ADI-R</td>
<td>Autism Diagnostic Interview – Revised</td>
</tr>
<tr>
<td>ADOS</td>
<td>Autism Diagnostic Observation Schedule</td>
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<tr>
<td>ADDM</td>
<td>Autism and Developmental Disabilities Monitoring network</td>
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<tr>
<td>AOTA</td>
<td>American Occupational Therapy Association</td>
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<tr>
<td>ASD</td>
<td>autism spectrum disorders</td>
</tr>
<tr>
<td>ASHA</td>
<td>American Speech-Language-Hearing Association</td>
</tr>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>CADTH</td>
<td>Canadian Agency for Drugs and Technology in Health</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>CPS</td>
<td>Canadian Paediatric Society</td>
</tr>
<tr>
<td>d.f.</td>
<td>degrees of freedom</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<tr>
<td>EIBI</td>
<td>early intensive behavioural intervention</td>
</tr>
<tr>
<td>INSAR</td>
<td>International Society for Autism Research</td>
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IQ          intelligence quotient
Log         natural logarithm
M-CHAT      Modified Checklist for Autism in Toddlers
MDT         multi-disciplinary team
MP          Melanie Penner
NEDSAC      National Epidemiologic Database for the Study of Autism in Canada
NICE        National Institute for Health and Care Excellence
NP          Nurse practitioner
NPS         National Physician Survey
NS          Not specified
OR          Odds ratio
OT          Occupational therapist
PEI         Prince Edward Island
PDD-NOS     pervasive developmental disorder - not otherwise specified
PRISMA      Preferred Reporting Items for Systematic Reviews and Meta-Analyses
Q-Q         Quantile-quantile
REDCap      Research Electronic Data Capture
s.d.        Standard deviation
SLP         Speech-language pathologist
Time 1      The wait time from referral to the first visit of the ASD diagnostic assessment
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<td>UK</td>
<td>United Kingdom</td>
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1 Introduction

1.1 Statement of problem

The rise in the estimated prevalence of autism spectrum disorders (ASD) has created an increased demand for ASD diagnostic assessments (Centre for Disease Control National Center on Birth Defects and Developmental Disabilities, 2014). Wait times for these assessments occur during a time period when the brain is optimized for social learning (Dawson, 2008) and these wait times can jeopardize long term outcomes for children with ASD by delaying access to early behavioral intervention programs (Perry et al., 2011).

Numerous guidelines have been developed for the assessment and diagnosis of ASD, which have been noted to vary in their recommended practices (Canadian Agency for Drugs and Technology in Health, 2013). One frequent recommendation from these guidelines is that the assessment should be conducted by a multi-disciplinary team (MDT), defined here as two or more professionals from different backgrounds that each carry out part of the assessment and decide on the diagnosis based on their expertise (Dua, 2003; The Miriam Foundation, 2008; Volkmar et al., 2014). Due to the requirement of multiple expert assessors, these practice guidelines may place further stress on the health care system to efficiently assess cases of suspected ASD.

While the Canadian Agency for Drugs and Technology in Health (CADTH) has synthesized a review of guidelines as they pertain to screening and diagnostic tools, a higher-level overview of these guidelines and their implications for practice has not been performed. Guidelines exist for different governmental jurisdictions (Dua, 2003; National Collaborating Centre for Women's and Children's Health, 2011; The Miriam Foundation, 2008) as well as for different professional associations (Filipek, Accardo, Ashwal, Baranek, Cook, et al., 2000; Johnson, Myers, & American Academy of Pediatrics Council on Children With Disabilities, 2007). A comprehensive policy analysis of these guidelines is needed to provide a necessary evaluation of the existing recommendations for practice, as well as to examine the ideas, institutions, and interests that have shaped their development.

There currently is no information available about Canadian wait times for ASD diagnosis, as well as where any potential bottlenecks occur in the referral process. Existing studies from the
United States have focused mainly on patient demographic factors that influence wait times (Mandell, Novak, & Zubritsky, 2005; Wiggins, Baio, & Rice, 2006). There is similarly no information about practice patterns (such as the use of MDTs and tools for assessment), and their associations with wait times. Further information is needed about Canadian practice realities and patterns. Unfortunately, there is no current mechanism in Canada to obtain these data from health administrative records or similar data sources. A survey of clinician practices is, at present, the most feasible way to collect information about national wait times for ASD diagnosis. This information can be used to determine resource use associated with various diagnostic models, as well as their respective wait times. This information is essential for further Canadian policy development and resource planning for ASD diagnosis.

1.2 Definition of Autism Spectrum Disorder

The term Autism Spectrum Disorder (ASD) covers a heterogeneous constellation of characteristics and severity levels of autistic features. ASD is a lifelong neurodevelopmental disorder characterized by social communication deficits and restrictive repetitive behaviours, as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2013). The DSM-5 diagnostic criteria are presented in Table 1. These symptoms must be present in early life, but may not cause impairment until later in life, when the social and behavioral demands placed on the child exceed their capacity for social interactions and accepted behavior. Further, these symptoms must cause impairment in the child’s daily functioning. Clinicians are also encouraged to comment on the presence of intellectual and/or language impairment. A new addition to the DSM-5 was descriptions of levels of severity of social communication impairments and restrictive repetitive behaviors, categorized into “Requiring support”, “Requiring substantial support”, and “Requiring very substantial support”. The diagnosis of ASD is made based on clinical criteria listed in the DSM; there is no “gold standard” objective test for ASD.
### Table 1: Diagnostic Criteria for Autism Spectrum Disorder

A: Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (all three are required):

1. Deficits in social emotional reciprocity;
2. Deficits in nonverbal communicative behaviors used for social interaction;
3. Deficits in developing, maintaining, and understanding relationships.

B: Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech;
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior;
3. Highly restricted, fixated interests that are abnormal in intensity or focus;
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment.

C: Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies later in life.

D: Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E: These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Source: DSM-5 (American Psychiatric Association, 2013); illustrative examples present in the original text have been removed for brevity.
Previous editions of the DSM described multiple, distinct ASD diagnoses (under the umbrella term “pervasive developmental disorders”) that were differentiated based on severity: autistic disorder was defined by communication, social and behavioral impairments; Asperger’s syndrome was characterized by typical language and cognitive development; and pervasive developmental disorder – not otherwise specified (PDD-NOS) was a manifestation of some, but not all, of these features (American Psychiatric Association, 2000). Over time, the validity of these subcategories came into question. Clinically, the distinctions between the diagnoses blurred, with a realization that language and cognitive skills could range from very delayed to very advanced in children with ASD (Miller & Ozonoff, 2000). The rapidly emerging information about the etiological underpinnings of ASD failed to show biological support for the categorical classifications (Ronald et al., 2006). In practice, these clinical subtypes were difficult to distinguish from one another, even for trained professionals using standardized tools (Mahoney et al., 1998). The previous conceptualization of distinct ASD subtypes added further diagnostic complexity to an already complex disorder.

In response to this new evidence and thinking about ASD, the more recent DSM-5 combined these diagnoses into a single, broad ASD term with two symptom dimensions: social communication/interaction and restricted/repetitive behaviors (American Psychiatric Association, 2013). A validation study using latent class analysis and factor analysis to categorize symptoms from nearly 15,000 siblings of children with ASD (9,000 with ASD and 6,000 without) showed that a categorical model (ASD versus non-ASD) with two symptom dimensions was more parsimonious than other models (Frazier et al., 2012).

One diagnostic label is also likely to simplify the diagnostic process for clinicians. ASD studies conducted prior to the DSM-5 show the greatest disagreement between subtypes of ASDs, particularly the atypical autism types (Mahoney et al., 1998). Large community-based studies in the United States have shown a very small migration from diagnoses of ASD to non-ASD (only 4% of cases; Wiggins et al., 2012).

### 1.3 Prevalence of ASD

The most widely cited estimates of ASD prevalence are provided by the Autism and Developmental Disabilities Monitoring (ADDM) network, a surveillance system coordinated by the Centers for Disease Control in the United States (Centre for Disease Control National Center
on Birth Defects and Developmental Disabilities, 2014). To garner these estimates, the ADDM uses up to fourteen population-based sites and focuses on eight-year-old children. The ADDM requests health and education records in each of these sites, and trained clinicians review those with indications of developmental or educational concerns to determine ASD case status, based on a documented diagnosis of ASD or on clinical descriptions consistent with DSM criteria.

The most recent estimates from the ADDM are that ASD affects one in 68 children, representing a steady increase in prevalence since 2002. These numbers are based on surveillance from eleven sites reporting for the year 2010. Of note, this reflects prevalence under the previous DSM-IV-TR criteria. There were significant variations in ASD prevalence based on geographic area, sex, race/ethnicity, and intellectual ability. The authors note that the degree to which this variation has been influenced by diagnostic practices, under-recognition in some race/ethnic groups, socioeconomic disparities, and regional differences in health or educational practices is unclear. The recommended public health actions suggested by the authors included use of standardized measures to document ASD severity and functional impairments, improved recognition and documentation of ASD (particularly in children without intellectual disability and children in certain racial/ethnic groups), and decreasing the age of first evaluation for a diagnosis of ASD to allow enrollment in community supports.

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) was created in 2001 to monitor the prevalence of ASD in various regions of Canada (The National Epidemiologic Database for the Study of Autism in Canada, 2009). Their latest report, published in 2012, reported on ASD prevalence in Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario (The National Epidemiologic Database for the Study of Autism in Canada, 2012). Estimates of prevalence are based on identification of children with ASD provided by service agencies, with subsequent telephone interviews to confirm the diagnosis and obtain further information. Prevalence was calculated as the number of cases aged two to fourteen identified in the region divided by the total number of children aged two to fourteen in that region (as determined by Statistics Canada). The prevalence among the five- to nine-year-old children in the sample closely matches the ADDM values, with a reported prevalence of one in 93, one in 104, and one in 63 for Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario, respectively. All three regions reported an approximate increase of 100% in the reported prevalence in 2008-2010 versus 2003.
Both the ADDM and NEDSAC demonstrate a steadily increasing prevalence of ASD over the past decade. Despite increasing awareness of ASD and a push for earlier identification, the age at diagnosis remained static, and even increased in some cases (The National Epidemiologic Database for the Study of Autism in Canada, 2012). This indicates that a thorough investigation of the processes for early identification and diagnosis of ASD is warranted.

1.4 Screening and surveillance for ASD

The first step toward diagnosing ASD is identifying children who show signs of the disorder. Screening involves the administration of a specific instrument at a specified point in time to identify risk in a chosen population, whereas surveillance is an ongoing process of detecting risk (Johnson et al., 2007). Screening can be directed at the whole population (universal screening), or at a subset with elevated risk, such as children with a family history of ASD or children showing developmental concerns.

Varying approaches have been proposed and adopted to improve the identification of children showing signs of possible ASD. The American Academy of Pediatrics (AAP), the most respected international authority in pediatric practice, has published guidelines recommending universal surveillance for ASD in the primary care setting, coupled with universal screening with an ASD screening tool at eighteen and twenty-four months (Johnson et al., 2007). Critics of universal screening have noted that the positive predictive value of current screening tests would generate an excessive number of false positive referrals for diagnostic evaluation, though it is worth noting that these analyses occurred prior to the most recent estimates of ASD prevalence (Groen, Swinkels, van der Gaag, & Buitelaar, 2007).

The Canadian counterpart to the American Academy of Pediatrics, the Canadian Paediatric Society (CPS), does not recommend universal ASD screening. Instead, their Early Years Task Force has recommended an enhanced eighteen-month well-baby visit that includes a general developmental screening tool, along with ongoing developmental surveillance (Williams & Clinton, 2011). There is no specific mention of ASD in the recommendations, though there is a note that primary care clinicians should be able to identify children who require further investigation, diagnosis, and treatment.
At present, there are no initiatives or policies published by the Canadian federal government relating to screening for ASD. The Miriam Foundation, a non-profit organization “helping people with autism spectrum disorder and intellectual disability lead fulfilling lives” (The Miriam Foundation, 2015), has published “Canadian Best Practice Guidelines” for screening, assessment, and diagnosis of ASD (The Miriam Foundation, 2008). In these, they suggest a model of universal developmental surveillance in primary care settings, coupled with secondary ASD screening for those with identified developmental concerns or who are at higher risk due to an affected sibling. In 2009, the province of Ontario implemented enhanced eighteen-month developmental screening as an initial screen targeting all children, with suggested use of generic developmental screening tools (the Rourke Baby Record and the Nipissing District Developmental Screen, not ASD-specific) and an accompanying billing code to provide additional incentive to complete this screening (Ontario Ministry of Child and Youth Services, 2011c). This was intended to ensure that all children received developmental screening, in addition to recommended surveillance. Of note, there is no published data indicating the sensitivity and specificity of these generic developmental screening tools to identify ASD.

Government-led initiatives for ASD and other developmental screening have been popular in other jurisdictions. The United States federal government released their “Birth to Five: Watch Me Thrive!” initiative in concert with the latest ADDM report of increasing ASD prevalence (U. S. Department of Health and Human Services, 2014). This initiative is aimed at increasing universal developmental screening by providing a toolkit of developmental screening tools with suggestions that they be performed at nine, eighteen, and twenty-four months.

The above examples point to an increased policy interest in screening and surveillance programs; however, there have been no accompanying strategies to deal with the increase in identified cases of suspected ASD, including false positive cases. This has the potential to create a bottleneck to access a definitive diagnosis, which is often required to access ASD-targeted interventions.

1.5 Diagnosis of ASD

There is no gold-standard test for ASD, and the diagnosis is made based on fulfillment of the diagnostic criteria in the DSM-5 (American Psychiatric Association, 2013). Clinicians are encouraged to elicit history of the diagnostic criteria and to pair this with observations of the
child. Fulfillment of the criteria requires an impairment of the child’s day-to-day functioning as a result of the autistic symptoms.

The DSM-5 does not put any additional requirements on the diagnostic process; however, jurisdictions may mandate elements of the diagnostic assessment by linking them to eligibility for publicly funded services. One example is British Columbia (BC)’s practice guideline for diagnosis, for which the diagnostic tools used must be documented for the child to receive funding for behavioural therapy (Dua, 2003).

In addition to determining whether a diagnosis of ASD is warranted, the assessment also informs the child’s developmental profile, or a holistic description of the child’s developmental strengths and weaknesses. The neurodevelopmental profile can help to provide additional understanding of the child’s cognition, emotions and behavior, and can also be used to tailor treatment to the child’s needs.

1.5.1 Personnel in the diagnostic assessment

The number and type of clinicians that must be involved in the diagnostic process is not specified in the DSM-5, though many guidelines suggest that assessments performed by multiple health professionals represent best practice (Dua, 2003; Filipek, Accardo, Ashwal, Baranek, Cook, et al., 2000; National Collaborating Centre for Women's and Children's Health, 2011; The Miriam Foundation, 2008; Volkmar et al., 2014). These groups of professionals are often referred to as a multi-disciplinary team (MDT), defined here as two or more professionals that carry out aspects of the assessment based on their particular expertise.

1.5.1.1 Accuracy of different personnel using DSM-IV-TR criteria for ASD subtypes

There is only one published study that examines the opinion of a single clinician diagnosis compared to a team of ASD specialists. The study by Mahoney et al. (1998) compared diagnosis made by a solo child psychiatrist to a case review by a team of three expert raters who had access to the assessment, but not the diagnostic formulation (the team did not directly assess the study participants). The study occurred during the era of multiple diagnostic subtypes of ASD, and thus measured agreement between the solo child psychiatrist and the MDT on their classification of ASD diagnostic subtypes. The overall Kappa for the sample was 0.55, or moderate (0.56 for
autistic disorder, 0.52 for Asperger’s syndrome, 0.29 for atypical autism). There was excellent agreement on non-ASD cases (Kappa = 0.81). The authors concluded that the low agreement for atypical autism suggested that single clinician diagnosis of these cases was of questionable value.

A retrospective study by Daniels et al. (2011) examined the stability of initial ASD diagnoses in community settings by the type of practitioner that made the diagnosis. More than 7000 parents reported whether their child’s current diagnosis was different than the initial diagnosis given (including DSM-IV-era diagnostic subtypes). The rates of diagnostic shift were compared between cases diagnosed by MDTs and cases diagnosed by various types of solo clinicians. The highest odds of shift compared with MDT occurred with solo paediatrician diagnosis (OR = 1.73, 95% CI 1.31, 2.29). One hypothesis for this higher rate of shift was that solo clinicians may see children earlier than MDTs; however, there was no difference in age at evaluation between the groups (though there was a higher rate of diagnostic shift in children who were diagnosed at an earlier age). The data did not allow for determination of whether the child’s diagnostic status changed between ASD/non-ASD; as such, the application of these findings in the era of DSM-5 is unclear.

1.5.1.2 Evaluation of less-specialized assessors

The recommendation for multiple experienced assessors has not changed with the increasing prevalence of ASD diagnoses and resulting demand for ASD assessments. Few studies have evaluated the abilities of less-specialized assessors in the diagnosis of ASD. McClure, Mackay, Mamdani, and McCaughey (2010) performed a study attempting to increase local diagnostic capacity in Lomond and Argyll in Scotland. The investigators trained teams of three professionals (a paediatrician, a psychiatrist and a speech-language pathologist), all of who initially had little ASD experience, to conduct ASD assessments. The local teams agreed with a subspecialist MDT as to an ASD/non-ASD diagnosis on 92% of the 33 cases. Moreover, the average wait list time decreased by 23 weeks.

Warren and colleagues in Tennessee have developed a training program, the Screening Tools and Referral Training-Evaluation and Diagnosis training program, to assist community paediatricians in the diagnosis of ASD (Warren, Stone, & Humberd, 2009). This program emphasizes diagnostic history-taking, communication of results to the family, and billing codes, as well as training participants in use of the Modified Checklist for Autism in Toddlers (M-CHAT) and the
Screening Tool for Autism in Toddlers and Young Children. Their pilot evaluation of the program with five community paediatricians showed diagnostic agreement between the paediatricians and a MDT assessment in 71% of twenty-one cases, equivalent to a kappa of 0.42, or fair agreement (Warren et al., 2009). A subsequent evaluation of this program published evaluated paediatrician self-reports of practice change related to identifying ASD as well as diagnostic agreement in a small sample of cases (Swanson et al., 2014). The authors found that the twenty-seven community paediatricians who participated in the training program reported an 85% increase in diagnostic identification of ASD eighteen months after training. Using a forced-choice classification, there was diagnostic agreement between the community paediatrician and the MDT in twelve of fourteen cases (86%; one false-positive, one false-negative). When community paediatricians were allowed to indicate uncertainty in their diagnostic classification, the agreement improved to 93%, with one false negative.

1.5.1.3 Parent preferences for assessment personnel

Parent preferences have not always supported the involvement of multiple clinicians in the diagnostic process. A 1997 survey of over 1,200 patients in the United Kingdom (UK) found that the child’s age at diagnosis and the length of delay until final diagnosis (both of which can be impacted by the multiple referrals required to access a subspecialist diagnosis) were significantly associated with parent dissatisfaction (Howlin & Moore, 1997). In Canada, a 2001 study reported that families saw an average of 4.46 (standard deviation 2.42) professionals during the diagnostic process, with the majority of parents reporting they were dissatisfied with the process (Siklos & Kerns, 2007). Goin-Kochel, Mackintosh, and Myers (2006) found that in their sample of nearly 500 parents surveyed, there was an inverse relationship between parental satisfaction and the number of professionals seen (chi square = 36.0, p<0.0001). Interestingly, satisfaction was not associated with the type of professional making the diagnosis. Moh and Magiati (2012) found that in their sample of over 100 parents of children with ASD, the number of professionals consulted was positively related to parental stress (t = 2.44, p = 0.02). Qualitative studies have shown that parents cite that the period of time spent knowing that their child may warrant a diagnosis of ASD but not having this confirmed was difficult (Abbott, Bernard, & Forge, 2013). While eliciting paediatric patient preferences for diagnosis may not be possible, a UK study of adults with high-functioning ASD asking about their perceptions of the diagnostic process found that the number of professionals seen was marginally significantly associated with dissatisfaction.
(p = 0.04), while the quality of information given (p = 0.007) and time to diagnosis (p = 0.005) had a stronger association with satisfaction (Jones, Goddard, Hill, Henry, & Crane, 2014).

Though the evidence base is limited, limiting ASD diagnosis to multiple expert assessors is likely to increase resource use and decrease access to assessment. At present, there is little evidence to support improved accuracy of MDT diagnosis over solo clinician diagnosis or enhanced benefits in terms of satisfaction with the diagnostic process from the perspective of parents or individuals with ASD.

1.5.2 Standardized diagnostic tools

It is not possible to discuss diagnosis of ASD without discussing the available standardized diagnostic tools. There has been little study of the broad accuracy of diagnostic models, but much emphasis has been placed on developing and contrasting tools for diagnostic assessment for ASD.

A report from the International Society for Autism Research (INSAR) Special Interest Group in Global Knowledge Translation in Early Identification and Identification in Autism (2013) notes that many of these tools were developed in a research environment for the purposes of assessing individuals with ASD in a way that was standardized and, as an extension, comparable. They also note that these tools, due to the “rich clinically-relevant” information they provide, have transitioned into routine clinical use, and that this is consistent with the “widely recognized general principle that standardized [authors’ emphasis] assessment is beneficial in aiding clinical evaluation.”

Research has been performed on these tools to establish their accuracy when compared to a MDT consensus best estimate of ASD diagnosis. The vast majority of this literature focuses on two tools, the Autism Diagnostic Interview – Revised (ADI-R) (Rutter, Lecouteur, & Lord, 2003) and the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2012) as well as their performance in combination.

The ADI-R is a structured parent interview administered by a trained clinician, which elicits behaviors consistent with ASD (using the DSM-IV-TR diagnostic criteria). It takes approximately two to three hours to administer. The most recent research to establish clinical cut points for ASD published for children aged 12 to 47 months (with a mental age of at least ten
months) have algorithms for three clinical groups: children without speech (sensitivity 85 to 90%; specificity 64 to 94%), children with single words (sensitivity 94 to 97%; specificity 58 to 83%), and children with phrase speech (sensitivity 80 to 89%; specificity 70 to 94%; Kim & Lord, 2012b; Kim, Thurm, Shumway, & Lord, 2013).

The ADOS is a standardized, semi-structured observation and interaction protocol used to elicit and code social communication skills and restrictive, repetitive behaviours. It takes approximately 60-90 minutes to administer and score. Using the “autism” cut point (as opposed to the lower “autism spectrum” cut point, actual score varies by module) sensitivities for children under age five have been reported from 86 to 98%, with specificities ranging from 80 to 100% (Oosterling et al., 2010).

The ADI-R and ADOS, while having been individually validated for the assessment of ASD, have also been evaluated in combination. Falkmer, Anderson, Falkmer, and Horlin (2013) published a systematic review aiming to optimize diagnostic procedures and identify the best diagnostic instruments. The authors found that the combined use of the ADI-R and ADOS produced correct classification rates similar to the accuracy of MDTs, which they quote as being 80.8%. They recommend the combined use of the ADI-R and ADOS, though note that further research in the costs and benefits of ASD diagnosis is warranted.

A recent Swedish study of 268 children under 48 months (n = 171 with ASD) aimed to evaluate the relative value of each test, as well as their combination, in a clinical (as opposed to research) environment (Zander, Sturm, & Bolte, 2015). Their results showed the sensitivity for the current research cut point of the ADI-R alone to be unacceptably low (44 to 52%), which improved with an adjusted lower cut point score (60 to 62%). The specificity decreased from a range of 91 to 96%, to 77 to 82% with this adjustment. The ADOS performed well, provided the higher “autism” and not the “autism spectrum” cut point was used, as the latter was associated with high sensitivity and low specificity. When the two instruments were combined (using the adjusted cutoff for the ADI-R), the sensitivity was 77 to 80% and the specificity was 87 to 90%. The authors conclude that the combination of the two tools is preferred. An important limitation of this study (and others like it, see Kim & Lord, 2012a, 2012b; Kim et al., 2013) is that the clinical consensus diagnosis is not fully independent of the results of the tools, as both the ADI-R and ADOS are used to inform the clinical consensus diagnosis.
Though much of the evidence appears to favor the combined use of standardized tools in the assessment of ASD, dissenting voices have emerged to challenge the notion that these tools should be recommended for diagnosis in all cases and contexts. The aforementioned INSAR Special Interest Group noted that these tools require specific expertise and are too resource intensive for community use, particularly within a global context (International Society for Autism Research Special Interest Group: Global Knowledge Translation in Early Identification and Intervention in Autism, 2013). They also caution that these tools become “corrupted” when their use is required for publication in peer-reviewed journal or for eligibility for community resources. An editorial by Gupta and Lauffer in the *Journal of Developmental and Behavioral Pediatrics* (2012) asked whether the diagnosis of ASD should be made based only on the result of a standardized test. They fear that the suggested combination of the ADI-R and ADOS will be too time-consuming for clinicians with an additional high cost of training. Their conclusion was as follows: “It is the art of clinical medicine that should be honed and mastered along with the myriad of tests that we are striving to perfect for the diagnosis of autism.”

A recent high-profile review of evidence-based practice for ASD, published in the *Canadian Medical Association Journal* by pre-eminent Canadian researchers and clinicians, similarly suggested a use of personnel and tools in the diagnostic assessment that did not rely on MDT or standardized tools (Anagnostou et al., 2014). The article contains a fictional case description of a child diagnosed with ASD by his general paediatrician after a history and non-standardized observation and interaction. In their proposed clinical pathway to diagnosis, the diagnosis can be made by an experienced paediatrician, developmental paediatrician, or clinical psychologist, provided the clinician carries out an assessment eliciting the symptoms and behaviours listed in the DSM-5 criteria.

Guidelines for ASD diagnosis have also been ambivalent with regard to the need for standardized measures. A 2013 Rapid Response review by the CADTH identified and evaluated evidence-based guidelines with respect to the available screening and/or diagnostic tools for the recognition or diagnosis of ASD in children (Canadian Agency for Drugs and Technology in Health, 2013). Their conclusion from a review of the guidelines was that there were inconsistent recommendations with regard to the use of diagnostic tools, with more consistent recommendations for routine application of diagnostic criteria and the need for trained clinicians, specifically psychologists and physicians.
There has been a recent and palpable shift in thinking about the necessary elements of ASD diagnosis, as demonstrated by the inconsistency in guidelines and the opinions of respected Canadian ASD experts. While the resource-intensive nature of MDT assessment with standardized tools has been mentioned, an additional worrisome feature of mandating these assessments is the impact on wait times and the resulting impact on access to intervention.

1.5.3 The developmental profile

One of the strongest arguments for MDT assessments for ASD is the need for a developmental profile, which is a more holistic view of the child’s strengths and weaknesses (National Collaborating Centre for Women's and Children's Health, 2011). Beyond (and within) the diagnostic criteria, there is considerable heterogeneity of symptom severity, developmental and life skills, and trajectories (Szatmari et al., 2015).

In some cases, particularly in cases of co-occurring intellectual disability or multiple developmental delays, formal testing of the child’s developmental or intellectual quotient may be helpful to determine whether the social communication skills and restrictive, repetitive behaviors are impaired beyond the child’s overall level of functioning. Though no formal testing is mentioned (such as the need for an intelligence quotient, or IQ), the need to consider the general developmental level is given its own criterion in the DSM-5 criteria (American Psychiatric Association, 2013).

The results of the developmental profile are also said to guide therapeutic intervention strategies (Klinger & Renner, 2000). The attachment of this developmental profile to the determination of the diagnosis may not be the most efficient use of resources, particularly given the aim of guiding interventions and the long wait lists for these interventions in some jurisdictions (Gordon, 2012). Over the years-long wait for interventions, it is possible that the child’s developmental trajectory and pattern of strengths and weaknesses may change (Fountain, Winter, & Bearman, 2012; Szatmari et al., 2015), necessitating a re-evaluation of treatment goals.

1.6 The importance of diagnostic assessment for access to intervention

While a full review of available Canadian policies on eligibility for publicly funded interventions for ASD will follow, a preliminary scan of provincial policies shows that a definitive diagnosis
of ASD is often required to access these interventions (Dua, 2003; Government of New Brunswick, 2010; Ontario Ministry of Child and Youth Services, 2006). Wait times for intervention in Ontario have been reported to exceed two years (Auditor General of Ontario, 2013; Gordon, 2012), meaning that the age of diagnosis and referral to these services impacts significantly on the “earliness” of intervention.

The importance of early access to intervention is frequently emphasized. Dawson (2008) summarized the underlying biological processes affected by early intervention, and notes that the pre-school years are a time that the developing brain is uniquely sensitive to social learning interventions. Interventions during this period have the potential to shape the connections in the developing brain, which is theorized to be more effective than delivering interventions after these connections have been formed.

This theorized impact of younger age for intervention has met with mixed meta-analytic reviews of applied behavioral analysis (ABA), the ASD-targeted intervention with the most evidence of efficacy. One meta-analysis and meta-regression found no significant effect of age on the effectiveness of ABA (Virues-Ortega, 2010). The participants’ mean ages from the included studies ranged from 22.6 to 66.3 months. An additional meta-analysis showed a trend toward better outcomes with younger age, which failed to reach statistical significance ($p = 0.059$) (Makrygianni & Reed, 2010). Further analysis by the authors revealed that programs delivered before age 35-months had more consistently positive outcomes, and that outcomes were more variable after this point. Data published from the Ontario Autism Intervention Program, which employs an intensive version of ABA called early intensive behavioral intervention (EIBI), shows significantly better improvements in intellectual, language, and adaptive skill in children who access this intervention before age four when compared to those with later access (Perry et al., 2011).

### 1.7 Wait times for diagnosis

There is very little Canadian data evaluating the wait times experienced by families on their journey to an ASD diagnosis. NEDSAC has published on the age at diagnosis in the four regions of Canada that they monitor: Manitoba, Prince Edward Island, Southeastern Ontario, and Newfoundland/Labrador. A 2009 publication by this group found significant inter-regional differences between these locations, with median ages at diagnosis ranging from 39 months in
Newfoundland/Labrador to 55 months in Southeastern Ontario (Ouellette-Kuntz et al., 2009). An updated report from 2012 showed that the age of diagnosis increased in all three monitored locations (Prince Edward Island, Newfoundland/Labrador, and Southeastern Ontario), with a statistically significant increase in age in Newfoundland/Labrador (The National Epidemiologic Database for the Study of Autism in Canada, 2012).

While the increasing prevalence of ASD diagnoses suggests that wait times for assessment may be contributing to late age at diagnosis, there are additional factors to consider. In the NEDSAC publication, they note that the subtype of ASD diagnosis (under DSM-IV-TR classification) was significantly associated with the age at diagnosis, with milder subtypes being diagnosed at a later age (Ouellette-Kuntz et al., 2009). These children may not show significant impairment associated with ASD until their skills are exceeded by social demands, which will occur later for more mildly affected children. This is supported by studies from the US, which have shown that severe language impairment/regression, unusual mannerisms, and toe walking were features of the clinical presentation associated with younger age at diagnosis (Mandell et al., 2005; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). Co-occurring or alternative diagnoses such as attention deficit hyperactivity disorder may also delay diagnostic evaluation for ASD, as demonstrated in an epidemiologic study of children in Nova Scotia (Frenette et al., 2013).

Factors external to the child also impact that age at diagnosis. The above-mentioned study from Nova Scotia also found that older maternal age was associated with a decreased age at diagnosis (Frenette et al., 2013). Having relatives with ASD has also been shown to decrease the age at diagnosis (Valicenti-McDermott et al., 2012). Both of these may be suggestive of caregivers that are more aware of the possibility of ASD. Children with four or more primary care providers receive a diagnosis on average six months later than their peers (Mandell et al., 2005), emphasizing the importance of ongoing developmental surveillance. Lower socioeconomic status, being a visible minority, and living in a rural setting are all associated with an older age at diagnosis (Fountain, King, & Bearman, 2011; Mandell et al., 2005; Valicenti-McDermott et al., 2012).

Age at diagnosis is an incredibly important metric; however, due to the number of potential confounders, it is difficult to isolate the impact of wait times for assessment on the diagnosis age.
One study from the ADDM evaluated factors related to wait times for diagnosis, which was thirteen months on average in their sample (Wiggins et al., 2006). Reported associations in this study were mostly between wait times and patient demographic factors but there was not association between the use of a standardized diagnostic tool and mean age of first ASD diagnosis. Unfortunately, there has been no Canadian collection of wait time data for ASD assessment to date. Due in part to the lack of ASD-specific billing codes, there have also been no published reports of wait times in individual provinces. Further, the scientific literature lacks analyses of practice patterns (such as use of MDTs and referral sources) that are associated with increased wait times for diagnosis.

1.7.1 Collection of national wait time data for other services

Wait times for general physician services have been collected at a national level through the use of physician surveys. These methods are routinely employed in the National Physician Survey (The College of Family Physicians of Canada, Canadian Medical Association, & The Royal College of Physicians and Surgeons of Canada, 2010) and by the Fraser Institute for their annual wait times report (Fraser Institute, 2013). A recent report of wait times from primary care referral (collected from electronic medical records) to being seen by a specialist (collected from health administrative databases) found that physician-reported wait times were similar to those collected by electronic medical records/administrative databases, but tended to be shorter than the wait times collected by this method (Jaakkimainen et al., 2014). Physician surveys of wait times have been shown to be a reasonably valid measure, and are likely the most feasible method to capture wait time data for ASD diagnosis in Canada given the lack of ASD-specific billing codes. Further, these wait times need to be contrasted based on elements of the clinical assessment, such as available personnel and tools, to determine their impact on time to assessment as well as resource use.

1.8 Guidelines and their relationship to practice realities

Guidelines have been developed for the diagnosis of ASD (Dua, 2003; Filipek, Accardo, Ashwal, Baranek, Cook, et al., 2000; Johnson et al., 2007; National Collaborating Centre for Women's and Children's Health, 2011; The Miriam Foundation, 2008; Volkmar et al., 2014), yet little is known about whether these guidelines are being followed. A Scottish study evaluated the impact of the Scottish Intercollegiate Guidelines Network guideline (2007) for the diagnosis of
ASD (Hathorn, Alateeqi, Graham, & O'Hare, 2014). These guidelines recommended referral for specialist assessment for children with suspected ASD, MDT assessment, and only suggested consideration of standardized tools. Adherence to the guidelines (measured by retrospective chart review) appeared to be related to the strength of the suggestion, with 100% adherence to the recommendations for specialist referral and MDT assessment, and only 60% of cases having a standardized history and 60% with a standardized observation tool noted.

The impact of guidelines on wait times and resource use has also been poorly studied. A paper evaluating the implementation of local practice parameters for early identification of ASD in Switzerland found an initial significant decrease in the age of diagnosis, which unfortunately was not maintained with time (Holzer et al., 2006). A study from the UK evaluating the recommendation for MDT assessments found that for one MDT clinic, only 19% of children received services within the recommended 30 weeks from referral to completion of the assessment (Preece & Mott, 2006). As a rationale for their study attempting to increase local diagnostic capacity for ASD, McClure et al. (2010) noted: “Given the disparity between ideal service and the non-ideal reality in many services, it is not surprising to encounter challenges to the aspirations of guideline committees.”

1.9 Summary

ASD, a neurodevelopmental disorder defined by impairment in social communication and the presence of restricted repetitive behaviours (American Psychiatric Association, 2013), has steadily increased in reported prevalence over the past decade (Centre for Disease Control National Center on Birth Defects and Developmental Disabilities, 2014). The diagnostic classification of ASD has changed with time, with a recent change from multiple diagnostic subtypes (American Psychiatric Association, 2000) to one diagnostic category with two domains, social communication and restricted repetitive behaviours (American Psychiatric Association, 2013).

Many guidelines and policies have been put forth related to screening and surveillance for ASD (Johnson et al., 2007; The Miriam Foundation, 2008; U. S. Department of Health and Human Services, 2014); however, these fail to propose strategies to deal with the resulting increased demand for diagnostic assessments for children who are identified as being at risk for ASD.
There have also been numerous guidelines published with recommendations for diagnostic assessments for ASD (Dua, 2003; Filipek, Accardo, Ashwal, Baranek, Cook, et al., 2000; Johnson et al., 2007; National Collaborating Centre for Women's and Children's Health, 2011; The Miriam Foundation, 2008; Volkmar et al., 2014). Guidelines have varied in their recommendations for the personnel involved in the diagnostic assessment (including the requirement of MDT for diagnosis), as well as for the tools required for diagnosis (Canadian Agency for Drugs and Technology in Health, 2013). A growing body of opinions from leading ASD researchers suggests a changing attitude toward a more flexible approach to the use of MDTs and standardized tools for ASD diagnosis (Anagnostou et al., 2014; Gupta & Lauffer, 2012; International Society for Autism Research Special Interest Group: Global Knowledge Translation in Early Identification and Intervention in Autism, 2013). To date, there has not been a critical analysis of ASD diagnostic guidelines, including their evidence base and the ideas, institutions, and interests that have shaped their development (Triple-I policy framework) (MacLean & Wood, 2010). Such an analysis will provide a lens through which to evaluate discrepancies in current guidelines, as well as suggesting a more rational foundation for future guideline development.

The most pressing concern about models for diagnostic assessment is how they may influence wait times in an already constrained health care system. If the supply of practitioners does not meet the demand for diagnostic services, a wait time can occur. In the case of ASD, waiting for a diagnostic assessment occurs during a critical period of brain development (Dawson, 2008). Because a diagnosis is often necessary to access intervention (Dua, 2003; Government of New Brunswick, 2010; Ontario Ministry of Child and Youth Services, 2006), these wait times may decrease the effectiveness of interventions (Perry et al., 2011). There have been no evaluations of the association between aspects of ASD diagnostic approaches and wait times for diagnosis.

Together, a critical examination of the policies and guidelines governing ASD diagnosis along with an analysis of Canadian diagnostic practices and wait times will inform a detailed description of ASD diagnosis in Canada. This information will be of value to institutions and clinicians involved in ASD diagnosis, as well as providing an empirical foundation for future study of and policy development for ASD diagnosis.
1.10 Research objectives

The objectives of this research are to:

1. Perform a systematic review of guidance documents that govern ASD diagnosis, comparing and contrasting their quality and content;
2. Perform a policy scan to compare and contrast the national and international government policies that govern ASD diagnosis clinical practice;
3. Determine the practices of Canadian paediatricians and paediatric health providers with regard to their diagnostic practices for ASD, including ascertainment of the breadth of referral pathways, identification of the types of personnel included in the assessment, use of multi-disciplinary teams for diagnosis, use of standardized tools, time spent on assessment, billing codes used, and lengths of wait times; and
4. Identify the determinants of wait times for ASD diagnosis based on elements of clinical diagnostic practice. Wait times are hypothesized to be positively associated with:
   a. The level of specialization of the primary assessor (due to limited access to expert assessors such as developmental paediatricians versus general paediatricians);
   b. A MDT diagnostic assessment versus solo clinician assessment (due to limited access to multiple assessors);
   c. The time spent on the assessment (due to a longer assessment period);
   d. The acceptance of referrals from primary care physicians (due to a higher number of false positive referrals);
   e. Practicing in a province requiring a more comprehensive assessment (due to a longer assessment period and limited access to multiple assessors);
   f. Practicing with a larger catchment (due to limited geographic access to alternative diagnosticians); and
   g. Decreased years in practice (due to less hours worked by more junior clinicians).
2 Methods

This chapter will provide details for the methods utilized for each of the three research objectives. It begins with a description of the methods for the systematic review of guidance documents, followed by the methods for the government policy scan, followed by the survey distribution, and finally the analyses performed to determine the determinants of wait times for ASD diagnosis.

2.1 Objective 1: Systematic review of guidance documents for ASD diagnosis

2.1.1 Scope

The systematic review of guidance documents included clinical practice guidelines published by Canadian, American and UK health and educational professional associations whose members may participate in the diagnosis of ASD, as well as guidance documents published by governments in Canada or the UK. The definition of a guidance document was taken from the Institute of Medicine definition of clinical practice guidelines, which are “statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options” (Institute of Medicine of the National Academies, 2011).

2.1.2 Inclusion criteria

The systematic review extended from 2000, when the DSM-IV-TR was published (American Psychiatric Association, 2000) to the present, though the emphasis was on reporting current documents that guide ASD diagnosis. The systematic review focused on diagnosis for preschool-aged children (children less than 6 years of age). Documents related to services for older children that met eligibility criteria relevant to the diagnostic period (i.e. needing to submit the results of an ADOS to be deemed eligible for a program) were included. Documents did not have to specify this age group to be included; however, documents that were specific to individuals aged six or older were excluded. Documents pertaining to screening for ASD were included, as screening processes are likely to influence the number of children requiring a diagnostic assessment.
All identified professional association statements, practice parameters, and practice guidelines were assumed to govern practice and were included as clinical guidance documents. In the systematic review, if the document failed to clearly identify itself as a clinical guidance document as described above, the Institute of Medicine definition was applied such that there needed to be documentation of a systematic review as well as recommendations for clinical practice for the document to be included.

2.1.3 Exclusion criteria

Documents pertaining only to treatment and other ASD management issues were excluded, unless the eligibility criteria for treatment programs required certain diagnostic tests or assessment models. Published literature reviews and commentaries were excluded to limit the scan to documents most likely to guide clinical practice.

2.1.4 Search strategy

2.1.4.1 Search terms

The search aimed for maximum sensitivity to identify all potentially relevant documents, and then to apply the inclusion and exclusion criteria. The search terms used included ASD, which is the current diagnostic label under the DSM-5 (American Psychiatric Association, 2013) and diagnostic terms included in the DSM-IV-TR (American Psychiatric Association, 2000) including autism, autistic disorder, pervasive developmental disorder, Asperger’s syndrome and pervasive developmental disorder – not otherwise specified (PDD-NOS).

2.1.4.2 Identification of professional association documents

A practicing professional in each of the listed fields reviewed the preliminary list of Canadian, American and UK professional associations in Table 2 to ensure the list was comprehensive. Each association’s website and journal were searched for practice guidelines using the ASD search terms and by searching indexed guidelines.
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<td></td>
<td>Society for Developmental and Behavioral Pediatrics</td>
<td><a href="http://www.sdbp.org">http://www.sdbp.org</a></td>
</tr>
<tr>
<td></td>
<td>British Academy of Childhood Disability</td>
<td><a href="http://www.bacdis.org.uk">www.bacdis.org.uk</a></td>
</tr>
<tr>
<td>Neurologists</td>
<td>American Academy of Neurology</td>
<td><a href="https://www.aan.com">https://www.aan.com</a></td>
</tr>
<tr>
<td></td>
<td>Canadian Neurological Sciences Federation</td>
<td><a href="http://www.cnsfederation.org">http://www.cnsfederation.org</a></td>
</tr>
<tr>
<td></td>
<td>British Paediatric Neurology Association</td>
<td><a href="http://www.bpna.org.uk">www.bpna.org.uk</a></td>
</tr>
<tr>
<td></td>
<td>The Association for Child and Adolescent Mental Health (UK)</td>
<td><a href="http://www.acamh.org">www.acamh.org</a></td>
</tr>
<tr>
<td>Clinical Psychologists</td>
<td>Canadian Psychological Association</td>
<td><a href="http://www.cpa.ca">http://www.cpa.ca</a></td>
</tr>
<tr>
<td></td>
<td>British Psychological Society</td>
<td><a href="http://www.bps.org.uk">www.bps.org.uk</a></td>
</tr>
<tr>
<td>Speech-Language Pathologists</td>
<td>Speech-Language and Audiology Canada</td>
<td><a href="http://sac-oac.ca">http://sac-oac.ca</a></td>
</tr>
<tr>
<td></td>
<td>American Speech-Language-Hearing</td>
<td></td>
</tr>
<tr>
<td>Association</td>
<td><a href="http://www.asha.org">http://www.asha.org</a></td>
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<tr>
<td>----------------------------------------------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>The Royal College of Speech and Language Therapists (UK)</td>
<td><a href="http://www.rcslt.org">www.rcslt.org</a></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Occupational Therapists</th>
<th>Canadian Association of Occupational Therapists</th>
<th><a href="https://www.caot.ca">https://www.caot.ca</a></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>American Occupational Therapy Association</td>
<td><a href="http://www.aota.org">http://www.aota.org</a></td>
</tr>
<tr>
<td></td>
<td>British Association of Occupational Therapists and College of Occupational Therapists</td>
<td><a href="http://www.cot.co.uk">www.cot.co.uk</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Teachers</th>
<th>Canadian Teachers’ Federation</th>
<th><a href="http://www.ctf-fce.ca/en">http://www.ctf-fce.ca/en</a></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>American Federation of Teachers</td>
<td><a href="http://www.aft.org">http://www.aft.org</a></td>
</tr>
<tr>
<td></td>
<td>Association of American Educators</td>
<td><a href="http://www.aaeteachers.org">http://www.aaeteachers.org</a></td>
</tr>
<tr>
<td></td>
<td>National Union of Teachers (UK)</td>
<td><a href="http://www.teachers.org.uk">www.teachers.org.uk</a></td>
</tr>
<tr>
<td></td>
<td>National Association of Schoolmasters Union of Women Teachers (UK)</td>
<td><a href="http://www.nasuwt.org.uk">www.nasuwt.org.uk</a></td>
</tr>
</tbody>
</table>

UK = United Kingdom

### 2.1.4.3 Health and education citation databases

To maximize sensitivity, health, psychology, and education citation databases (including MEDLINE, EMBASE, PsychINFO, CINAHL and ERIC) were searched. The relevant Medical Subject Heading search terms for ASD included Child Development Disorders, Pervasive; Asperger Syndrome; and Autistic Disorder. These were combined with the Medical Subject Heading “Diagnosis.” Where possible, the publication type was limited to: Government Publication, Guideline, Legislation or Practice Guideline. If these categories were not available as limits, they were used as search terms and combined using AND with the ASD search terms. The date range extended from 2000 to present. Search results were recorded, including the number of documents retrieved per database, the number of duplicates, and how many of these met the inclusion and exclusion criteria according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & the Prisma Group, 2009). The National Guideline Clearinghouse, operated by the
Agency for Healthcare Research and Quality through the United States Department of Health and Human Services (2015), was also searched using the ASD search terms.

2.1.5 Filtering

One reviewer (MP) reviewed the list of retrieved titles and abstracts for relevance. Titles and abstracts were screened for eligibility based on their applicability to ASD diagnosis. All documents with titles and/or abstracts that were identified as being relevant underwent full text review with application of the inclusion and exclusion criteria. The number of documents that did not meet inclusion criteria was documented, along with the reason for exclusion.

2.1.6 Data extraction

One reviewer (MP) extracted relevant information from each document using a custom Data Collection Sheet – Government for government documents (Appendix A). Items extracted included targeted ages or wait times for diagnosis, required personnel or tools for diagnosis, optional personnel and tools, requirement for MDT assessment, and eligibility for ASD services and funding. If elements of the document were unclear to the reviewer, the document was reviewed with other team investigators and attempts were made to contact the relevant government agency.

Relevant information from professional association documents was recorded using the Data Collection Sheet – Professional Association (Appendix B). The items extracted included targeted ages or wait times for diagnosis, required personnel or tools for diagnosis, optional personnel and tools, and requirements for MDT assessment. Any unclear elements of the documents were similarly discussed among team investigators with attempts to contact the association to clarify the document.

2.1.7 Quality appraisal

All guidelines were assessed for quality by one reviewer (MP) using the Appraisal of Guidelines Research and Evaluation, 2nd edition (AGREE-II) tool (Brouwers et al., 2010). The AGREE-II is an internationally recognized tool that assesses the quality and reporting of practice guidelines. It has 23 items divided into six domains (Scope and Purpose; Stakeholder Involvement; Rigour of Development; Clarity of Presentation; Applicability; and Editorial Independence) along with two
global rating scales. Each item is scored on a scale of 1 (Strongly Disagree) to 7 (Strongly Agree). The domain scores were summed and a scaled domain score was determined for each domain using the formula:

\[
\text{Scaled domain score} = \frac{\text{Obtained score} - \text{Minimum possible score}}{\text{Maximum possible score} - \text{Minimum possible score}}
\]

2.1.8 Content analysis of guidance document systematic review

A content analysis of the guidance documents was conducted and the process for diagnostic assessment and impact on eligibility for ASD services and funding was delineated for each document. Key elements compared and contrasted include restrictions on which personnel can diagnose ASD, requirements for MDT assessment, requirements for specific tools, and eligibility requirements for funding or services, including whether the child can access services with a provisional diagnosis, defined as an unconfirmed diagnosis of ASD that is communicated to the family.

Descriptive statistics were used to describe the quality of the guidance documents. The scaled AGREE-II domain scores and ranks are reported for each document, as well as the overall mean score and rank. The overall quality of all the documents was evaluated by calculating group means and standard deviations for each of the domains and for the overall mean score. Comparisons were also made between the quality of documents from governments versus those from professional associations, as well as between jurisdictions.

2.2 Objective 2: Government policy scan

2.2.1 Scope

The scan of government publications aimed to identify and evaluate Canadian practices for ASD diagnosis, and as such included Canadian federal and provincial/territorial (hereafter referred to as provincial) government publications related to ASD diagnosis. National government publications from the UK were included as an international comparison. The UK was chosen both because of its publicly funded health care system, as well as due to the availability of the National Collaborating Centre for Women’s and Children’s Health/National Institute for Health Care Excellence.
and Care Excellence (hereafter referred to as the NICE guideline) (National Collaborating Centre for Women's and Children’s Health, 2011).

2.2.2 Eligibility criteria

The policy scan similarly extended from 2000 to the present, though the emphasis was on reporting current policies that govern ASD diagnosis. As in the guidance document review, the focus was on diagnosis in children less than age six, though documents pertaining to intervention or older children were included if they contained eligibility criteria based on necessary elements of the diagnostic assessment.

Documents in the government policy scan did not have to clearly identify themselves as clinical guidance documents. In this scan, any government document (including guidance documents, policies, legislation, application forms for funding or services, websites, and brochures) pertaining to ASD diagnosis as described above was included in order to fully describe the process for ASD diagnosis in the jurisdiction.

Documents pertaining only to treatment and other ASD management issues were excluded, unless the eligibility criteria for treatment programs required certain diagnostic tests or assessment models.

2.2.3 Government publication search strategy

The government search strategy employed the “Grey Matters” grey literature search tool published by the CADTH (Canadian Agency for Drugs and Technology in Health, 2014). Grey Matters is a checklist for grey literature searches that includes national and international health technology assessment websites, health economic resources, Canadian health statistics databases and drug formulary/regulatory websites. The checklist is also used as a document to record search terms, availability of each website, and the relevancy of the information retrieved (Canadian Agency for Drugs and Technology in Health, 2014).

Federal/national departments whose jurisdiction includes ASD were included in the policy scan. In Canada, these included Senate/Parliament reports, Health Canada (including the Public Health Agency of Canada) and the Canada Revenue Agency (for tax credits). Relevant documents from the United Kingdom (UK) were included as an international comparison.
Provincial ministries involved with ASD were hypothesized to vary by province, including health, education, children and youth, and social and community services. The first step in the provincial policy scan was to determine the ministerial jurisdictions related to ASD screening, diagnosis and management. This was accomplished by entering ASD (and related search terms listed above in 2.1.1.4.1) into the official provincial website search bar. The jurisdictional responsibilities for ASD were then delineated from the search results based on their roles in screening, diagnosis and management. Each responsible ministry’s page was searched in the same fashion to produce relevant policy documents, which were then subject to the inclusion and exclusion criteria.

2.2.4 Filtering

One reviewer (MP) reviewed the search results for relevance. Titles were screened for eligibility based on their applicability to ASD diagnosis. All documents with relevant titles underwent full text review with application of the inclusion and exclusion criteria.

2.2.5 Data extraction

One reviewer (MP) extracted relevant information from each document using a custom Data Collection Sheet – Government (Appendix B). Items extracted included targeted ages or wait times for diagnosis, required personnel or tools for diagnosis, optional personnel and tools, requirement for MDT assessment, and eligibility for ASD services and funding. If elements of the policy were unclear to the reviewer, the document was reviewed with other team investigators and attempts were made to contact the relevant government agency.

2.2.6 Content analysis of policy scan

A content analysis of the documents was conducted to describe processes governing diagnostic assessment and eligibility for ASD services and funding in each jurisdiction. Key elements compared and contrasted include restrictions on which personnel can diagnose ASD, requirements for MDT assessment, requirements for specific tools, and eligibility requirements for funding or services, including whether the child can access services with a provisional diagnosis, defined as an unconfirmed diagnosis of ASD that is communicated to the family.
2.2.7 Reporting of results

The results of the policy scan are reported by provincial/national government and by professional group. Current policies relating to screening, diagnosis and treatment eligibility are reported. The discussion includes a critical analysis of the policy landscape for ASD diagnosis with a focus on ideas, interests, and institutions (Triple-I policy analysis framework; MacLean & Wood, 2010). “Ideas” refers to the values and beliefs that are attached to truths, and these ideas can influence how problems are defined, how evidence is framed, and how possible solutions are constructed and proposed (N. Smith, Mitton, C., Davidson, A., Williams, I., 2014). “Interests” refers to the stakeholders trying to exert influence over policy; these stakeholders may be classified as winners or losers based on the specific policy decision. Finally, “institutions” refers to the rules and tools through which policies are developed, enacted, and changed (MacLean & Wood, 2010). All three elements of this framework are hypothesized to be relevant to ASD diagnosis guideline and policy development.

2.3 Objective 3: Determination of national paediatric ASD diagnostic practices

2.3.1 Study design

This was a cross-sectional study of current ASD diagnostic practices across Canada. It employed a national survey to collect this data.

2.3.2 Target population

Paediatricians are a group of clinicians that is frequently involved in ASD diagnosis in children prior to school age (Siklos & Kerns, 2007). For this reason, the CPS was chosen as the ideal organization through which to determine ASD diagnostic practices. The CPS is the national association of paediatricians in Canada, with membership comprised of more than 3,000 paediatricians, paediatric subspecialists, paediatric residents, and other clinicians involved in providing care to a paediatric population, including speech-language pathologists (SLPs), occupational therapists (OTs), physiotherapists, and psychologists (Canadian Paediatric Society, 2015).

Based on an evaluation of membership groups within the CPS, three sections were chosen for survey distribution. The Developmental Paediatrics section is comprised of paediatricians with
an interest in child development and neurodevelopmental disorders, many of whom were hypothesized to participate in ASD diagnostic assessment. Community paediatricians were recruited from the Community Paediatrics Section. Sampling this group provided information about the wait time from primary care physician referral to a general paediatrician (who, in many cases, would subsequently refer the child for a subspecialist ASD assessment). Members of this group were also asked whether they give a diagnosis of ASD in their clinic setting based on a hypothesis that they too participate in ASD diagnosis. The Mental Health section of the CPS is a network for paediatricians as well as psychiatrists, psychologists and other health professionals who practice in the area of paediatric mental health. Accessing this group allowed access to additional professionals who may be involved in the ASD diagnostic process.

As a member of the CPS, MP was permitted to request to survey the sections listed above. A request for survey distribution was sent to the executive committees for each of the listed sections, who each provided their approval (Appendix C).

2.3.3 Survey design and pilot phase

The survey instrument was designed by MP based on a review of the literature and her clinical experiences diagnosing children with ASD in her role as a developmental paediatrician. As a result, MP is familiar with standardized tools available for diagnosis and the professionals often involved in a MDT.

The survey was piloted over a 2-week period in November 2014 with two developmental paediatricians at a tertiary rehabilitation hospital (Holland Bloorview Kids Rehabilitation Hospital) and two general paediatricians at the Hospital for Sick Children. Feedback from each of the pilot participants was provided via telephone or face-to-face after the participant’s completion of the pilot survey. This allowed pilot participants to provide additional comments that resulted in revisions that improved the survey’s face validity, clarity, and length. Based on the piloting of the survey, additional questions about billing codes were added. Table 3 gives a list of billing codes by province along with text descriptions and amounts. The study investigators then reviewed the revised survey.
<table>
<thead>
<tr>
<th>Billing code</th>
<th>Text description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta - 3.08A</td>
<td>Base code: comprehensive consultation; paediatrics. Includes recording a complete history, performing a complete physical examination, and recording advice to the patient. It may include order appropriate diagnostic tests and procedures as well as discussion with the patient (Government of Alberta, 2015c).</td>
<td>$198.04</td>
</tr>
<tr>
<td>Alberta - 03.03F</td>
<td>Base code: follow-up visit post-consultation; paediatrics (Government of Alberta, 2015a).</td>
<td>$99.02</td>
</tr>
<tr>
<td>Alberta - 03.03FA</td>
<td>Additional time-based code in addition to 03.03F: prolonged follow-up visit post-consultation; paediatrics (Government of Alberta, 2015a).</td>
<td>$99.02 + $59.41 per 15 min unit after 30 min</td>
</tr>
<tr>
<td>Alberta - 03.08J</td>
<td>Additional time-based code: prolonged consultation. Can be claimed in addition to 03.08A after 30 minutes (Government of Alberta, 2015a).</td>
<td>$59.41 per 15 min unit after 30 min</td>
</tr>
<tr>
<td>Alberta - CMXC30</td>
<td>Modifier code: complex patient consultation or visit requiring that the physician spend 30 minutes or more on management of the patient’s care (Government of Alberta, 2014).</td>
<td>Base code plus $31.11</td>
</tr>
<tr>
<td>BC - 00511</td>
<td>Consultation for complex behavioural, developmental, or psychiatric condition in a child. To consist of a physical and neurological examination, review of history, laboratory, X-ray findings, and additional visits necessary to render a written report. Minimum time is 90 minutes (Government of British Columbia, 2014).</td>
<td>$411.87</td>
</tr>
<tr>
<td>BC - 00512</td>
<td>Repeat or limited consultation, where formal consultation for the same illness is repeated within six months of the last visit (Government of British Columbia, 2014).</td>
<td>$99.19</td>
</tr>
<tr>
<td>BC - 00554</td>
<td>Extended subsequent office visit exceeding 38 minutes (actual time spent with patient); applicable to patients with chronic and complex medical needs (Government of British Columbia, 2014).</td>
<td>$76.71</td>
</tr>
<tr>
<td>Manitoba - 8552</td>
<td>Developmental assessment and report; includes history taking, assessment, collateral contacts (teachers, other health care professionals), and preparation of the assessment report (The Minister of Health for Manitoba, 2015).</td>
<td>$60.00 per 15 min unit</td>
</tr>
<tr>
<td>Province</td>
<td>Description</td>
<td>Units</td>
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<tr>
<td>---------------</td>
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</tr>
<tr>
<td>New Brunswick</td>
<td>Major or regional consultation. The consultant is obliged to perform an assessment, review the laboratory or other data and submit his/her findings, opinions and recommendations in writing to the referring physician. A major consultation includes a full history and enquiry into and examination of all parts and systems, as pertinent to the specialty. A regional consultation includes a full history of the presenting complaint and detailed examination of the affected part, region, or system as needed to make a diagnosis (Government of New Brunswick, 2015a).</td>
<td>155</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>Repeat consultation within 30 days for same illness or complication thereof (Government of New Brunswick, 2015a).</td>
<td>95</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>First office visit with complete examination. Visit refers to services rendered by the physician in the physician’s office to a patient for diagnosis and/or treatment (Government of New Brunswick, 2015a).</td>
<td>66</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>Neurodevelopmental examination for learning disabilities (Government of New Brunswick, 2015a).</td>
<td>188</td>
</tr>
<tr>
<td>Newfoundland</td>
<td>Consultation: includes a complete history and physical examination commensurate with the presenting complaint, review of pertinent x-ray films, laboratory or other data, and submission of an opinion and recommendations to the referring physician (Government of Newfoundland and Labrador, 2013).</td>
<td></td>
</tr>
<tr>
<td>Newfoundland</td>
<td>Specific assessment: consists of a full history of the presenting complaint, detailed examination of the affected part, region, or system as needed to make a diagnosis, exclude disease and/or assess function and advise the patient (Government of Newfoundland and Labrador, 2013).</td>
<td></td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>Comprehensive consultation (prolonged). A consultation requires a written report to the referring physician or other health care practitioner, a complete history and physical examination, and an appropriate record and advice to the patient. It may include ordering diagnostic tests and procedures and discussion with the patient, other persons relevant to the case, and the referring clinician (Nova Scotia</td>
<td>71</td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
<td>Cost</td>
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</tr>
<tr>
<td>Ontario - A265</td>
<td>Consultation: includes the services necessary to enable the consultant to prepare a written report (including findings, opinions, and recommendations) to the referring physician or nurse practitioner. The consultant is required to perform a general, specific, or medical specific assessment, including a review of all relevant data (Ontario Ministry of Health and Long-Term Care, 2015).</td>
<td>$167.00</td>
</tr>
<tr>
<td>Ontario - A667</td>
<td>Neurodevelopmental consultation: a consultation in which the physician provides all the elements of a consultation for an infant, child, or adolescent with complex neurodevelopmental conditions (e.g. autism, global developmental disorders, etc…) and spends a minimum of 90 minutes in direct contact with the patient and caregiver (Ontario Ministry of Health and Long-Term Care, 2015).</td>
<td>$395.65</td>
</tr>
<tr>
<td>Ontario - A260</td>
<td>Special paediatric consultation: a consultation in which the physician provides all the elements of a consultation and spends a minimum of 75 minutes in direct contact with the patient (Ontario Ministry of Health and Long-Term Care, 2015).</td>
<td>$300.70</td>
</tr>
<tr>
<td>Ontario - A2662</td>
<td>Extended special paediatric consultation: a consultation in which the physician provides all the elements of a consultation and spends a minimum of 90 minutes in direct contact with the patient (Ontario Ministry of Health and Long-Term Care, 2015).</td>
<td>$395.65</td>
</tr>
<tr>
<td>Ontario - A2661</td>
<td>Complex medical specific reassessment: a reassessment of the patient because of the complexity, obscurity, or seriousness of the patient’s condition. The physician must report his/her findings, opinions, and recommendations in writing to the primary care physician (Ontario Ministry of Health and Long-Term Care, 2015).</td>
<td>$68.80</td>
</tr>
<tr>
<td>Ontario - K119</td>
<td>Paediatric developmental assessment initiative: refers to the service rendered by a paediatrician most responsible for providing ongoing management of a paediatric patient at developmental risk. The service is for ongoing management using a developmental surveillance approach and requires</td>
<td>$100.00</td>
</tr>
<tr>
<td>Province</td>
<td>Code</td>
<td>Description</td>
</tr>
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</tr>
<tr>
<td>Ontario</td>
<td>K122</td>
<td>Individual developmental and/or behavioural care: encompasses any form of assessment and treatment by a paediatrician for mental illness, behavioural maladaptations, developmental disorders, and/or any other problems that are assumed to be of a developmental or emotional nature. To claim, 35% of annual fee-for-service claims in any 12 month period must consist of certain codes and additional training in paediatrics or psychiatry (Ontario Ministry of Health and Long-Term Care, 2015).</td>
</tr>
<tr>
<td>Ontario</td>
<td>K123</td>
<td>Family developmental and/or behavioural care: encompasses any form of assessment and treatment by a paediatrician for mental illness, behavioural maladaptations, developmental disorders, and/or any other problems that are assumed to be of a developmental or emotional nature. To claim, 35% of annual fee-for-service claims in any 12 month period must consist of certain codes and additional training in paediatrics or psychiatry (Ontario Ministry of Health and Long-Term Care, 2015).</td>
</tr>
<tr>
<td>Quebec</td>
<td>09127</td>
<td>Primary visit: includes an examination of the patient to make a diagnosis and, if necessary, recommend treatment (Regie de l'assurance maladie Quebec, 2015).</td>
</tr>
<tr>
<td>Quebec</td>
<td>09165</td>
<td>Consultation: consultation means a request for opinion regarding the diagnosis or treatment of a disease in a patient whose condition appears serious or complex (Regie de l'assurance maladie Quebec, 2015).</td>
</tr>
<tr>
<td>Quebec</td>
<td>09129</td>
<td>Monitoring visit (Regie de l'assurance maladie Quebec, 2015)</td>
</tr>
<tr>
<td>Quebec</td>
<td>15164</td>
<td>Developmental monitoring visit: a meeting with one or more speakers, or a parent, or a child with psychosocial disorders (e.g. autism, behavioral problems, developmental delay, attention deficit hyperactivity, and others) or has an complex disease (severe acute illness or chronic disease) at a pediatric medical assessment, with or without the presence of the child (Regie de l'assurance maladie Quebec, 2015).</td>
</tr>
<tr>
<td>Saskatchewan - 9C</td>
<td>Consultation: includes all visits necessary to complete a history and examination, review of laboratory and/or other data, and written submission of the consultant's opinion and recommendations to the referring physician (Government of Saskatchewan, 2015a).</td>
<td>$125.00</td>
</tr>
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</tr>
<tr>
<td>Saskatchewan - 3C</td>
<td>Complete assessment including pertinent family history, patient history, history of presenting complaint, functional enquiry, examination of all parts and systems, diagnosis, assessment, necessary treatment, advice to patient, and record of service provided (Government of Saskatchewan, 2015a).</td>
<td>$89.40</td>
</tr>
</tbody>
</table>

For brevity, only those billing codes endorsed by survey respondents are described above. Two written responses, NB-90 + 2172 and Nunavut K1/K2 were not located online.

2.3.4 Approach and recruitment

Using an electronic mail list serve, the CPS Educational Assistant sent all potential participants an email explaining the survey and containing an online link to complete the survey (Appendix D). Participants were informed that no identifying information was to be collected and that it was not possible to connect responses with the individual participants. There were no direct benefits to participants from completing the survey.

Participants were informed that their consent was implied if they followed the link and initiated the survey. They were informed that they may stop at any point, but the information they had previously entered would be collected and analyzed.

2.3.5 Survey administration

An electronic version of the survey (Appendix E) was created using REDCap (Research Electronic Data Capture), a software program created by Vanderbilt University and supported by the REDCap Consortium to facilitate Research Ethics Board-approved clinical research and basic research. REDCap is a self-managed, secure, web-based survey platform tool. Participants did not have to create personal logins and were not provided with passwords; however, if they did not finish the survey, they were provided with a validation code to return and complete the survey. The study data were housed at the Hospital for Sick Children. REDCap is backed up
offsite on a daily basis and is hosted in a secure environment by the Data Management Team at Sick Kids.

The survey was administered in March 2015. Participants had a total of three weeks to complete the survey. A reminder email (Appendix F) was sent out to all potential respondents by the CPS Education Assistant one week after the information letter and survey link had been sent, with a subsequent second reminder sent one week following the first reminder (Appendix G).

REDCap collected a survey timestamp for those that completed the survey, which was not included in the exported data. Time to completion and number of starts were not recorded. To reduce the burden on respondents, questions that were directly related to the research objective (use of MDTs, personnel in assessment, tools, and wait times) were mandatory for survey completion, while additional exploratory questions (billing codes, percentage of cases of ASD for which the clinician completes a definitive diagnostic assessment) were optional for survey completion.

2.3.6 Statistical analysis

After the survey data collection period was completed, data were exported from REDCap. Data were converted to a comma separated values format and exported electronically from REDCap. Because there was no identifying information collected, all exported data were anonymous.

All statistical analysis related to the survey were performed using R (Vienna, Austria, 2014). Demographic statistics were calculated for the sample and were compared with the 2014 National Physician Survey demographic results for paediatricians (Canadian College of Family Practice, 2014). Descriptive statistics were calculated for all question responses, including frequency distributions for categorical data and means, standard deviations and ranges for normally distributed continuous data or medians and inter-quartile ranges for non-parametric data. Continuous data were checked for normality using a Shapiro-Wilk test.

The median amount billed for each clinic visit was calculated. Billing codes corresponding to time units were excluded from this analysis because the total amount billed per visit would vary depending on the amount of time the clinician spent with each patient. Where the respondent selected more than one billing code per visit but only one of those selected could be used for a
patient visit according to the province’s fee schedule, the billing code with the higher amount was included in the analysis.

The proportion of the whole sample reporting use of each type of diagnostic assessment tool or combinations of tools was reported. Similarly, for participants who report using a MDT for diagnosis, the proportion of the sub-sample using each type of team member was reported, as well as a description of the composition of teams.

The wait time for the first visit of the diagnostic assessment (Time 1) was reported in months on the survey and was converted to days in the analysis. The wait time from the first visit of the diagnostic assessment to the communication of the diagnosis to the family (Time 2) was reported in weeks on the survey and was converted to days for the analysis. The total wait time (in days) was calculated for each participant by adding Time 1 and Time 2.

2.4 Objective 4: Identifying practice determinants of wait times for ASD diagnosis

Two types of analyses were performed to determine the practice determinants of wait times. First, linear regressions were performed using a continuous measure of wait time as the dependent variable. A second set of analyses using logistic regression was performed to determine predictors of meeting wait time targets from the clinical guidance documents. These analyses are further described below.

2.4.1 Linear regression analysis of wait time determinants

2.4.1.1 Dependent variable for linear regression

Regression analyses were performed using three different continuous measures of wait times (in days). Wait times data were collected in the survey described in Objective 2. Components of wait times used as dependent variables in the analyses included the time from referral to first clinic visit (Time 1), the time from first clinic visit to communication of the diagnosis of ASD to the family (Time 2), and the total wait time from referral to communication of the diagnosis (total wait time). It was important to evaluate the wait time from referral until the family receives the diagnosis (instead of the time until the first appointment), as the diagnosis of ASD may require more than one appointment and is often necessary to access ASD-targeted publicly
funded interventions (Dua, 2003; Government of New Brunswick, 2010; Ontario Ministry of Child and Youth Services, 2006). The distributions of the wait times were plotted using a histogram and evaluated for normality using a Shapiro Wilk test.

2.4.1.2 Covariates for linear regression

Multiple covariates were hypothesized to be associated with wait times. An assessor with medical specialization (as determined by the professional designation of the survey participant) was hypothesized to be associated with longer wait times, due to limited access to subspecialists. Practicing in a MDT was hypothesized to be positively correlated with wait times due to a longer assessment period to see the multiple team members.

Assessment time was calculated for each survey participant by multiplying the number of visits required to make a diagnosis by the average length of each visit (participants were given a list of options for visit length, such as 31 to 45 minutes [see Appendix E]; the mid-range value of the selected range was taken as the average length of each visit). A longer assessment time was hypothesized to be positively correlated with wait time due to decreased clinic slots for assessment.

Participants were asked whether they accept referrals from family physicians. Accepting referrals from family physicians (instead of only accepting referrals from paediatricians) was hypothesized to be associated with longer self-reported wait times due to a higher volume of referrals for assessment in the absence of an intermediary gate-keeping role played by the consultant general paediatrician. A consultant general paediatrician would filter referrals, and not refer cases with a very low suspicion of ASD. It is important to note that this only reflects the self-reported wait time of the clinician making the diagnosis of ASD, not the total wait time from first concern to diagnosis experienced by the family.

The province in which the respondent practices was included as a covariate, as provincial policies may dictate necessary elements of the assessment process (Dua, 2003). Provinces requiring a more comprehensive diagnostic assessment were hypothesized to have longer wait times due to longer assessment times and limited access to multiple professionals. After review of the policy scan, the degree of inter-provincial variation in requirements for ASD diagnosis precluded categorization of provinces.
The size of the clinician’s catchment was hypothesized to be associated with wait times. Varying geographic access to diagnosticians may influence wait times, with published evidence of later age at diagnosis for children from rural settings (Valicenti-McDermott et al., 2012).

The participant’s number of years in practice was also identified as a covariate that may influence wait times. There is some suggestion that more recent graduates of medical training programs work reduced hours compared to their more experienced counterparts (Royal College of Physicians and Surgeons of Canada, 2009; Staiger, Auerbach, & Buerhaus, 2010); this may lead to increased wait times for more junior clinicians.

2.4.1.3 Statistical analysis of linear regression

Data analysis was performed using R (Vienna, Austria, 2014). Missing data were handled by first examining the number of missing data per variable. If the number exceeded ten percent of the sample, the missing data was not considered to be missing at random and the variable was not included in the analysis. If the number was less than ten percent of the sample, respondents with missing data were removed from the analysis.

All variables were first explored to determine their distributions and tested for normality. A series of bivariate analyses of the association between hypothesized covariates and each of the dependent variables were performed to determine which explanatory variables to include in a multiple linear regression model. The significance level for inclusion in the model was set at 0.2. Because none of the variables were normally distributed, non-parametric tests were used to determine the significance of the bivariate association (Wilcoxon rank sum test for dichotomous variables, Kruskal-Wallis for categorical variables, and Spearman rank correlation coefficients for continuous variables). In the displayed results, all provinces with only one respondent were collapsed to ensure that individual respondents’ wait times were not identifiable.

To ensure that variables were independently associated with the dependent variables (multicolinearity), non-parametric tests were used to determine the relationship between covariates (Wilcoxon rank sum test to evaluate a dichotomous versus continuous variable, Kruskal-Wallis to evaluate a categorical versus continuous variable, Spearman rank correlation coefficients for two continuous variables, and Fisher exact test for two categorical variables). Variables were considered to be multicollinear when they were significantly associated (p <
Multicolinear variables were not tested together in the model. All models to be tested were determined based on the groupings of independent (non-multicolinear) covariates.

For each of the analyses, the dependent variable (Time 1, Time 2, or total wait time) and each of the variables that were significant in the bivariate analyses were inputted one by one into a multivariate linear regression model. A forward regression was used to determine which variables to include in the model. The first variable included in the model was the variable that was most highly correlated with the dependent variable. If this variable was significantly correlated with the dependent variable (p < 0.05) it remained in the model. The next variable included was the variable with the next highest partial correlation with the dependent variable. The same inclusion criterion of p < 0.05 was maintained for each variable’s inclusion in the model. As each variable was added, the significance of the other variables in the model was examined to assess the relationships between all variables.

To determine if the model met the assumptions of linear regression, the normality of distribution of residuals was assessed. This was accomplished by first determining the sum of residuals (if normally distributed, this sum should be zero), by evaluating a quantile-quantile (Q-Q) plot of the residuals, and by performing a Shapiro Wilk test on the residuals (with a p < 0.05 indicating that residuals were not normally distributed). All of the regression analyses for Time 1 and total wait time required natural logarithm (ln) transformation of the dependent variables (Time and total wait time), with normal distributions of the residuals confirmed for the ln-transformed analyses. Transformations were attempted for the regression analysis for Time 2, including ln transformation and a Box Cox analysis to determine the optimal exponential factor. None of the transformed analyses produced normally distributed residuals, and as a result, no linear regressions were performed for Time 2. Homoscedasticity represents constant variance across observations and was assessed by plotting residuals against the range of fitted values and against the range of predictor values.

Influential observations were determined by calculating dfbeta values, which measure the change in the regression coefficients to the overall model after removing the nth observation and using the standard deviation to standardize. The critical value for dfbeta values was determined by \( \frac{2}{\sqrt{n}} \). Regression analyses were re-run after removal of influential observations for comparison with the analyses using the full data set.
Goodness of fit was tested with $R^2$ (the coefficient of multiple determination) and adjusted $R^2$. $R^2$ was used to evaluate the proportion of variance explained by the included variables in the model. Adjusted $R^2$ was used to evaluate the proportion of variance explained by the model variables while adjusting for multiple variables in the model.

Effect sizes and their respective confidence intervals were calculated for all variables in the final model. Back transformation of the ln-transformed dependent variable was performed by first calculating the Duan smearing estimate (Duan, 1983). This was performed by taking the mean of the anti-ln of the residuals (the mean of $e^{\text{residuals}}$). The predicted values of wait time (along with their 95% confidence intervals) were multiplied by the smearing estimate to determine the mean adjusted wait times (with 95% confidence intervals) based on the included covariate(s).

2.4.2 Logistic regression analysis of predictors of meeting wait time targets

2.4.2.1 Dependent variables for logistic regression

The dependent variables for these analyses were dichotomous and based on whether the participant’s reported wait times met the targets suggested by the guidance documents. Three wait time targets were identified from the Miriam Foundation guideline, which was chosen because its aim is to act as a best practice guideline for Canada (The Miriam Foundation, 2008): 1) a wait time from referral to first visit of the diagnostic assessment (Time 1) of three months or less; 2) a time from first visit to communication of the diagnosis (Time 2) of two months or less; and 3) a total wait time (from referral to diagnosis) of five months or less.

2.4.2.2 Covariates for logistic regression

The covariates hypothesized to be associated with meeting wait time targets were the same as those described in 2.3.2.2.

2.4.2.3 Statistical analysis of logistic regression

Data analysis was performed using R (Vienna, Austria, 2014). Missing data were handled in the same manner as described above in 2.3.2.3.

Bivariate analyses were performed to explore the relationship between the covariates and the dependent variable, with a significance level for inclusion in the model set at 0.2. Chi-squared
tests were used to test the association between two categorical variables, with the exception of cases with cell counts lower than five, where Fisher’s exact tests were used. The continuous variables were not normally distributed, and associations between these variables and the dependent variable were tested using Wilcoxon rank sum tests. In the tables reporting these results, provinces with only one respondent were collapsed to ensure that individual respondents’ wait times were not identifiable.

Tests were used to determine whether multicollinearity was present between covariates (Wilcoxon rank sum test to evaluate a dichotomous versus continuous variable, Kruskal-Wallis to evaluate a categorical versus continuous variable, and Fisher’s exact test for two categorical variables). Variables were considered to be multicollinear if they were significantly associated (p < 0.05) and were not tested together in the models.

Three logistic regression analyses were performed to test associations with each of the wait time targets (Time 1 of three months or less, Time 2 of two months or less, and total wait time five months or less). A forward regression model method of variable selection was used as detailed for the linear regression in 2.3.2.3, with the inclusion criterion of p < 0.05 maintained for inclusion in the model.

Discriminative ability of the model was determined using the concordance index. This index examined pairs of participants who did and did not meet the wait time target and indicates whether the predicted probability was higher for the participant that meets the target, with values over 0.8 indicating good discrimination. Somer’s Dxy was also used to assess discrimination by testing the correlation between predicted probabilities and observed responses. This score ranges from zero (random predictions) to one (perfect predictions).

Reliability of model projections was measured using the Brier’s score, which ranges from zero to one. This determines the “correctness” of predictions, with values closer to zero reflecting higher reliability.

Bootstrapping was used to assess for overfitting of the model. Bootstrapping employs random sampling of the data set to produce a corrected intercept and slope. The degree of change between the proposed model and the bootstrapped model was assessed to determine if overfitting was present. Overfitting was also assessed with the gamma shrinkage estimate, for which a value
of one indicates no overfitting. Calculating dfbeta values, as described above in 2.3.2.3,
identified influential observations. The models were retested with the influential observations
removed. Odds ratios and their respective confidence intervals were calculated for all variables
in the final model.

2.5 Data management

2.5.1 Systematic review and policy scan data management

Data on retrieved documents and reason for exclusion were stored in an electronic database
maintained by MP. All documents included in the full text review, completed AGREE-II tools
and synthesized results were stored in the protected hospital server study folder and on MP’s
laptop.

2.5.2 Survey data management

REDCap is a self-managed, secure, web-based survey platform tool. REDCap is backed up
offsite on a daily basis and is hosted in a secure environment by the Data Management Team at
Sick Kids. Authentication for administrators is required with a login and password.
Administrative accounts were obtained for MP and all other study investigators from the Data
Management Team at Sick Kids. MP was listed as the Project Manager (capable of making
changes to the survey) and the other investigators were listed as Regular Users (read-only
capabilities). No identifying information was collected from the survey. Participants followed a
link to the survey, and their email address was not associated with their responses. They did not
have to log in and create a password.

Exporting of data was tested by MP using pilot responses and at the midway point of data
collection to ensure there were no technical issues with data collection. Raw data collected from
the survey were managed by the REDCap program and were exported as a comma separated
values file. This file was stored on a password-protected secure network drive at the Sick Kids
Research Institute accessible only to the research team. The file was uploaded into R on MP’s
personal computer for analysis only through a secure direct connection to the Sick Kids Research
Institute network. No survey data files were stored on MP’s personal laptop.
2.6 Ethics

This project underwent scientific peer review by Drs. Robin Hayeems and Eleanor Pullenayegum in August 2014. It was submitted to the Research Ethics Board at the Hospital for Sick Children and received initial approval November 14\textsuperscript{th}, 2014. Based on piloting of the survey, changes were made to the survey and an amendment was submitted and subsequently approved February 26\textsuperscript{th}, 2015.

2.6.1 Consent process

Participants were provided with the information letter for the study in the text of the email they received from the CPS (Appendix D). They were informed that by following the link and starting the survey, they were providing informed consent for participation in the study.
3 Results: Systematic review of clinical guidance documents

This chapter presents the results of the systematic review for clinical guidance documents. It begins with a description of the documentation identification process. The quality of the included documents is presented with results from the AGREE-2 scores and rankings for each document. Finally, the content of the documents is described based on elements of the diagnostic assessment, including screening/surveillance, personnel in the assessment, and tools in the assessment.

3.1 Identification of guidance documents

A summary of the process of document selection is presented in Figure 1. A total of 837 unique documents were retrieved using the chosen search terms. Titles and abstracts for these documents were screened for relevance as well as availability in English, with 813 removed during this stage of filtering. Twenty-four documents underwent full-text review. Fifteen documents did not meet the inclusion criteria; twelve documents were not clearly identified as guidance documents and did not include both of a systematic review and recommendations for practice; two were summaries of other published guidelines; and one was a guideline but was not relevant to the diagnostic assessment for ASD. Nine guidance documents were included in the analysis. Two documents were no longer endorsed by their professional associations. The 2001 document published by the American Academy of Pediatrics (AAP) was replaced by a subsequent document in 2007, and the American Speech-Language-Hearing Association (ASHA) guideline was rescinded in 2015.
Figure 1: Clinical guidance document identification process

- **Identification**
  - Records identified (n = 867)

- **Screening**
  - Records after duplicates removed (n = 837)

- **Eligibility**
  - Records screened (n = 837)

  - Records excluded (n = 813)

  - Full-text articles assessed for eligibility (n = 24)

  - Full-text articles excluded (n = 15)
    - Not clear guidelines (n=12)
    - Summaries (n=2)
    - Not relevant (n=1)

- **Included**
  - Studies included in qualitative synthesis (n = 9)
3.2 Type of guidance documents

There were various types of guidance documents identified. These are summarized in Table 4 along with definitions of their scope. The scope of the documents ranged from providing aims, ideals, and guidance for clinical practice (such as in the Miriam Foundation and AAP guidelines) to providing minimum standards required for diagnosis in a particular jurisdiction (such as the British Columbia [BC] guidelines). The main difference between a recommendation and a requirement in the guidance documents was that a requirement determines eligibility for ASD-related services and funding.
### Table 4: Type and scope of guidance documents

<table>
<thead>
<tr>
<th>Guideline, Year</th>
<th>Type of document</th>
<th>Scope of document</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAN, 2000</td>
<td>Practice Parameter</td>
<td>“Practice parameters are strategies for patient management that assist physicians in clinical decision making. A practice parameter is one or more specific recommendations based on analysis of evidence of a specific clinical problem,” (Filipek, Accardo, Ashwal, Baranek, Cook, et al., 2000).</td>
</tr>
<tr>
<td>AAP, 2001</td>
<td>Policy statement</td>
<td>“Policy statements are organizational principles to guide and define the child health care system and/or improve the health of all children,” (American Academy of Pediatrics, 2015).</td>
</tr>
<tr>
<td>BC, 2003</td>
<td>Standards and Guidelines</td>
<td>“…to provide minimum standards required in British Columbia to make a diagnosis of ASD in children under the age of six; to assist in establishing eligibility for ASD intervention services; and to establish consistency in the ASD diagnostic process across the province,” (Dua, 2003).</td>
</tr>
<tr>
<td>Miriam, 2008</td>
<td>Best practice guidelines</td>
<td>“[These guidelines are] not mandatory and may or may not be consistent with current provincial legislation or organizational policy. They are intended as aims or ideals for clinical practice, research and policy, given the current scientific evidence and expert consensus,” (The Miriam Foundation, 2008).</td>
</tr>
<tr>
<td>AOTA, 2009</td>
<td>Practice guideline</td>
<td>“…define the occupational therapy domain, process, and intervention that occur within the boundaries of acceptable practice,” (Tomchek, 2009).</td>
</tr>
<tr>
<td>NICE, 2011</td>
<td>Guideline</td>
<td>“NICE guidelines make evidence-based recommendations... These aim to promote integrated care where appropriate,” (National Institute for Health and Care Excellence, 2014).</td>
</tr>
</tbody>
</table>

3.3 Quality appraisal of guidance documents

The scaled domain scores and rankings of all included documents are presented in Table 5. The mean total score on the AGREE-II for all included documents was 68.6 (s.d. = 11.9, range 45, 89). The three documents with the highest overall scores were the NICE guideline (National Collaborating Centre for Women's and Children's Health, 2011), the American Speech-Language-Hearing Association (ASHA) guideline (American Speech-Language-Hearing Association, 2006), and the BC standards and guidelines document (Dua, 2003). Analysis of the domain scores from the AGREE-II showed that in general, the documents were high quality in terms of scope and purpose (domain 1, mean score 90.6, s.d. 10.2) and clarity of presentation (domain 4, mean score 89.9, s.d. 10.6); these domains also had the lowest variation in scores as measured by the standard deviation. Scores were lowest in applicability (domain 5, mean score 42.7, s.d. 23.4) and rigor of development (domain 3, mean score 51.6, s.d. 25.8). There was considerably more variability in scores in these domains, as well as in the domain of editorial independence, with a s.d. of 33.8.

Six of the nine documents provided a search strategy (the AAP and BC documents did not). Four of the documents noted the inclusion of non-empirical materials such as other guidelines (the Miriam Foundation and BC guidelines) and book chapters (the AAN and AACAP practice parameters). Only two of the documents provided graded recommendations (the AACAP and AAN practice parameters); of these, the AAN excluded diagnostic assessment from graded recommendations, and the AACAP permitted clinical consensus to influence the strength of the recommendations.

Documents were compared based on the type of organization/institution that produced them. The mean total AGREE-II score for the six guidelines produced by professional associations was 64 (s.d. 10.7), with a median of 65. The mean of the three guidelines that were not produced by professional associations (two from governments, one from a non-governmental organization) was higher at 77.7 (s.d. 9.9). The median score of the non-professional association group of guidelines was lower at 73; this was largely due to the high score of the NICE guideline on ASD.

When comparing documents based on jurisdiction, the six US guidelines are all contained within the professional association guidelines, with the same mean of 64, s.d. 10.7. The Canadian guidelines (the BC guideline and the Miriam Foundation guideline) received scores of 71 and 73,
respectively. The NICE guideline, representing the UK, was the only guideline from this jurisdiction, which also had the highest score (89).
<table>
<thead>
<tr>
<th>Guideline, Year</th>
<th>D1: Scope and purpose</th>
<th>D2: Stakeholder involvement</th>
<th>D3: Rigor of development</th>
<th>D4: Clarity of presentation</th>
<th>D5: Applicability</th>
<th>D6: Editorial Independence</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAN, 2000</td>
<td>89  3</td>
<td>61  6</td>
<td>65  3</td>
<td>83  7</td>
<td>8    9</td>
<td>100 1</td>
<td>67 5</td>
</tr>
<tr>
<td>AAP, 2001</td>
<td>67  9</td>
<td>61  6</td>
<td>8  9</td>
<td>83  7</td>
<td>50   4</td>
<td>0    9</td>
<td>45 9</td>
</tr>
<tr>
<td>BC, 2003</td>
<td>100 1</td>
<td>67  4</td>
<td>38  7</td>
<td>94  3</td>
<td>88   1</td>
<td>50  6</td>
<td>73 3</td>
</tr>
<tr>
<td>ASHA, 2006</td>
<td>94  3</td>
<td>89  1</td>
<td>44  6</td>
<td>94  3</td>
<td>38  5</td>
<td>100 1</td>
<td>77 2</td>
</tr>
<tr>
<td>AAP, 2007</td>
<td>94  3</td>
<td>56  8</td>
<td>31  8</td>
<td>94  3</td>
<td>54   3</td>
<td>50  6</td>
<td>63 7</td>
</tr>
<tr>
<td>Miriam, 2008</td>
<td>100 1</td>
<td>78  3</td>
<td>65  3</td>
<td>94  3</td>
<td>38  5</td>
<td>50  6</td>
<td>71 4</td>
</tr>
<tr>
<td>AOTA, 2009</td>
<td>94  3</td>
<td>67  4</td>
<td>48  5</td>
<td>67  9</td>
<td>21   8</td>
<td>83  4</td>
<td>63 7</td>
</tr>
<tr>
<td>NICE, 2011</td>
<td>94  3</td>
<td>83  2</td>
<td>98  1</td>
<td>100 1</td>
<td>58   2</td>
<td>100 1</td>
<td>89 1</td>
</tr>
<tr>
<td>AACAP, 2014</td>
<td>83  8</td>
<td>50  9</td>
<td>67  2</td>
<td>100 1</td>
<td>29   7</td>
<td>83  4</td>
<td>69 5</td>
</tr>
</tbody>
</table>

3.4 Content analysis of guidance documents

3.4.1 Screening and surveillance

A full discussion of screening and surveillance is outside the scope of this policy analysis; still, these elements of early identification make up a considerable proportion of the content of the included clinical guidance documents. All six guidelines that discuss screening and surveillance (the AAN guideline, the two AAP guidelines, the BC guideline, the NICE guideline, and the Miriam Foundation guideline) recommend routine developmental surveillance at primary care visits in early childhood. Only one document (the 2007 AAP guideline) recommends routine screening for ASD at primary care well-child visits, and mentions the M-CHAT as a potential tool for this. The remainder of the guidelines that discuss screening and surveillance favor an approach of targeted use of ASD screening tools for children showing signs of developmental concerns (particularly in the areas of communication, social skills, and behavior) picked up through surveillance.

3.4.2 Diagnostic assessment recommendations

Table 6 summarizes the diagnostic recommendations of each of the guidelines.
### Table 6: Diagnostic recommendations in guidance documents

<table>
<thead>
<tr>
<th>Document</th>
<th>Year</th>
<th>Target audience</th>
<th>Age target</th>
<th>Wait time target</th>
<th>Clinicians that can diagnose</th>
<th>MDT recommended</th>
<th>Recommended assessments</th>
<th>Optional assessments</th>
<th>Tools recommended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Associations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AAN</td>
<td>2000</td>
<td>NS(^1)</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>Yes</td>
<td>Cognitive Speech &amp; language(^2)</td>
<td>OT Neuropsych. Behavioral Academic</td>
<td>Yes, at least one(^3)</td>
</tr>
<tr>
<td>AAP</td>
<td>2001 (2007)</td>
<td>Paediatricians</td>
<td>NS</td>
<td>NS</td>
<td>Physician comfortable conducting a comprehensive evaluation</td>
<td>Ideally</td>
<td>Physical examination Audiology SLP “Some measure of overall cognitive functioning and adaptive skills”</td>
<td>NS</td>
<td>Ideally</td>
</tr>
<tr>
<td>ASHA</td>
<td>2006 (2015)</td>
<td>SLPs</td>
<td>NS</td>
<td>NS</td>
<td>Specifies experienced SLPs can diagnose</td>
<td>Ideally</td>
<td>Audiology “Appropriate referrals to assess needs and comorbidities”</td>
<td>“Appropriate referrals to assess needs and comorbidities”</td>
<td>No</td>
</tr>
<tr>
<td>AAP</td>
<td>2007</td>
<td>Paediatricians</td>
<td>NS</td>
<td>NS</td>
<td>Physician Psychologist SLP</td>
<td>Ideally</td>
<td>NS(^2)</td>
<td>NS</td>
<td>Ideally</td>
</tr>
<tr>
<td>AOTA</td>
<td>2009</td>
<td>OTs, OT Assistants(^5)</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>Yes</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>AACAP</td>
<td>2014</td>
<td>Child and Adolescent Psychiatrists</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>Yes</td>
<td>Medical Cognitive SLP</td>
<td>OT Physical therapy</td>
<td>No</td>
</tr>
<tr>
<td>Governments</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BC</td>
<td>2003</td>
<td>Professionals involved in screening,</td>
<td>NS (applies to 6 wks(^6))</td>
<td>Pediatrician Clinical psychologist</td>
<td>Yes</td>
<td>Clinical diagnostic assessment</td>
<td>OT “Family assessment”</td>
<td>Yes(^7)</td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>Year</td>
<td>Description of Screening, Identification, Assessment, and Diagnosis of Young Children with ASD</td>
<td>Event</td>
<td>Age</td>
<td>Diagnosis</td>
<td>Yes/No</td>
<td>Core Team Members</td>
<td>Optional Team Members</td>
<td>Notes</td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------</td>
<td>-----</td>
<td>----------</td>
<td>--------</td>
<td>-------------------</td>
<td>----------------------</td>
<td>------</td>
</tr>
<tr>
<td>UK (NICE)</td>
<td>2011</td>
<td>Professionals involved in screening, identification, assessment, and diagnosis of young children with ASD</td>
<td>NS</td>
<td>3 mos</td>
<td>Diagnosis conferred by MDT consisting of core team members</td>
<td>Yes</td>
<td>Core team members: Physician (pediatrician/psychiatrist) Psychologist SLP</td>
<td>Optional team members: Pediatrician Psychiatrist Neurologist Educational psychologist Clinical psychologist OT Nurse Specialist teacher Social worker</td>
<td>No</td>
</tr>
</tbody>
</table>

**Non-Profit Associations**

<table>
<thead>
<tr>
<th>Organization</th>
<th>Year</th>
<th>Description of Screening, Identification, Assessment, and Diagnosis of Young Children with ASD</th>
<th>Event</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Yes/No</th>
<th>Core Team Members</th>
<th>Optional Team Members</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miriam</td>
<td>2008</td>
<td>Clinicians who screen for or diagnose ASD</td>
<td>NS</td>
<td>5 mos</td>
<td>Physician&quot; Psychologist&quot;</td>
<td>Yes</td>
<td>Medical Cognitive</td>
<td>Audiology Behavioral Dietician Education Neurological NP OT Pediatrician Psychiatrist Psychologist Social worker SLP</td>
<td>Ideally'</td>
</tr>
</tbody>
</table>

Guidelines are grouped by type and displayed in chronological order. AACAP = American Association of Child and Adolescent Psychiatrists; AAN = American Academy of Neurology; AOTA = American Occupational Therapy Association; ASD = autism spectrum disorder; ASHA = American Speech-Language-Hearing Association; MDT = multi-disciplinary team; mos = months; Neuropsych = neuropsychological assessment;
NP = Nurse Practitioner; NS = Not specified; OT = Occupational therapy; SLP = Speech language pathology; wks = weeks; ( ) indicates year the guideline was rescinded, if applicable

1. Endorsed by other professional associations including: the AAP, the American Occupational Therapists Association (AOTA), the American Psychological Association, the American Speech-Language-Hearing Association, and the Society for Developmental and Behavioral Pediatrics

2. If child fails language developmental screening

3. Recommended instruments: the Gilliam Autism Rating Scale, the Parent Interview for Autism, the Pervasive Developmental Disorders Screening Test – Stage 3, the Autism Diagnostic Interview – Revised (ADI-R), the Childhood Autism Rating Scale (CARS), the Screening Tool for Autism in Two-Year-Olds, the Autism Diagnostic Observation Schedule-Generic (ADOS)

4. Required elements include: 1) Health, developmental, and behavioral histories; 2) Physical examination; 3) Developmental and/or psychometric evaluation; 4) Categorical DSM-IV-TR diagnosis; 5) Assessment of parents’ knowledge of ASD; and 6) Laboratory investigation to search for a known etiology or coexisting condition

5. Also specifies individuals who manage, reimburse or set policy for OT; parents, educators, health care facilities, managed care organizations

6. Specifies wait time of one month to specialized assessment, six weeks to diagnostic assessment, and multi-disciplinary assessment within three months

7. One standardized interview tool and one standardized observational tool are required. Recommended tools include the ADI-R, ADOS, and CARS

8. The diagnosing clinician (either a physician or psychologist) must be a member of a professional order or college that permits the transmission of diagnoses, must have graduate (doctoral level) or post graduate training encompassing specific training in child development and ASDs and other developmental disorders in young children, and must have received supervised clinical experience in the assessment and diagnosis of ASDs in young children. Training with the ADOS and ADI-R is encouraged but not mandatory.

9. Three months to interdisciplinary assessment; two months from the start of the assessment to the communication of results

10. Elements to be included in every diagnostic assessment: 1) detailed questions about the concerns; 2) details of the young person’s home life, education, and social care; 3) developmental history focusing on diagnostic criteria; 4) assessment of social and communication skills and behaviors focusing on diagnostic criteria; 5) medical history; 6) physical examination; 7) consideration of the differential diagnosis; 8) systematic assessment for conditions that may coexist with autism; 9) development of a profile of the strengths, skills, impairments, and needs; 10) communication of the assessment findings

11. Recommends the ADOS and ADI-R should be advanced as the standard assessment protocol in assessment clinics across Canada, but that the lack of access to a diagnostician with this specific training should not prevent children from accessing services. Developmental assessment must be conducted using standardized, norm-referenced instruments (though this can be following the assessment process).
3.4.3 Personnel in the diagnostic assessment

3.4.3.1 Recommendations for MDT assessment

The guidelines were generally very supportive of diagnosis using MDT. Four of seven professional association guidelines recommend MDT for diagnostic assessment, while the remaining three state that MDT should ideally be used. Among the other guidelines, the Miriam Foundation and NICE guideline both recommend MDT, and the BC guideline requires MDT for diagnosis in order to be eligible for provincially funded intervention.

Despite this strong support, there is little empirical evidence provided to support MDT for diagnosis. The AAN guideline splits their guideline into three sections: recommendations based on empiric evidence, recommendations for research, and “consensus-based general principles of management” (Filipek, Accardo, Ashwal, Baranek, Cook Jr, et al., 2000). While the first two sections of the guideline contain evidence-informed recommendations for screening/surveillance, laboratory investigations, and other investigations, recommendations specific to the diagnostic assessment are relegated to the consensus-based section. Similarly, the AACAP guideline gives its MDT recommendation the highest rating of strength of recommendation (clinical standard). According to their legend explaining strength of recommendations, a rating of “clinical standard” is given if there is “rigorous empirical evidence (e.g. meta-analyses, systematic reviews, individual randomized controlled trials) and/or overwhelming clinical consensus” (Volkmar et al., 2014). Because no such empirical evidence is cited, one is left to assume that the use of MDT represents the overwhelming clinical consensus. The NICE guideline is the only one to describe and critique the empirical evidence for MDTs; one study was identified (the study by Mahoney et al. [1998] described in the introduction). In the end, the NICE recommendation for MDT assessment was based on the idea that a solo practitioner could not develop a profile of the child’s strengths and weaknesses.

Despite the claims of broad clinical consensus to support the recommendations (including the clinical standard rating of recommendation by the AACAP), some of the guidelines noted cases where MDT assessment may not be necessary. The scientific committee who advised on the Miriam Foundation guideline argued that flexibility is needed in the diagnostic approach in “cases in which the diagnosis is obvious” and also for cases where the practitioner cannot easily access a MDT assessment (The Miriam Foundation, 2008). The AAP notes that ideally, the
assessment is completed by a MDT, but also leaves room for primary care paediatricians to do the assessment, stating that: “Depending on the level of comfort, the [primary care paeditritician] may opt to refer to an experienced pediatric subspecialist” (Johnson et al., 2007). The ASHA guideline (rescinded in 2015) contained the most notable departure from the requirement for MDT. While still stating that MDT assessment is ideal, the ASHA guideline recommended that: "the SLP who has been trained in the reliable and valid use of diagnostic and assessment tools as well as in the clinical criteria for ASD may be qualified to diagnose these disorders as an independent professional" (American Speech-Language-Hearing Association, 2006). This guideline was rescinded in March 2015 and current information on the ASD section of ASHA’s website no longer states that SLPs can independently diagnose ASD, and instead highlights the necessity of “a medical evaluation, including general physical and neurodevelopmental examination” (American Speech-Language-Hearing Association, 2015).

The most commonly cited reason for MDT assessment for ASD is the need to develop the neurodevelopmental profile of the child’s strengths and weaknesses, an element of the assessment that does not necessarily influence the diagnostic determination of ASD. This was the primary reason given for MDT assessment in the NICE guideline, despite the lack of empirical evidence supporting this practice. This is also given as a reason for MDT assessment in both the BC and Miriam Foundation guidelines. These guidelines posit that one clinician alone cannot provide a sufficient assessment to inform this profile; still, there has been no empiric evidence supporting this, and in fact, the empiric evidence that exists suggests that families prefer to see fewer clinicians on their journey to a diagnosis (Goin-Kochel et al., 2006).

An additional reason given for the need for MDT assessment is the evaluation of the differential diagnosis for ASD. This is the primary reason given in the Miriam Foundation guideline. The differential diagnosis refers to consideration of alternative diagnoses, and is therefore related to the accuracy of the diagnostic process. According to the Miriam Foundation guidelines, “the process of differential diagnosis speaks to the need for interdisciplinary cooperation as no single discipline is equipped to assess all possible disorders” (The Miriam Foundation, 2008). The Miriam Foundation divides its list of potential differential diagnoses generally by the professional that would assess for them: intellectual disabilities (requiring cognitive evaluation by a psychologist), medical conditions, psychological/emotional/behavioural diagnoses, and
hearing/speech/language disorders. Once again, no empirical evidence is presented here about the ability of a solo clinician to develop a comprehensive list of differential diagnoses.

An additional reason for MDT related to differential diagnosis is that of co-occurring conditions in ASD. ASD can be associated with a number of medical conditions, including seizures, gastrointestinal issues, and sleep difficulties. Further, ASD has frequent co-occurring intellectual disability, as well as other learning challenges. Psychiatric and behavioural disorders frequently co-occur in ASD (Anagnostou et al., 2014). The Miriam Foundation and AACAP guidelines refer to the potential for “diagnostic overshadowing”, where there is a failure to recognize co-occurring conditions in the face of the more “noticeable” diagnosis of ASD (The Miriam Foundation, 2008; Volkmar et al., 2014). The ASHA guideline deals with the issue of co-occurring conditions by suggesting that there should be referrals to assess for these conditions, but not requiring that it be part of the diagnostic assessment. The NICE guideline provides a list of co-occurring conditions and also suggests that appropriate assessments and referrals should be made. Neither of these guidelines specifically states that these assessments and referrals must be included in the diagnostic assessment. The NICE guideline is the only one to evaluate supporting evidence for assessment of co-occurring conditions, noting wide variance in reported prevalence of these conditions, under-reporting of some conditions, and an overall insufficiency of study in this area.

3.4.3.2 Recommended personnel for assessment

The guidelines vary with respect to their recommendations for personnel in the diagnostic assessment, even when MDT is recommended. The most common recommended assessments are a medical assessment to be performed by a physician, an assessment of language to be performed by a SLP, and a cognitive assessment to be performed by a psychologist. All three of these were recommended in five of the guidelines, though not necessarily in the same ones. Some of the statements did not fully imply the type of professional that needs to be involved, such as the statement in the 2001 AAP document which recommends “some measure of overall cognitive functioning and adaptive skills” but stops short of saying this needs to be a formal assessment performed by a psychologist (Committee on Children With Disabilities, 2001).
3.4.3.3 Optional personnel for assessment

Five of the guidelines listed specific personnel or types of assessments that may be of clinical value in the diagnostic process. Here, OTs were the most commonly mentioned optional assessment and were listed for the purposes of assessing sensory processing, which is often affected in ASD. Even the AOTA guideline does not recommend participation of OTs in all diagnostic assessments for ASD, stating only that the OT should “understand the team structure and his or her role as a member of the team” (Tomchek, 2009). Beyond OTs, there was a wide range of types of professionals that could be involved, including nurses, teachers, social workers, dieticians, and others. The clinical indications for the other listed optional assessments were not clearly stated in any of the guidelines.

3.4.4 Tools in the assessment

One of the greatest areas of variation in the guidelines was the recommendation for tools to inform an ASD diagnosis. The AAN guideline recommends at least one tool, and the BC guideline requires multiple tools in order to access provincially funded interventions. The Miriam Foundation guideline recommends that the ADI-R and ADOS be considered the gold standard for diagnosis of ASD in Canada, but do allow leeway by stating that “a lack of ADI-R, ADOS data should not prevent a child from receiving much needed services if a diagnostician with sufficient expertise conducts the assessment” (The Miriam Foundation, 2008). The ASHA guideline does not endorse specific tools, but in their recommendation that SLPs can independently diagnose ASD, they limit this ability to SLPs “trained in the reliable and valid use of diagnostic and assessment tools” (American Speech-Language-Hearing Association, 2006). Both AAP guidelines suggest that diagnostic tools should ideally be used, but stop short of recommending them for all ASD diagnoses. The AACAP guideline lists available tools, but provides a relatively lukewarm endorsement of their use: “As a practical matter, all these instruments vary in their usefulness for clinical practice. Some require specific training. The use of such instruments supplements, but does not replace, informed clinical judgment” (Volkmar et al., 2014).

The NICE guideline was the only one to provide a critical analysis of the evidence base for the tools. All of the identified studies evaluating the tools were deemed to be of very low quality demonstrating uncertain clinical benefits, though they did acknowledge the assistance these tools
could provide in performing a systematic, ASD-specific semi-structured interview and observation. There was also consideration given to the possibility of harm that could arise from relying solely on the score provided by the tool. In consideration of all of this, NICE recommends the use of a semi-structured interview and observation for ASD but does not recommend a specific tool.

3.4.5 The diagnostic assessment and eligibility for ASD services

Diagnosis is often essential for access to ASD-specific services, and some of the guidelines addressed the link between assessment and access in their recommendations. The 2001 AAP guideline recommends that any child with developmental delays or symptoms of ASD should be allowed to enroll in early intervention or school-based programs without the requirement of a definitive diagnosis. The 2007 AAP guideline recommends that, in the presence of a positive ASD screen, the paediatrician should simultaneously refer for a comprehensive ASD evaluation and to early intervention/early childhood education services. The AAN has a similar pathway endorsing referral to early intervention upon a positive screen for ASD. These guidelines all pertain to US jurisdictions, wherein early intervention legislation impacts upon eligibility for these interventions. This will be explored further in the Institutions analysis in Chapter 5.

The guidelines pertaining to non-American jurisdictions were less uniform in their links between diagnosis of ASD and eligibility for services. This issue is generally not covered in the NICE guideline, which may be related to the infrastructure for service delivery for ASD in the UK, further explored in Chapter 4. Eligibility for intervention is listed as in the BC guideline introduction as one of the primary motivations for development of standards for diagnosis. The Miriam Foundation’s recommendations are among the more rigorous with regard to elements of assessment required, yet they are careful to note that children should not be denied access to services if elements of the assessment (specifically the ADI-R and ADOS) have not been completed, provided an experienced diagnostician has done the assessment.

3.4.6 Wait times for assessment

None of the professional association guidelines provided maximum suggested wait times for assessment. In these guidelines, the need for early identification (facilitating access to early intervention) is largely discussed in sections dealing with screening and surveillance. Here
again, US service delivery structures, which do not require a formal diagnosis to access early intervention services, decrease the impetus to provide a suggested wait time for a definitive ASD assessment.

Once again, the guidelines pertaining to non-US jurisdictions differed in that they do provide suggested maximum wait times for a definitive ASD assessment, albeit with no supporting evidence for these recommendations, or clear general consensus. The Miriam Foundation guideline recommends a maximum wait time of three months from referral to the start of the diagnostic assessment, and a maximum of two months from the start of the assessment to communication of the results. The BC guideline provides clear maximal wait times for each step in the diagnostic process: one month to specialized assessment (the intermediate step toward a diagnosis), six weeks to diagnostic assessment (from the time of referral from the specialized assessor), and three months to completion of the assessment (from the time of referral from the specialized assessor). The NICE guideline recommends that the MDT assessment begin within three months of referral, but does not specify the amount of time from beginning the assessment to communicating the results.
4 Results: Government policy scan of Canadian and UK policies and processes for ASD diagnosis

This chapter describes government policies for ASD screening/surveillance, diagnosis, and eligibility for services. It begins with a table summarizing all of the government policies, followed by an in-depth description of diagnostic processes and policies for each province and territory, as well as the Canadian federal government and the UK.

4.1 Government policy scan

A summary of the policies for each province and territory, as well as Canadian and UK national policies is included below in Table 7. Detailed summaries for each jurisdiction follow.

Table 7: Summary of government policies for ASD diagnostic assessment and intervention

<table>
<thead>
<tr>
<th>Provincial Guidelines</th>
<th>BC</th>
<th>AB</th>
<th>SK</th>
<th>MB</th>
<th>ON</th>
<th>QC</th>
<th>NB</th>
<th>NS</th>
<th>PE</th>
<th>NL</th>
<th>YT</th>
<th>NT</th>
<th>NU</th>
<th>CN</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires MDT</td>
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<td>✓</td>
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<td>✓</td>
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<td>✓</td>
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<tr>
<td>Requires certain professionals</td>
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<td>✓</td>
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<tr>
<td>Requires certain tools</td>
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<td>✓</td>
</tr>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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</tr>
<tr>
<td>Provisional diagnosis accepted</td>
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<td>✓</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Direct service available for ABA</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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</tr>
<tr>
<td>Direct funding available for ABA</td>
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<td>✓</td>
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<td>✓</td>
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<td>✓</td>
</tr>
</tbody>
</table>

AB = Alberta; BC = British Columbia; MB = Manitoba; NB = New Brunswick; NL = Newfoundland and Labrador; NS = Nova Scotia; NT = Northwest Territories; NU = Nunavut; ON = Ontario; PE = Prince Edward Island; QC = Quebec; SK = Saskatchewan; YT = Yukon Territory; CN = Canadian federal government; UK = United Kingdom
There was a fair amount of variation between jurisdictions. Four of the provinces require MDT (BC, Quebec, New Brunswick, and Nova Scotia), though of these, New Brunswick provides the MDT assessment at the intervention stage. Ontario also has an additional assessment that occurs at the intervention stage because they limit EIBI to children with more severe ASD. Most of the provinces had policies on who could diagnose ASD, with many of these policies linked to determination of service eligibility, such as Ontario’s Autism Intervention Program guidelines (Ontario Ministry of Child and Youth Services, 2006). Three of the provinces (BC, Nova Scotia, and PEI) required certain tools; in all three these tools were the ADI-R and ADOS. Only two of the provinces, BC and Nova Scotia (the provinces with the most requirements for diagnosis), have published target wait times for assessment.

The provinces varied greatly in their approach to intervention. Seven provided only direct ABA services, four provided only direct funding for ABA, and Ontario provided an option for parents to choose direct funding or direct service. A summary of provincial ministries responsible for providing ABA services is provided in Table 8. There was no obvious pattern between the provision of government-funded ABA services and the requirements for diagnosis. Five provinces permitted children to access ABA services prior to a definitive diagnosis; here again, there was no clear relationship with diagnostic requirements.

When examining regional patterns, there was a tendency toward fewer diagnostic requirements in the Prairie Provinces (particularly Saskatchewan and Manitoba), as well as in the territories. Instead of reflecting regional health care preferences, this may be more reflective of challenges accessing MDT or subspecialist assessments in jurisdictions that are less densely populated than other Canadian provinces.

Finally, there was a significant difference between the two countries included in the scan, namely the Canadian federal government and the UK. As detailed below, the jurisdictional responsibility for health care differs for these two countries, which may explain this difference.
Table 8: Provincial ministries funding ASD interventions

<table>
<thead>
<tr>
<th>Ministry</th>
<th>Family/Children</th>
<th>Health</th>
<th>Education</th>
<th>Community/ Social Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>BC</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alberta</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saskatchewan</td>
<td></td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Manitoba</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
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<td></td>
</tr>
<tr>
<td>Quebec(^1)</td>
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<td>✔</td>
</tr>
<tr>
<td>New Brunswick(^2)</td>
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<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td></td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PEI(^1)</td>
<td></td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Newfoundland(^1)</td>
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<td>✔</td>
<td>✔</td>
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<tr>
<td>Northwest Territories(^1)</td>
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<tr>
<td>Yukon (^1)</td>
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<td></td>
<td>✔</td>
</tr>
</tbody>
</table>

This table was adapted from the summary provided by Madore (2006). Nunavut is not included due to their lack of a provincially funded ASD intervention program.

1. Quebec, PEI, Newfoundland and Labrador, the Northwest Territories, and the Yukon Territory all have combined Ministries of Health and Social/Community Services (marked under both Health and Community/Social Services here).

2. Quebec’s program is funded by the Ministry of Health and Social Services (marked under both Health and Community/Social Services here).
4.2 Individual government policies and processes for ASD diagnosis

4.2.1 British Columbia (BC)

Assessment for ASD in BC for children under age six is governed by the Standards and Guidelines document published in 2003 (Dua, 2003). The body responsible for publicly funded assessment for ASD in British Columbia is the British Columbia Autism Assessment Network (British Columbia Ministry of Child and Family Development, 2014). Families may also choose to pursue a diagnosis privately. If they wish to do so, eligibility for government funding requires that the diagnosis adhere to the Standards and Guidelines, including documentation of an ADI-R and ADOS (British Columbia Ministry of Child and Family Development, 2010).

The process of identification, assessment, and diagnosis follows BC’s emphasis on “Tiers of Expertise” in the care of children with special needs (British Columbia Ministry of Health Services, 2008). All children undergo developmental surveillance through primary care (tier one), and those with suspected ASD are referred to the second tier for a more detailed assessment. If there is still a suspicion of ASD, the child is then referred to tier three for a subspecialist MDT assessment (Dua, 2003). The Standards and Guidelines document (included in the guideline analysis) mandates that the following are required for a diagnosis of ASD in BC:

1. A history taken using the ADI-R;
2. A structured observation using the ADOS;
3. A psychological assessment by a clinical psychologist;
4. A medical assessment by a paediatrician; and
5. A language assessment by a SLP.

The province of BC does not provide direct services to children with ASD, but instead provides $22,000 of funding per child per year up to age six for families to contract their own service providers (British Columbia Ministry of Child and Family Development, 2009). After age six, families may be eligible for up to $6,000 per year to purchase services for their child. Both require documentation of a diagnosis in accordance with the Standards and Guidelines document. The Parent Handbook contains lists of eligible and ineligible expenses related to ASD intervention (British Columbia Ministry of Child and Family Development, 2013). In addition, for students with ASD to receive funding attached to a special needs designation in the education
system, a diagnosis meeting the BC standards must be documented (British Columbia Ministry of Education, 2013)

4.2.2 Alberta

The Alberta Ministry of Health website topic overview page on ASD notes that “there are guidelines your doctor will use to see if your child has symptoms of autism” On the government Programs and Services website for Parents (Government of Alberta, 2015b), the Government of Alberta provides a link to the Miriam Foundation (The Miriam Foundation, 2015), implying support for their Canadian Best Practice Guidelines (The Miriam Foundation, 2008).

A document from the Ministry of Education about ASD notes that the diagnosis is often made by a “pediatrician, child psychiatrist or clinical psychologist with expertise in the area of autism spectrum disorders” (p.3, Government of Alberta, 2003). This document also states that ideally, assessment and diagnosis involve a MDT, comprised of a paediatrician or psychiatrist, psychologist, and a speech language pathologist.

Funding for services is provided with through Family Support for Children with Disabilities (Alberta Human Services, 2013). To qualify for this, a medical form must be completed by one of the following, providing the diagnosis is in their scope of practice: a physician/psychiatrist, SLP, OT, PT, audiologist, clinical social worker, or psychologist. The diagnosis does not have to be confirmed, but it must be noted that the child is awaiting a diagnosis. Parents are responsible for choosing a service provider with the funding provided through this program.

Specialized services are available for children with “severe” disorders or disabilities and consist of a team-based approach assisting parents to manage difficult behaviours and teach their child new skills (Government of Alberta, 2015d). In the case of ASD, documentation of a “severe” diagnosis by a psychiatrist, psychologist, or medical professional specializing in ASD is required to access these services (Government of Alberta, 2004).

4.2.3 Saskatchewan

Saskatchewan’s policy document outlining their framework for ASD service delivery highlights the importance of early diagnosis and their commitment to providing timely access to assessment (Saskatchewan Ministry of Health, 2008). Parents who are concerned about possible ASD are
encouraged to contact their health region’s ASD hub. From there, they undergo screening by an ASD Consultant, who can arrange for further assessment. The province’s website notes that diagnosis is often “a multistep process” which may include a number of professionals (Government of Saskatchewan, 2015b).

All children with suspected ASD will have access to an ASD Consultant, who will act as the first point of contact for services, providing case management and helping to coordinate an assessment. This individual will also provide ASD screening; those children that screen positive will have access to an ASD Support Worker, who provides direct intervention to the child. A confirmed diagnosis of ASD is not necessary to access these services.

4.2.4 Manitoba

There is little in the way of published policies or guidelines for ASD diagnosis in Manitoba. In 2011, the government of Manitoba announced *Thrive! A five-year plan for helping Manitobans with autism spectrum disorder and their families* (Manitoba Family Services and Consumer Affairs, 2011). Aims of this program include timely diagnosis and increased diagnostic capacity, and province-wide access to ASD experts. There are no further specifications on requirements for a diagnosis of ASD.

Services and funding for children with ASD are provided through Family Services Manitoba’s Children’s DisABILITY Services. Eligibility for these services is reserved for children under age 17 who are residents of Manitoba and present with a disability including ASD (Province of Manitoba Family Services, 2015). A family services worker works with the family to develop a Service Plan that is based on the assessed needs of the child and family as well as the resources available to them. The website provides a menu of available supports, including ABA for ASD (Province of Manitoba Family Services, 2015).

4.2.5 Ontario

Ontario places relatively few restrictions on the assessment process for ASD. The Autism Parent Resource kit was published in 2011 by the Ministry of Child and Youth Services in Ontario (Ontario Ministry of Child and Youth Services, 2011a). This parent-focused document provides a list of clinicians that can make a diagnosis of ASD, which includes family physicians, paediatricians, psychiatrists, psychologists, and psychological associates. The document also
notes that the diagnosing professional may use tools including the ADI-R, CARS, and/or the ADOS, and that regardless of the specified method, observation of the child is critically important. This description of the assessment process is also described in the Autism Intervention Program guidelines (Ontario Ministry of Child and Youth Services, 2006), which states that a diagnosis made by a physician, psychologist, or psychological associate is necessary for eligibility.

There are two main provincially funded ASD interventions in Ontario, the Autism Intervention Program and ABA-based services. The Autism Intervention Program consists of EIBI delivered for 20 to 40 hours per week over a duration of approximately two years, though the amount of time can vary for individual children (Ontario Ministry of Child and Youth Services, 2006). Parents may choose the Direct Service option, in which the child receives intensive behavioral intervention at a government-contracted centre, or the Direct Funding option, where the parent receives the equivalent sum of money to privately contract a behavioral interventionist. Eligibility for this program requires a diagnosis of severe ASD made by a physician, psychologist, or psychological associate. Of note, there is an additional eligibility assessment that occurs after referral to the program to further determine eligibility, though eligibility criteria for this assessment are not published. There is a note that all Ontario EIBI programs must use certain tools in this assessment, including the DSM diagnostic criteria, the CARS, and the Vineland Adaptive Behavior Scales.

ABA-based services are similarly available for children with ASD who have received their diagnosis from a family physician, paediatrician, psychiatrist, psychologist, or psychological associate, but with no level of severity required (Ontario Ministry of Child and Youth Services, 2011b). These services consist of blocks of ABA-based therapy, often provided to groups of children, for two to four hours per week over two to six months.

4.2.6 Quebec

The province of Quebec published guidelines for diagnosis of ASD in 2012 (note that these were not included in the formal guideline review due to their unavailability in English; College des Medecins du Quebec & L’Ordre des Psychologues du Quebec, 2012). This document discusses the tension between the shorter wait times for solo clinicians and the hypothesized benefits of integrating opinions of multiple professionals in MDT assessment. The proposed resolution to
this “paradox” is to employ provisional diagnoses, wherein a solo clinician can identify that the child has a likely diagnosis of a disorder and can refer for services. The document notes that assessment is a process that occurs along a continuum integrating many professionals and partners. The first step of the assessment describes a traditional history as taken by a physician or psychologist paired with observation of the child. Any signs denoting possible ASD should lead the clinician to complete an ASD-specific screening tool (the M-CHAT is referenced). Results indicating possible ASD should prompt the clinician to refer for visual and auditory testing, direct the family to available resources, and to refer for further assessment. This assessment can consist of referral to a subspecialist or team who can substantiate the initial clinical findings and facilitate early stage interventions.

In the intermediary stage, it is necessary that a physician evaluate the child to determine if there are medical factors contributing to the presentation. The initial medical evaluation may be supplemented by use of the ADI-R and ADOS. A psychology assessment may also be helpful to assess cognitive skills and behavioral presentation. Similarly, an assessment by a SLP may help to distinguish ASD from other communication disorders. The guidelines note that it may be possible to make a diagnostic determination of ASD based on history and good clinical observation; however, the evaluation process should continue to a MDT assessment to provide a global assessment of the child that will inform intervention.

The section on MDT assessment begins with a description that the goal of assessment is not simply to determine whether the label of ASD applies, but instead to build a holistic description of the child’s strengths and needs. The rationale for MDT is to fulfill a multi-axial diagnosis as described in the DSM, including determining the presence of intellectual disability (Axis II) and ruling out medical conditions (Axis III). MDT assessment is also noted to minimize individual bias in assessment. Recommended assessors include a physician, a psychologist, and a SLP. Of note, until 2009, psychologists in Quebec were not allowed to diagnose ASD (Quebec National Assembly, 2009).

Both responsibility for delivery of ABA as well as assessment of needs sits with the “readaptation centres” (Province du Quebec, 2003). The provincial government directly provides a minimum of 20 hours per week of ABA to children with a diagnosis of ASD prior to school entry (Madore, 2006).
4.2.7 New Brunswick

The assessment process for ASD in New Brunswick is not only limited to the determination of the diagnosis, but also occurs at the entry to intervention. After diagnosis, the family is referred to a local authorized agency that provides developmental assessment as well as delivering the intervention (Government of New Brunswick, 2015b). This assessment is completed by a MDT with a note that it should not duplicate assessments that have already been completed (New Brunswick Department of Social Development, 2008). The assessment must include assessment of cognitive, communication, perception/social, emotional regulation, and motor skills.

Intervention for ASD in New Brunswick is provided through the Intervention Services for Preschool Children with Autism Spectrum Disorder program and consists of either ABA or EIBI (Government of New Brunswick, 2005b). Parents are provided with up to $27,500 in funding per year per child (until school age) to purchase services from six province-approved agencies across the province (Government of New Brunswick, 2014).

A parent-targeted pamphlet notes that eligibility for this program requires diagnosis by a qualified physician or psychologist, but does not further specify the necessary qualifications (Government of New Brunswick, 2005a). These specifications are included in the Standards for Agencies Delivering Intervention Services for Preschool Children with Autism Spectrum Disorder document (New Brunswick Department of Social Development, 2008), which states that the diagnosis must be made by a paediatrician, physician, paediatric neurologist, psychologist, or psychiatrist. New Brunswick provides a Confirmation of Diagnosis form (Government of New Brunswick, 2010) which indicates the only element of assessment necessary to qualify for intervention is that the diagnosing professional must be either a physician or psychologist.

4.2.8 Nova Scotia

The Mental Health Services Standards document (Government of Nova Scotia, 2009) states that each district health authority has access to specialists with advanced training in neurodevelopmental disorders, including psychology, paediatrics, neurology, and psychiatry. There should be a diagnosis or formulated impression of the child within ninety days of
disposition. Assessments should include current, reliable, and valid tools. All three of these standards are assigned an evidence level of “expert consensus of effectiveness or value.”

In 2008, the government of Nova Scotia convened a committee and commissioned a report with regard to lifespan needs for ASD (Autism Management Advisory Team [Nova Scotia], 2010). Section five of this report deals with diagnostic processes in Nova Scotia. For the pre-school age group, each district health authority in Nova Scotia has an ASD diagnostic team, and they estimated that the wait for diagnosis across the province ranges from three to twelve months. The recommended diagnostic approach in this report is through MDT, generally composed of a psychologist, a SLP, a social worker, and an OT. This report also states that in Nova Scotia, the ADI-R and ADOS are recommended for the diagnosis of ASD. Children who have entered school may have an initial assessment through special staff trained to recognize ASD. If a diagnosis is suspected after this assessment, a referral can be made to the local autism team or mental health clinic. There is note in this report that the wait for diagnosis across the province is generally too long. Children with suspected ASD should be referred for screening immediately and “comprehensive medical testing” (note: unclear if this refers to diagnostic assessment) should occur within one month. Following diagnosis, intervention should begin within three months. In acknowledgement of another suggestion from this report, the province of Nova Scotia implemented 18-month developmental screening in 2012, though not specifically screening for ASD (as the Advisory Team recommended; Government of Nova Scotia, 2012).

Actual diagnostic practice governed by Nova Scotia Health may differ slightly from that described in the Autism Management Advisory Team report. A government document obtained from a clinician in Nova Scotia distinguishes between the “core” assessment (to be used for “straight-forward” diagnoses) and “further” assessment (to be used when the diagnosis is complex; Nova Scotia Health, 2008). The core assessment consists of a medical assessment by a paediatrician, an ADOS, and a clinical interview and observation. There is a note that language/communication and cognitive assessments should be done at some point in the diagnostic process (effectively necessitating a MDT diagnostic assessment). Further assessment elements include the ADI-R, an adaptive behavior assessment, and observation of interaction with peers (which may be videotaped).
The province of Nova Scotia directly provides one year of EIBI for young children (prior to school-age) with ASD. The intervention begins with fifteen hours per week and gradually tapers, with an emphasis on parent training to maintain learned skills (Province of Nova, 2012). The child can have a confirmed or provisional diagnosis of ASD and the diagnosis must be made according to the criteria used by each district health authority (Autism Management Advisory Team [Nova Scotia], 2010). The child must also be able to participate for six months before school entry. Requirements for tuition support for school-aged children require that the diagnosis of ASD be made by a licensed physician, registered psychologist, or candidate-registered psychologist (Government of Nova Scotia, 2015).

4.2.9 Prince Edward Island (PEI)

There are no documents pertaining specifically to the diagnostic assessment process for ASD in PEI; however, guidelines for ASD services (Prince Edward Island Department of Education and Early Childhood Development, 2012) and funding (Prince Edward Island Department of Education and Early Childhood Development, 2014) require that children with ASD be diagnosed by a physician, psychologist, or psychiatrist. There is also a requirement that the diagnosis be made with standardized tools, “including but not limited to the [ADOS] and [ADI-R]” (Prince Edward Island Department of Education and Early Childhood Development, 2014). Children with a provisional diagnosis of ASD can be referred and placed on the waiting list for services, though a written confirmation of the diagnosis must be received prior to starting the intervention (Prince Edward Island Department of Education and Early Childhood Development, 2012).

In their Early Years Autism Services, the province provides an “Autism Specialist” that observes and assesses the child across environments to create an individualized program for each child (Prince Edward Island Department of Education and Early Childhood Development, 2012). After this assessment period is complete, the “employer” (childcare centre or family, depending on the location of the intervention) is responsible for recruiting and hiring an “Autism Assistant” who delivers the individualized program to the child. The province funds $13.18 per hour for up to 25 hours per week to offset the cost of the Autism Assistant (Prince Edward Island Department of Education and Early Childhood Development, 2014). Funds are submitted to the employer upon receipt of documentation of hours of intervention.
4.2.10 Newfoundland and Labrador

A document on Teaching Students with ASD (Government of Newfoundland and Labrador, 2003) notes that the diagnosis should ideally be made by a MDT including a psychologist, SLP, and either a paediatrician or psychiatrist. It also notes that in some cases, an OT can provide additional information about sensory integration and motor skills. It further states that diagnoses in the province are usually made at the main tertiary children’s hospital, the Janeway, and that a child often receives a provisional diagnosis while waiting for the tertiary assessment.

A Freedom of Information request filed in 2014 resulted in the release of government documents pertaining to ASD (Government of Newfoundland and Labrador, 2014). In a March 2014 briefing note, there is documentation that paediatricians, psychiatrists, and psychologists with clinical competency in ASD can make a diagnosis. There are four diagnostic teams in the province (one per regional health authority). In addition, there are three paediatricians in the province that do assessment and diagnosis in their practices.

Newfoundland and Labrador has an intensive ABA program available for children up to Grade 3. Children pre-school-age can receive up to thirty hours per week, with up to fifteen hours per week for children from school entry to Grade 3. The only requirement for the service is an ASD diagnosis by a qualified professional (Government of Newfoundland and Labrador Department of Health and Community Services, 2015).

4.2.11 Yukon Territory

There is little documented policy for the Yukon Territory regarding the assessment process for ASD. An educational document outlining diagnoses eligible for an individual education plan states that ASD must be diagnosed by a psychiatrist, registered psychologist, or medical professional in order to be accepted (Yukon Department of Education, 2013).

4.2.12 Northwest Territories

There is relatively little information available about the diagnostic process and access to services in the Northwest Territories. The Ministry of Health and Social Services has published a document outlining early developmental strategies for the territories, which includes a commitment to introduce universal developmental screening (not ASD-specific, no targeted age).
There is no specific mention of ASD in the document, though there is a commitment to support at-risk children and families using an interdisciplinary approach. A search of government websites does not reveal any ASD intervention programs; however, a document prepared by the Library of Parliament summarizing provincial and territorial ASD interventions identifies an ABA program in the Northwest Territories for preschool- and school-aged children with ASD (Madore, 2006). According to this document, children under age six receive direct therapeutic intervention and children receive extra supports and services once in school.

4.2.13 Nunavut

A search of the website for the government of Nunavut reveals no pages related to ASD or related terms. For children with unspecified developmental challenges, the Healthy Children Initiative provides additional funding to licensed childcare facilities to support children’s development, particularly those children with special needs (Government of Nunavut, 2015). Additional supports may include OT, SLP, and supported childcare.

4.2.14 Canadian federal government

In Canada’s federalist governance structure, the federal government provides funding through health and social transfers to the Canadian provinces and territories, who have jurisdictional control over how health and social services are delivered (Canada Department of Finance, 2011). The Canadian government’s influence in delivery of ASD services is thereby limited, unless there are requirements in place to receive these funds (the only current funding requirement is adherence to the Canada Health Act; Health Canada, 2004) or additional funding incentives provided for meeting certain benchmarks. In the current “classical federalism” governance structure, federal transfers are provided with few provisions as to how the money is spent (Cameron & Simeon, 2002).

Given this structure, it is not surprising that there is little information provided on ASD diagnosis and intervention by the Canadian federal government. An info sheet published by Health Canada mentions “a team of health professionals will use various standardized tests to make the diagnosis” (Health Canada, 2012). A 2007 Senate report entitled Pay Now or Pay Later: Autism Families in Crisis (The Standing Senate Committee on Social Affairs & Technology, 2007)
focused on national policy options for treatment, but also mentioned that wait times for assessment were an important problem (though made no recommendations specific to assessment practices). The Canadian government does provide tax assistance for families with a child with ASD. The child’s physician can complete the disability tax credit application can be completed provided the child has “marked restriction” in the mental functions necessary for everyday life (Canada Revenue Agency, 2015), a qualification that may not include all children with ASD.

4.2.15 United Kingdom (UK)

While the UK’s universal, publicly funded health coverage is similar to that of Canada, the governance structure differs in that the National Health System is responsible for delivery of health care in the UK (The National Health Service, 2015). To enact its national mandate for funding and delivery of health care, the National Institute for Health and Care Excellence (NICE) develops national care guidelines and evaluates their implementation (National Institute of Health and Care Excellence, 2014). In 2011, NICE published a guideline on diagnostic assessment for ASD (National Collaborating Centre for Women's and Children's Health, 2011). This guideline was reaffirmed in July 2014. The NICE guideline requires that the diagnosis of ASD be made by a MDT, with core members of the MDT listed as a physician (paediatrician or psychiatrist), psychologist, and a SLP, with a number of optional team members listed (see Table 6 for full list). The rationale given for MDT assessment was the need for multiple team members to inform the child’s neurodevelopmental profile, which was thought to be too complex for one professional to do alone. The target wait time from referral to the MDT to the start of the assessment is three months.

Subsequent to the publication of the diagnostic guideline, NICE developed a clinical pathway delineating the system of care depending on the patient’s age and clinical presentation (National Institute for Health and Care Excellence, 2014). Any physician can refer directly to the autism assessment team, who then decides whether the case merits assessment. Assessment is automatically provided in the case of regression in language or social skills in a child less than three years of age; in cases of older children with regression or with the presence of regression of motor skills, the autism team will first refer to a paediatrician or paediatric neurologist before performing an assessment. In cases without regression, the autism team decides on whether to
carry out the assessment based on the evidence presented in the physician’s referral. In cases where a decision is made by the autism team to proceed to assessment, the assessment is carried out in accordance with the NICE guideline.

With regard to intervention for ASD, NICE also published a guideline entitled *Autism: the management and support of children and young people on the autism spectrum* (National Institute for Health and Care Excellence, 2013). This document outlines the evidence and makes recommendations for various types of interventions (including “consideration” of psychosocial interventions to address the core features of ASD), but does not address the funding of and eligibility for these interventions. The provided quality standard evaluation for access to intervention is instead a documented discussion about available services with a member of the autism team.

The National Health Service website describing funding for ASD treatments notes that these treatments are resource intensive and have considerable cost if not covered by their service (The National Health Service, 2013). They also note that many local education authorities provide some funding toward specialist education and training, but the provision of this funding varies widely from region to region. On the UK’s National Autistic Society website, they suggest that parents investigate the local publicly funded services available through the National Health Service, social services department, and schools (The National Autistic Society, 2015). In sum, while standard processes exist for the assessment and diagnosis of ASD in the UK, the link between this diagnostic process and the interventions it is designed to facilitate is unclear.
5 Results: Ideas, interests, and institutions in ASD clinical guidance documents and government policies

This chapter will provide a policy analysis of the clinical guidance documents and government policies relating to ASD diagnosis using the Ideas, Interests, and Institutions I-3 policy framework (MacLean & Wood, 2010). Each of these components of the framework will be explored in sections to follow.

5.1 Ideas

Ideas are the values and beliefs attached to truths (N. Smith, Mitton, C., Davidson, A., Williams, I., 2014). The content of the documents included in this analysis describes a multi-step process of early identification through screening and/or surveillance, followed by assessment, and finally management of the diagnosis, each supported by varying degrees of evidence and reflecting varied ideas about the assessment process.

5.1.1 The relative importance of evidence versus clinical consensus

One of the fundamental ideas related to clinical guidelines is that they should be based on a systematic review of evidence, and that this evidence should inform the strength of recommendations (Institute of Medicine of the National Academies, 2011). The presented documents deal with the differing amounts of empirical evidence supporting recommended diagnostic practices in various ways. The NICE guideline provides a thorough critique of the available evidence and is transparent in the reasons for its decision to recommend MDT assessment in the absence of quality evidence (namely, the development of a comprehensive and holistic profile of the child’s strengths and weaknesses). By comparison, the AAN guideline reserves its recommendations for MDT assessment for a section wholly outside of the evidence-based recommendations, also excluding this section from the “recommendations for research” attached to the evidence-based recommendations in the guideline (Filipek, Accardo, Ashwal, Baranek, Cook, et al., 2000). The AACAP guideline allows for its strongest recommendations, “clinical standard”, to include “overwhelming clinical consensus” (Volkmar et al., 2014). Within their two clinical standard recommendations pertaining to the diagnostic assessment for ASD, six of twenty-eight references are to chapters in books for which the lead author of the guideline is either an author or editor. These references support recommendations for psychological and SLP
assessments, as well as the potential need for occupational and physical therapy assessments. The significant variation in guideline recommendations is likely strongly influenced by their differing ideas of the relative primacy of evidence-based versus consensus-driven recommendations.

5.1.2 Emphasis on early identification

Much of the content of the guidelines is devoted to early identification strategies. The general idea inspiring this push for early identification is that children with ASD are not being identified during traditional interactions with health and other sectors. Generally developmental surveillance through primary health care is universally supported, with most guidelines suggesting use of an ASD-specific screening tool if concerning features are identified by surveillance (the 2007 AAP guideline is a notable exception to this). Five of the nine guidelines include checklists to help clinicians with the process of early identification (the two AAP guidelines, the NICE guideline, the BC guideline, and the Miriam Foundation guideline). Regardless of the approach chosen for early identification, the failure to identify children with early signs of ASD is often presented as the main barrier to children with ASD accessing interventions in a timely fashion; however, the energy directed toward early identification can miss the downstream consequences of a bottleneck of diagnostic assessments and interventions. The guidelines give these important resource implications far less emphasis, as evidenced by the low Applicability scores in the AGREE-II ratings.

5.1.3 The necessity of MDT assessment

Recommendations about the personnel required for assessment generally endorsed the idea that one clinician was not capable of completing a sufficient diagnostic assessment for ASD. The reasons given for this included the need to develop a comprehensive differential diagnosis to exclude other conditions that may mimic ASD, the need to evaluate children for co-occurring conditions, and the requirement to develop a holistic profile of the child’s strengths and weaknesses. None of these ideas is empirically supported, and as such, all remain within the realm of ideas about ASD diagnosis.

The argument requiring MDT assessment to ensure the accuracy of the diagnosis in light of the varied list of possible diagnoses, co-occurring conditions, and the need for a holistic profile is
not consistent among neurodevelopmental disorders. For instance, the 2011 AAP guideline for the diagnosis and management of attention deficit hyperactivity disorder (ADHD), a neurodevelopmental disorder with criteria defined in the DSM and with a number of co-occurring and alternative disorders in the differential, firmly places responsibility for diagnostic assessment in the scope of the primary care clinician without suggestion of an MDT. This guidelines states that “the high prevalence of ADHD and limited mental health resources require primary care pediatricians to play a significant role in the care of their patients with ADHD” (Subcommittee on Attention-Deficit/Hyperactivity Disorder et al., 2011). Ideas about required elements for diagnosis vary considerably between neurodevelopmental disorders, indicating different conceptualizations of these disorders.

5.1.4 Separating tools from clinical judgment

Tools used in the diagnostic process are given varying recommendations as well, from the NICE guideline not endorsing any specific tools to the Miriam Foundation guideline suggesting that the combined use of the ADI-R and ADOS should be put forth as the “standard assessment protocol” for ASD diagnosis in Canada (The Miriam Foundation, 2008). The use of these tools is presented as being so ingrained in the clinical process that it is not possible to tease out their relative contributions to the diagnosis. As mentioned in the introductory chapter, studies validating these tools have compared their results to the clinical judgment of MDTs; however, these clinical judgments were informed by the use of the tools themselves (Kim & Lord, 2012b; Kim et al., 2013). The entanglement of tools and clinical judgment is presented in the Miriam Foundation guideline, which states that “standardized tools may serve to structure clinical judgment” (The Miriam Foundation, 2008). The circuitous validation and recommendation of resource-intensive diagnostic tools for ASD has thus far allowed little room for critique and exploration of alternative diagnostic strategies.

In sum, the included guidelines and policies present varying ideas of ASD, as well as ideas that differentiate ASD from other neurodevelopmental disorders. These ideas are often a reflection of their authors, as the bodies contributing to the clinical and policy guidelines on ASD diagnosis express their interests in both their contribution to the discussion of ASD diagnosis, as well as the ways they position their roles in the assessment process.
5.2 Interests

5.2.1 Professional associations

While the guidelines included in this review generally adopt the DSM definitions of ASD, the collection of bodies producing the guidelines and policies suggest higher-level conceptualizations about the diagnosis of ASD. The fact that the widely accepted diagnostic criteria ASD come from the American Psychological Association’s Axis 1 of the DSM shows that ASD is within the realm of other psychological “clinical disorders” such as ADHD and obsessive compulsive disorder (American Psychiatric Association, 2013). The presence of multiple guidelines from medical organizations as well as the NICE guideline representing the National Health Service in the UK indicate that ASD is also considered to be a medical disorder. The statement by the AOTA places less emphasis on the definition of ASD as an occupational, motor, or sensory disorder, instead stressing that these features can accompany an ASD diagnosis.

The ASHA guideline indicates that ASD was considered by some to be primarily a communication disorder, though the rescindment of this guideline hints at reinterpretation of this idea. The ASHA guideline stood out as one of the few to allow solo clinician diagnosis, and was considerably unique in the suggestion that a clinician who was not a physician or psychologist (a SLP) could independently make the diagnosis. This statement, the most defining of the ASHA guideline, has now been removed from the ASD-related material on their website, with emphasis on the importance of assessment for medical aspects of ASD (American Speech-Language-Hearing Association, 2015). There has been no new evidence confirming or refuting the ability of a solo SLP to diagnose ASD, and this change (particularly the new emphasis on medical aspects of assessment) suggests that other interests may have influenced this decision.

The groups that have not influenced the diagnostic assessment process for ASD should also be noted. While educators and behavioral analysts are among the most important intervention resources for ASD, their professional associations have mainly focused on management strategies, such as the American Federation of Teachers document on “Helping Students with Autism” (American Federation of Teachers, 2009) and the Behavior Analyst Certification Board’s “Practice Guidelines for Autism Spectrum Disorder” (Behavior Analyst Certification Board, 2014). The latter guideline provides recommendations for assessment, but this assessment
is not linked to determining the diagnosis, and instead focuses on identifying the child’s behavioral needs and developing a plan to address these needs. Effectively, there is a disconnect between the groups that have defined the diagnostic process for ASD, and the groups charged with implementing management strategies, with no clear process for operationalizing the neurodevelopmental profile developed during the diagnostic assessment.

5.2.2 Governments

As stated in the BC guideline, one of the primary motivations for governments to weigh in on the assessment process is the determination of eligibility for ASD interventions (Dua, 2003). While the majority of Canadian provinces and territories provide some funding for these interventions, the evolution of this service delivery had contentious roots that began in BC. In the Auton case, several families pursued legal action against the province of BC arguing for coverage of ABA (Bond, 2005). The Supreme Court of BC ruled that the province was responsible for funding these services as “medically necessary” under the Canada Health Act (The Supreme Court of British Columbia, 2007); however, a ruling by the Supreme Court of Canada found that the province was not responsible for funding ABA as this was not within the scope of the Medicare services covered by the Canada Health Act (Supreme Court of Canada, 2004). Nevertheless, the majority of provinces began to fund ABA and related services for ASD, with a key role of diagnostic assessment to ensure that these services were restricted to children with ASD.

Different provinces have taken different approaches to the use of assessment to determine eligibility for services. Ontario requires only that a physician or psychologist provide the diagnosis, but also requires an additional eligibility assessment to determine eligibility for its EIBI program (it should be noted that this program is restricted to children with more severe ASD; Ontario Ministry of Child and Youth Services, 2006). The clinicians performing these eligibility assessments are psychologists (either Clinical Directors or Supervising Psychologists in the program). Nova Scotia requires a more rigorous diagnostic assessment, but also allows children to access the wait list for services with a provisional diagnosis (Autism Management Advisory Team [Nova Scotia], 2010). There does not appear to be a connection between the type of service offered (whether direct service delivery or funding provided to families to contract service providers) and the required elements of diagnostic assessment. As such, while diagnostic
assessments do provide a gate-keeping mechanism for access to costly behavioral interventions, the application of this mechanism has varied considerably across the country.

5.2.3 Family and self-advocates

As seen in the Auton case described above, the interests of family advocates can have a significant impact on ASD policy development. The use of family stakeholder input was mixed in the included guidance documents. At one end of the continuum, there was no documented family input in the AACAP, BC or AOTA guidelines. The AAN guideline had an endorsement from Cure Autism Now, the parent organization that went on to become Autism Speaks, the largest advocacy organization for ASD. Three of the guidelines (NICE and both AAP guidelines) had a parent liaison. The Miriam Foundation’s guideline was the most transparent in the way that parent influence shaped the recommendations, providing a summary of the parent committee statements for each of the recommendations.

A scan of parent advocacy websites showed relatively little attention devoted to the assessment process and far more to intervention and other post-diagnosis issues. The Autism Speaks Canada website entitled “How is Autism Diagnosed?” contains a description of the Modified Checklist for Autism in Toddlers – Revised screening tool, a link to complete this screening tool, and a link to the DSM-5 diagnostic criteria (Autism Speaks Canada, 2015). The US Autism Speaks website has a “First Concern to Action” toolkit that helps to guide parents through the process from early identification to diagnosis (Autism Speaks, 2013). In the toolkit, they detail multiple routes to a diagnosis and note that parents often pursue more than one route at a time. This relative inattention to the diagnostic process is not surprising given that many parents would access these resources after a diagnosis, a time period that is likely more concerned with obtaining much needed services.

None of the guidelines contained input from individuals with ASD. Some of this may be explained by the fact that the diagnosis of ASD often comes at a young age, and many self-advocates may not remember this process. The Autistic Self Advocacy Network states on its website that ASD is “diagnosed based on observation by a diagnostician or team of diagnosticians (e.g. neuropsychologist, psychologist, psychiatrist, licensed clinical social worker, etc.)” (Autistic Self Advocacy Network, 2015a). There is also dissention in the self-advocate community about the role of a clinician providing a diagnosis:
“Many Autistics were given a diagnostic label in childhood or sought a formal diagnosis in adulthood to obtain services and accommodations. Others have not done so for reasons that include…the political view that our community should not have professionals as its gatekeepers.” (Autistic Self Advocacy Network, 2015b)

This quotation hints at the strained relationship between clinicians, who define ASD as a neurodevelopmental disorder, and self-advocates, who primarily describe autism as a neurological variation (Autistic Self Advocacy Network, 2015a). This tension may help to explain why individuals with ASD were not consulted about the diagnostic process. Given the Autistic Self-Advocacy Network’s slogan of “Nothing About Us Without Us” (Autistic Self Advocacy Network, 2015b), the lack of consultation may have the unfortunate effect of widening an already sizeable gap between the two camps.

5.2.4 Authors

A step beyond the interests of groups in sculpting the diagnostic process is the interests of individuals directly involved in the guideline creation process, namely the individuals who have authored the guidelines. Conflicts of interest were differentially reported in the guidelines. The NICE and AOTA guidelines were the only ones to report that the authors had no conflicts of interest. The AAN guideline acknowledges unrestricted educational grants provided by pharmaceutical companies for the completion of the work, but also states that there are no pertinent financial interests of any of the authors, including “ownership, equity position, stock options, patent-licensing arrangements…consulting fees, or honoraria” (Filipek, Accardo, Ashwal, Baranek, Cook Jr, et al., 2000). The AACAP guideline discloses that the primary author, Fred Volkmar, has intellectual property with publishing companies. This disclosure did not prevent the repeated citation of many of this author’s books throughout the guideline, particularly in sections devoted to the diagnostic process. Finally, no conflicts of interest were discussed in either of the AAP guidelines, as well as in the BC and Miriam Foundation guidelines.

There is potential for a subtler influence of interests among the authors of the guidelines, the majority of whom are ASD experts who provide assessment. The majority of these individuals work in academic-affiliated institutions and are exposed to research-standard assessments. As such, their recommendations may be biased toward more resource-intensive assessments with
less consideration toward large scale access and service delivery issues. Of the included guidance documents, only the BC and NICE guidelines included community paediatricians in the guideline development groups. The potential for bias toward more resource-intensive assessments based on authorship has been outlined in a series on the development of clinical guidelines published in the British Medical Journal in 1999:

“There is a risk that healthcare systems and payers may be harmed by guidelines if following them escalates utilization, compromises operating efficiency, or wastes limited resources. Some clinical guidelines, especially those developed by medical and other groups unconcerned about financing, may advocate costly interventions that are affordable or that cut into resources needed for more effective services.” (Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999)

Effectively, there may be a bias toward research-style assessments in guidelines written by experts, emphasizing the importance of clinical assessment structures that mimic their own.

All of these interests have influenced the guidelines and policies for ASD diagnosis presented in this analysis, yet these interests do not present a full picture of the forces shaping diagnosis. Each of these ideas and interests must interact with institutions, or the rules and tools that govern the structures through which ASD diagnostic assessments are provided (MacLean & Wood, 2010).

5.3 Institutions

The institutions that provide services for ASD diagnosis differ across countries, which may contribute to the differing recommendations provided by different guidelines. The major difference occurs between the assessment structures in Canada and the UK, where assessments are generally conducted in health sectors, compared with the US, where federal law requires that the local early intervention agency (for children under three years of age, under the jurisdiction of the Department of Education) or school district (for children aged three years or older) provides a diagnostic evaluation within 45 days of receiving parental consent for children with suspected developmental concerns (U.S. Department of Education, 2004). This process involves MDT development of an Individualized Family Service Plan. For this reason, recommendations from US associations are less likely to challenge the use of MDT, as it is already legislated into the assessment process.
The UK guideline is more similar to Canada in that both rely on health systems to provide the diagnostic services. In these systems, publicly funded health sectors provide a means of universal access to young children, hence the strongly emphasized relationship between medical professionals and early identification. From there, diagnosis necessitates a transfer of care from the health services that provide the early identification and assessment to the social and educational services that provide the interventions. The NICE guideline, which is produced by the National Health Service in the UK, provides a detailed description of the diagnostic process, but only makes suggestions for interventions that are to be provided outside of the health sector. Particularly telling is the accompanying Quality Standard document listing performance indicators related to intervention. The purpose of this document is to set out benchmarks for monitoring by NICE to ensure that the recommendations in the guidance document are being met. The only listed indicator related to ASD intervention is the proportion of cases for which local resources are discussed with families by the diagnosing team, with no discussion of whether the child actually accesses interventions (National Institute for Health and Care Excellence, 2014). In the case of the UK, where health services are provided at a national level but intervention services vary by region, the diagnostic guideline is the only means by which the NHS can influence the quality of intervention services by providing an assessment that includes development of treatment goals.

In Canada, Medicare services provided by hospitals and physicians in the Canada Health Act (Health Canada, 2004) generally include assessment costs; however, interventions for ASD are not covered under the Canada Health Act, with a resulting mix of ministries including health, education, social and community services, and youth involved in funding interventions based on the provinces’ discretion and historical policy decision-making. Hence, both diagnosis and intervention are under the jurisdiction of the provinces and territories. Under this institutional structure, recommended diagnostic practices may serve a different purpose than in the UK. Here, the recommended construction of a neurodevelopmental profile of the child may be used to ease the transition between government sectors, particularly when diagnostic and intervention services are in different government siloes.

Through the inclusion of providers from intervention sectors, MDT assessment has the potential to create a common language connecting ministries and agencies, creating a more streamlined process. Unfortunately, the guidelines and policies included in this analysis generally provide
little in the way of blueprints for this cross-sectorial process. The division of diagnosis and intervention between sectors also creates a potential disconnect for resource considerations, such as advocating for resource-intensive diagnostic assessments without considering the impact on service delivery, or conversely, implementing lax diagnostic requirements without consideration of the impact of false positive cases on wait times and costs.

As the above analysis has shown, much of the variability in clinical guidance documents and policies can be explained through the lenses of ideas, interests, and institutions. Even the importance of empirical evidence, the guiding force behind the development of such guidelines (Institute of Medicine of the National Academies, 2011), was interpreted differently within the documents. The impact of such variation across professional bodies and jurisdictions, particularly on wait times which can influence time-sensitive access to intervention, will provide important information for future guidelines, and can inform the very process of guideline development.
6 Survey results: ASD diagnostic practices of Canadian paediatricians

This chapter will report the results of the national survey examining ASD diagnostic practices of paediatricians and allied paediatric health providers. It begins with a description of the total sample, followed by a description of respondents that did not diagnose ASD in their practices. Finally, there is a more detailed report of the practices of those participants that did diagnose ASD in their practices.

6.1 Response rate and demographics of sample

The response rate for the survey was 14% (91 responses out of 639 individuals solicited). This is comparable to the response rate of 16% in the 2014 National Physician Survey (NPS; Canadian College of Family Practice, 2014), but somewhat lower than the 18% response rate among paediatricians in the NPS. Eighty-six respondents completed the survey, with five incomplete surveys.

The demographic information for the total sample is displayed in Table 9. The median age of participants in the sample (54 years) was the same as the median age of paediatricians in the NPS (54 years). The larger proportion of females completing the survey (66%, versus 34% male) was significantly more pronounced compared to the NPS paediatricians (52% female, 47% male, 1% no response), with a p-value of 0.02. This may be reflective of a higher gender disparity within the sample of paediatricians with an interest in ASD. The sample included representation from all Canadian provinces with the exception of PEI, and from two of the three territories (no responses from the Northwest Territories). There was a proportionally large representation from Ontario. Participants reported a wide range of years in practice, as well as a varied distribution of catchments for their practices. A majority of respondents were general paediatricians, with approximately one quarter identifying as developmental paediatricians. The majority had no additional training in child development, while nearly one quarter had completed a fellowship in developmental paediatrics. The majority of respondents (63%) gave diagnoses of ASD in their practices. This should not be interpreted as the overall proportion of Canadian paediatricians that confer ASD diagnoses, as there is a strong possibility of responder bias to the survey.
<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
<th>Median</th>
<th>Range</th>
<th>Interquartile range</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
<td></td>
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<td>29-77</td>
<td>42-63</td>
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<td></td>
</tr>
<tr>
<td><strong>Years in practice</strong></td>
<td>21</td>
<td>0.5 - 46</td>
<td>8 - 30.5</td>
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</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>31</td>
<td>34.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>60</td>
<td>65.9%</td>
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<td></td>
</tr>
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<td><strong>Province of practice</strong></td>
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<td>Ontario</td>
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<tr>
<td>Alberta</td>
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<td>16.5%</td>
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<tr>
<td>Quebec</td>
<td>12</td>
<td>13.2%</td>
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</tr>
<tr>
<td>British Columbia</td>
<td>6</td>
<td>6.6%</td>
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</tr>
<tr>
<td>New Brunswick</td>
<td>4</td>
<td>4.4%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>4</td>
<td>4.4%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Nova Scotia</td>
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<td>4.4%</td>
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<td>Manitoba</td>
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</tr>
<tr>
<td>Saskatchewan</td>
<td>2</td>
<td>2.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nunavut</td>
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<td>1.1%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Yukon</td>
<td>1</td>
<td>1.1%</td>
<td></td>
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<tr>
<td><strong>Catchment</strong></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Within regional health authority</td>
<td>28</td>
<td>30.8%</td>
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<td></td>
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<tr>
<td>Within city only</td>
<td>24</td>
<td>26.4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>20</td>
<td>22.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>17</td>
<td>18.7%</td>
<td></td>
<td></td>
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<tr>
<td>Missing</td>
<td>2</td>
<td>2.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Type of professional</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>General Paediatrician</td>
<td>63</td>
<td>69.2%</td>
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</tr>
<tr>
<td>Developmental Paediatrician</td>
<td>23</td>
<td>25.3%</td>
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</tr>
<tr>
<td>Neonatologist</td>
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<td>2.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergist</td>
<td>1</td>
<td>1.1%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>SLP</td>
<td>1</td>
<td>1.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other*</td>
<td>1</td>
<td>1.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Extra training in child development</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>57</td>
<td>62.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fellowship in developmental paediatrics</td>
<td>22</td>
<td>24.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General paediatrics training with additional child development</td>
<td>5</td>
<td>5.5%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Continuing medical education</td>
<td>3</td>
<td>3.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fellowship in paediatric neurology</td>
<td>2</td>
<td>2.2%</td>
<td></td>
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<tr>
<td>Participation in a MDT</td>
<td>1</td>
<td>1.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Give diagnosis of ASD in practice</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>57</td>
<td>62.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>34</td>
<td>37.4%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* written response: “Specialist”; MDT = multi-disciplinary team; n = number in sample; SLP = speech language pathologist; percentages may not sum to 100% due to rounding.
6.2 Participants that did not diagnose ASD

Participants that did not diagnose ASD were asked about elements of their practice when performing consultations for developmental concerns (Table 10). This refers to the consultant paediatrician seeing a child referred by a primary care physician who has identified concerns about the child’s development. The consultant paediatrician in this group would either confirm or refute the developmental concern, but would not diagnose ASD (if this was the underlying developmental disorder), instead referring for further developmental assessment.

The reported wait times for developmental consultation with this group had a wide range, with most respondents indicating a wait time between four weeks and nearly six months. The distribution was U-shaped, with the highest proportions of respondents indicating wait times either less than one month or more than six months. It should be noted that this is not the time to receive a diagnosis of ASD, as children with suspected ASD referred to these paediatricians would subsequently be referred for a further diagnostic assessment. The length of these visits tended to be between 16 and 90 minutes, with the highest number of responses for 46 to 60 minutes. Twenty-two respondents (65% of this subset of the sample) indicated using paediatric consultation codes for these visits (see Table 3 for additional details about individual billing codes). Different billing codes could be used within the same province as the type of billing code used was dependent on the length of the assessment or the specialization of the assessor. Excluding the billing codes that were time-based, the median amount billed for a developmental consultation was $171.82.
### Table 10: Practice patterns for participants that do not diagnose ASD  (n = 34)

<table>
<thead>
<tr>
<th>Wait time for consultation for developmental concerns (days)</th>
<th>n</th>
<th>%</th>
<th>Median</th>
<th>Range</th>
<th>Interquartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 30 days</td>
<td>10</td>
<td>29.4%</td>
<td>84</td>
<td>14-560</td>
<td>28 – 171.5</td>
</tr>
<tr>
<td>31-60 days</td>
<td>6</td>
<td>17.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61-90 days</td>
<td>4</td>
<td>11.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>91-120 days</td>
<td>3</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>120-150 days</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>150-180 days</td>
<td>2</td>
<td>5.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;180 days</td>
<td>8</td>
<td>23.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visit length:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 15 min</td>
<td>0</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-30 min</td>
<td>4</td>
<td>11.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31-45 min</td>
<td>4</td>
<td>11.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46-60 min</td>
<td>13</td>
<td>38.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61-75 min</td>
<td>7</td>
<td>20.6%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>76-90 min</td>
<td>5</td>
<td>14.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;90 min</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Billing codes used:</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BC – 00511 ($411.87)</td>
<td>2</td>
<td>5.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BC – 00554 ($166.51)</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alberta 03.08A CMXV30 ($229.15)</td>
<td>4</td>
<td>11.8%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Ontario – A265 ($167)</td>
<td>8</td>
<td>23.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario – A260 ($300.70)</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario – K122 ($80.30/30 min)</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario – K123 ($91.10/30 min)</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec – 09165 ($187.25)</td>
<td>4</td>
<td>11.8%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Quebec – 09127 ($56.65)</td>
<td>3</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec – 15164 ($55.05/15 min)</td>
<td>1</td>
<td>2.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nova Scotia – 03.08 ($171.82)</td>
<td>3</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newfoundland – 101 ($174.04)</td>
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<td>2.9%</td>
<td></td>
<td></td>
<td></td>
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<td>Other*</td>
<td>2</td>
<td>5.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>5.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* written responses: “Alternate payment” and “Psychosocial visit under remuneration mixte”
% = percentage of responses; BC = British Columbia; n = number of responses in sample; percentages may not sum to 100% due to rounding.
6.3 Participants that did diagnose ASD

Participants indicating that they diagnose ASD were asked about elements of their practice, as well as about elements specific to their diagnostic assessment for ASD. These results are presented in Tables 11 through 16.

6.3.1 General practice patterns

Participants were asked questions describing the general aspects of their practice. The results are presented in Table 11. Practice patterns from this group show that most accept referrals directly from family doctors, which may result in one less referral in the diagnostic journey for children with suspected ASD. Most completed a diagnostic assessment for ASD in two visits, with most visits lasting between 30 and 90 minutes. Participants were asked a non-mandatory question regarding the percentage of cases of suspected ASD for which they provided a definitive assessment (i.e. not subsequently making a referral for further assessment). This question had a high number of missing responses; more than half of those that did respond indicated that they provided a definitive assessment in less than half of the cases they assessed. Slightly more than half of participants indicated that they practiced in a MDT, and of these, more than three quarters performed most assessments in a MDT.

Participants were also asked about their consultation with regional developmental intervention services, which often perform assessments prior to beginning their interventions. These consultations can allow the clinician to obtain input from other disciplines such as SLPs, OTs, and early interventionists in the absence of a formal diagnostic MDT. The majority of respondents had consulted with these services, though the proportion of cases for which they did so varied between participants.

Participants also indicated which test(s) they ordered in the majority of newly diagnosed cases of ASD. Hearing tests were indicated by over 80% of respondents, with less emphasis on vision testing (38.6% of respondents). Chromosomal microarray and Fragile X testing were each selected by approximately two thirds of participants. Less popular tests included metabolic screening, magnetic resonance imaging (MRI) and MECP2 testing for Rett Syndrome, though some respondents did select these responses.
<table>
<thead>
<tr>
<th>Table 11: Practice patterns for participants that diagnose ASD (n=57)</th>
</tr>
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<tbody>
<tr>
<td><strong>Accepts referrals from family doctor</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td><strong>Number of visits to make a diagnosis of ASD</strong></td>
</tr>
<tr>
<td>1 visit</td>
</tr>
<tr>
<td>2 visits</td>
</tr>
<tr>
<td>3 visits</td>
</tr>
<tr>
<td>4 visits</td>
</tr>
<tr>
<td>5 visits</td>
</tr>
<tr>
<td><strong>Reported typical visit length</strong></td>
</tr>
<tr>
<td>&lt; 30 min</td>
</tr>
<tr>
<td>31-60 min</td>
</tr>
<tr>
<td>61-90 min</td>
</tr>
<tr>
<td>91-120 min</td>
</tr>
<tr>
<td>121-180 min</td>
</tr>
<tr>
<td>&gt; 180 min</td>
</tr>
<tr>
<td><strong>For what percentage of cases of ASD do you provide a definitive assessment?</strong></td>
</tr>
<tr>
<td>0-25%</td>
</tr>
<tr>
<td>26-50%</td>
</tr>
<tr>
<td>51-75%</td>
</tr>
<tr>
<td>76-100%</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td><strong>Practice in MDT</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td><strong>Percentage of cases assessed with MDT</strong></td>
</tr>
<tr>
<td>1-25%</td>
</tr>
<tr>
<td>26-50%</td>
</tr>
<tr>
<td>51-75%</td>
</tr>
<tr>
<td>76-100%</td>
</tr>
<tr>
<td>(Did not practice in team) 0%</td>
</tr>
<tr>
<td><strong>Percentage of assessments with consultation with regional speech-language pathology</strong></td>
</tr>
<tr>
<td>0%</td>
</tr>
<tr>
<td>1-25%</td>
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<td>26-50%</td>
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<td>51-75%</td>
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<td>76-100%</td>
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<td><strong>Percentage of assessments with consultation with regional developmental early intervention staff</strong></td>
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<td>0%</td>
</tr>
<tr>
<td>1-25%</td>
</tr>
<tr>
<td>Percentage of assessments with consultation with regional occupational therapist</td>
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<tr>
<td>-------------------------------</td>
</tr>
<tr>
<td>0%</td>
</tr>
<tr>
<td>1-25%</td>
</tr>
<tr>
<td>26-50%</td>
</tr>
<tr>
<td>51-75%</td>
</tr>
<tr>
<td>76-100%</td>
</tr>
<tr>
<td>Missing</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Tests ordered for the majority of assessments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing</td>
</tr>
<tr>
<td>Chromosomal microarray</td>
</tr>
<tr>
<td>Fragile X</td>
</tr>
<tr>
<td>Vision</td>
</tr>
<tr>
<td>Metabolic screening</td>
</tr>
<tr>
<td>MRI brain</td>
</tr>
<tr>
<td>MECP2</td>
</tr>
<tr>
<td>EEG</td>
</tr>
<tr>
<td>Other*</td>
</tr>
<tr>
<td>None</td>
</tr>
</tbody>
</table>

* Text response: “Depends on presentation”; % = per cent of sample; ASD = autism spectrum disorders; EEG = electroencephalogram; MDT = multidisciplinary team; MECP2 = methyl cytosine phosphate guanine binding protein 2 (genetic testing for Rett Syndrome); MRI = magnetic resonance imaging; n = number in sample; percentages may not sum to 100% due to rounding; respondents could select more than one test and these percentages will not sum to 100% as a result.
6.3.2 Billing codes used in the ASD diagnostic assessment

The survey asked participants which billing code(s) they used based on the number of clinic visits they indicated. Reference descriptions for the billing codes are presented in Table 3 in the Methods chapter. The reported billing codes are presented in Table 12. Compared with respondents that did not diagnose ASD, there was increased use of neurodevelopmental billing codes here (such as BC 00511, Manitoba 8552, Ontario A667, and Ontario K122/K123). After excluding the billing codes that were based on units of time, the first visit was associated with a median billing cost of $229.15 (range $47 to $411.87). The second visit had a median cost of $187 (range $76.71 to $300.70), and the third visit also had a median cost of $187 (range $92.40 to $300.70). It is important to note that there were many time-unit based responses for the second and third visits. Calculation of median costs for the fourth visit was not possible due to responses being only for time-unit codes. There was one “Don’t Know” response for the fifth clinic visit and one response indicating an alternate funding plan. The only response for billing codes beyond the fifth visit was a participant indicating an alternate funding plan.
Table 12: Billing codes used in the ASD diagnostic assessment

<table>
<thead>
<tr>
<th>Billing code</th>
<th>Amount</th>
<th>First visit (n)</th>
<th>Second visit (n)</th>
<th>Third visit (n)</th>
<th>Fourth visit (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta - 3.08A</td>
<td>$198.04</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alberta - 03.08A CMXC30</td>
<td>$229.15</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Alberta - 03.08A + 03.08J</td>
<td>$198.04 + $59.41 per 15 min unit after 30 min</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alberta - 03.08A CMXC30 + 03.08J</td>
<td>$229.15 + $59.41 per 15 min unit after 30 min</td>
<td>1</td>
<td>1</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Alberta - 03.03F</td>
<td>$99.02</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Alberta - 03.03F + 03.03FA</td>
<td>$99.02 + $59.41 per 15 min unit after 30 min</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Alberta - 03.03F CMXV30 + 03.03FA</td>
<td>$130.13 + $59.41 per 15 min unit after 30 min</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>BC - 00511</td>
<td>$411.87</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>BC - 00512</td>
<td>$99.19</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>BC - 00554</td>
<td>$76.71</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Manitoba - 8552</td>
<td>$48.65 per 15 min unit (includes report writing)</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>New Brunswick - 14.1-93</td>
<td>$217</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>New Brunswick - 14.1-94</td>
<td>$133</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>New Brunswick - 14.2-85</td>
<td>$92.40</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>New Brunswick - 14.8C-91</td>
<td>$263.20</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Newfoundland - 101</td>
<td>$174.04</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Newfoundland - 113</td>
<td>$93.37</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Nova Scotia - 03.08</td>
<td>$171.82</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - A265</td>
<td>$167</td>
<td>10</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - A667</td>
<td>$395.65</td>
<td>10</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - A260</td>
<td>$300.70</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - A2662</td>
<td>$395.65</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - A2661</td>
<td>$68.80</td>
<td>0</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - K119</td>
<td>$100.00</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - K122</td>
<td>$80.30 per 30 min unit</td>
<td>-</td>
<td>4</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Ontario - K123</td>
<td>$91.10 per 30 min unit</td>
<td>-</td>
<td>12</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Quebec - 09127</td>
<td>$57</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Quebec - 09165</td>
<td>$187</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Quebec - 09129</td>
<td>$47</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Quebec - 15164</td>
<td>$55.05 per 15 min unit</td>
<td>-</td>
<td>2</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Saskatchewan - 9C</td>
<td>$125</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Saskatchewan - 3C</td>
<td>$89.40</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Nunavut K1/K2</td>
<td>(unable to determine)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>NB-90 + 2172</td>
<td>(unable to determine)</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td>5</td>
<td>8</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Alternate funding plan</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>57</td>
<td>49</td>
<td>16</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

The number of participants indicating use of each billing code or billing code combination is displayed. The fifth clinic visit and any additional visits are not displayed and are described in the text.

### 6.3.3 Tools used in the ASD diagnostic assessment

Participants indicated a variety of tools used in the assessment for ASD. The number of participants using each tool, along with the time spent on administration and scoring, is displayed in Table 13. The ADOS was the most commonly used tool, with the ADI-R also commonly used. The lower border of the administration time for the ADI-R was lower than expected, given that administration of the full tool often takes at least 90 minutes, indicating that some participants may be performing a truncated administration. Four participants wrote that they used the M-CHAT as part of their diagnostic assessment, which goes beyond the intended scope of the M-CHAT as a screening rather than a diagnostic tool for ASD. Also of note was the inclusion of “DSM-5 criteria” as a written in response, suggesting that some participants have adapted the diagnostic criteria into a tool, possibly as a checklist. Finally, twelve participants (21% of the sample) indicated that they did not use any tools in their diagnostic assessment.

Many participants indicated that they used more than one tool as part of their assessment. The combination of tools used is presented in Table 14. There was a great deal of variation in the combination of tools used, with administration of the ADOS alone having the highest number of responses among those that used tools.
Table 13: Time spent administering and scoring diagnostic tools

<table>
<thead>
<tr>
<th>Tools</th>
<th>Number using tool</th>
<th>Median (min)</th>
<th>Range (min)</th>
<th>Interquartile Range (min)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Diagnostic Observation Schedule (ADOS)</td>
<td>29</td>
<td>60</td>
<td>30 - 120</td>
<td>60 – 79</td>
</tr>
<tr>
<td>Autism Diagnostic Interview – Revised (ADI-R)</td>
<td>15</td>
<td>90</td>
<td>20 - 120</td>
<td>53 - 105</td>
</tr>
<tr>
<td>Childhood Autism Rating Scale</td>
<td>9</td>
<td>20</td>
<td>15 – 60</td>
<td>15 – 30</td>
</tr>
<tr>
<td>Social Responsiveness Scale</td>
<td>8</td>
<td>10</td>
<td>5 – 45</td>
<td>10 - 15</td>
</tr>
<tr>
<td>Vineland Adaptive Behavior Scales</td>
<td>7</td>
<td>45</td>
<td>18 - 90</td>
<td>38 - 60</td>
</tr>
<tr>
<td>Social Communication Questionnaire</td>
<td>4</td>
<td>23</td>
<td>10 - 45</td>
<td>18 - 30</td>
</tr>
<tr>
<td>M-CHAT</td>
<td>4</td>
<td>NS</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Adaptive Behavior Assessment System</td>
<td>2</td>
<td>10</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>“DSM-5 criteria”</td>
<td>2</td>
<td>NS</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>“Cognitive assessment”</td>
<td>2</td>
<td>90</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mullen Scales of Early Learning</td>
<td>1</td>
<td>60</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>“Neurodevelopmental assessment”</td>
<td>1</td>
<td>45</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>“Academic screen”</td>
<td>1</td>
<td>40</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Peabody Picture Vocabulary Test</td>
<td>1</td>
<td>30</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Beery-Butenica Test of Visual-Motor Integration</td>
<td>1</td>
<td>20</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Bayley Scales of Infant Development</td>
<td>1</td>
<td>NS</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Diagnostic Interview for Social and Communication Disorders</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>None</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NS = Not specified; Responses appearing in quotations are written-in responses not corresponding with an identified tool.
Table 14 Combinations of tools used in the ASD diagnostic assessment

<table>
<thead>
<tr>
<th>Tool Combination</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADOS alone</td>
<td>11</td>
<td>19.3</td>
</tr>
<tr>
<td>ADI-R alone</td>
<td>3</td>
<td>5.3</td>
</tr>
<tr>
<td>CARS alone</td>
<td>3</td>
<td>5.3</td>
</tr>
<tr>
<td>M-CHAT alone</td>
<td>3</td>
<td>5.3</td>
</tr>
<tr>
<td>SCQ alone</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>ADI-R + ADOS</td>
<td>6</td>
<td>10.5</td>
</tr>
<tr>
<td>ADI-R + CARS</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>ADOS + SRS</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>ADOS + VABS</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>CARS + M-CHAT</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>ADI-R + ADOS + CARS</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>ADOS + SRS + VABS</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>ADOS + CARS + Bayley</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>SCQ + SRS + ABAS</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>ADI-R + ADOS + SRS + VABS</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>ADI-R + ADOS + SCQ + SRS + VABS</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>ADI-R + ADOS + MSEL + SRS + VABS + PPVT + Beery</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>“Most of the above as part of a team”</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Other (not specified)</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>None</td>
<td>12</td>
<td>21.1</td>
</tr>
</tbody>
</table>

ABAS = Adaptive Behavior Assessment System; ADOS = Autism Diagnostic Observation Schedule; ADI-R = Autism Diagnostic Interview – Revised; Bayley = Bayley Scales of Infant Development; Beery = Beery-Butenica Test of Visual Motor Integration; CARS = Childhood Autism Rating Scale; M-CHAT = Modified Checklist for Autism in Toddlers; MSEL = Mullen Scales of Early Learning; PPVT = Peabody Picture Vocabulary Test; SCQ = Social Communication Questionnaire; SRS = Social Responsiveness Scale; VABS = Vineland Scales of Adaptive Behavior; percentages may not sum to 100% due to rounding.
6.3.4 MDT composition

Participants who performed diagnostic assessments as part of a MDT were asked to identify the clinicians that were available to the team, and those that participated in the majority of assessments (Table 15). No two MDTs across the country had the same composition of team members, even when limiting the analysis to those team members that participate in the majority of assessments. There were some commonalities among teams. All but three teams included a paediatrician (either a general paediatrician or a developmental paediatrician) for the majority of assessments. Only five of the thirty MDTs did not have access to a psychologist, with 57% of respondents indicating that psychologists participated in the majority of diagnostic assessments. SLPs and OTs were also frequently identified as team members. Behavioural therapists, who are involved in delivering behavioural interventions for ASD, were involved in the majority of assessments in only two teams, and available to a total of five of thirty teams.
Table 15: MDT composition for ASD diagnostic assessments (n = 30)

<table>
<thead>
<tr>
<th>Gen Paed</th>
<th>Dev Paed</th>
<th>Psyc</th>
<th>SLP</th>
<th>OT</th>
<th>PT</th>
<th>SW</th>
<th>Psyc MD</th>
<th>Psym</th>
<th>CG</th>
<th>Neur</th>
<th>GI</th>
<th>BT</th>
<th>TC</th>
<th>Audi</th>
<th>Diet</th>
<th>Nsg</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Team member available, not used in most assessments
- Team member available, used in most assessments
Audi = Audiologist; BT = Behavioural therapist; CG = Clinical geneticist; Dev Paed = Developmental paediatrician; Diet = Dietician; Gen Paed = General paediatrician; GI = Gastroenterologist; Neur = Neurologist; Nsg = Nurse; OT = Occupational therapist; Psyc = Psychologist; Psyc MD = Psychiatrist; Psym = Psychometrist; PT = Physiotherapist; SLP = Speech language pathologist; SW = Social worker; TC = Team coordinator. Other = ASD service provider, family liaison, neuropsychologist, psychoeducator, early childhood educator
6.3.2 Wait times for ASD diagnostic assessment

Participants were asked to indicate their patients’ wait times for two aspects of the assessment: the wait time for the first visit of the clinical assessment (Time 1), and the wait time from the first visit to the communication of the diagnosis of the family (Time 2). These wait times were summed for each participant to create the total wait time. The results for each of the three wait times (two components and total) are displayed in Table 16, with a histogram of total wait time following in Figure 2.

Wait times for Time 1 had a wide range, from one month to two years. The interquartile range for this time was three to nine months. Thirty-five percent reported the first visit occurred within 90 days, the recommended maximum wait time for first visit in the Miriam Foundation guideline (2008).

The wait time for Time 2 also had a wide range of responses, with half of the respondents reporting a wait time between two and six weeks, and some respondents indicating a much longer wait. Over 80% of respondents met the Miriam Foundation target for a maximum of two months.

The total wait time from initial referral to communication of diagnosis was lengthy with wide variation. Some participants reported a total wait time as short as two months, with others stretching over two years. Only 35% met the Miriam Foundation guideline recommendation of a maximum total wait time of five months.
Table 16: Wait times for ASD diagnostic assessment (n = 57)

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
<th>Median</th>
<th>Range</th>
<th>Interquartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Wait time for first visit</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 days</td>
<td>3</td>
<td>5.3%</td>
<td>182</td>
<td>30 - 730</td>
<td>91 – 274</td>
</tr>
<tr>
<td>60 days</td>
<td>7</td>
<td>12.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>90 days</td>
<td>10</td>
<td>17.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>120 days</td>
<td>4</td>
<td>7.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>150 days</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>180 days</td>
<td>10</td>
<td>17.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>210 days</td>
<td>2</td>
<td>3.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>240 - 270 days</td>
<td>5</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>300 - 365 days</td>
<td>7</td>
<td>12.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>366 - 540 days</td>
<td>5</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>638 - 730 days</td>
<td>3</td>
<td>5.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Wait time from first visit to diagnosis</strong></td>
<td></td>
<td></td>
<td>28</td>
<td>0 – 196</td>
<td>14 - 56</td>
</tr>
<tr>
<td>0 days</td>
<td>7</td>
<td>12.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 days</td>
<td>3</td>
<td>5.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 days</td>
<td>5</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21 days</td>
<td>5</td>
<td>8.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28 days</td>
<td>18</td>
<td>31.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42 days</td>
<td>2</td>
<td>3.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>56 days</td>
<td>7</td>
<td>12.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>84 days</td>
<td>4</td>
<td>7.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>140 days</td>
<td>2</td>
<td>3.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥180 days</td>
<td>4</td>
<td>7.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total wait from referral to diagnosis</strong></td>
<td></td>
<td></td>
<td>208</td>
<td>58 – 786</td>
<td>119 - 365</td>
</tr>
<tr>
<td>&lt; 60 days</td>
<td>3</td>
<td>5.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61 – 90 days</td>
<td>6</td>
<td>10.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>91 – 120 days</td>
<td>6</td>
<td>10.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>121 – 180 days</td>
<td>7</td>
<td>12.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>181 – 240 days</td>
<td>9</td>
<td>15.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>241 – 300 days</td>
<td>8</td>
<td>14.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>300 – 360 days</td>
<td>2</td>
<td>3.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>361 – 420 days</td>
<td>6</td>
<td>10.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>421 – 540 days</td>
<td>3</td>
<td>5.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>541 – 660 days</td>
<td>4</td>
<td>7.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>660 – 786 days</td>
<td>3</td>
<td>5.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percentages may not sum to 100% due to rounding.
Figure 2: Distribution of total wait times for ASD diagnosis

This figure shows the distribution of total wait times (in days) for ASD diagnosis with total wait time in days along the horizontal axis and the number of respondents indicating the specified wait time on the vertical axis.
7 Determinants of wait times for ASD diagnosis

This chapter will describe the regression analyses performed to identify determinants of wait times for ASD diagnostic assessments. Linear regressions were performed to evaluate determinants of wait times (wait time to first visit [Time 1], wait time from first visit to diagnosis [Time 2], and total time from referral to diagnosis). Subsequent analyses were performed with logistic regression to identify predictors of meeting the wait time targets as set out in the Miriam Foundation guideline described above.

7.1 Determinants of wait time from referral to the first visit of the assessment (Time 1)

Bivariate analyses were performed to determine the factors significantly associated with Time 1. The results are presented below in Tables 17 and 18. Assessment time was significantly associated with Time 1, with longer wait times reported for respondents with longer assessment times. The type of assessor was also significantly associated with Time 1, with general paediatricians reporting a shorter Time 1 compared to developmental paediatricians. Respondents who practiced in a MDT reported longer wait times, which met the significance threshold for inclusion in the model. Accepting referrals from a family doctor was significantly associated with a longer Time 1. Province had a high degree of variability in Time 1 between provinces and met the threshold for inclusion in the model. A catchment of within-city only had the lowest median Time 1, but this did not reach statistical significance.
Table 17: Bivariate analyses of associations between putative continuous variables and Time 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on assessment (minutes)</td>
<td>Spearman rank correlation coefficient $r_s = 0.35$</td>
<td>0.001*</td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in practice</td>
<td>Spearman rank correlation coefficient $r_s = -0.01$</td>
<td>0.94</td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis
Table 18: Bivariate analyses of associations between categorical putative variables and Time 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median wait time (days)</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of assessor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Paediatrics</td>
<td>182.4</td>
<td>Kruskal-Wallis chi-squared = 5.59</td>
<td>0.06*</td>
</tr>
<tr>
<td>General Paediatrics</td>
<td>121.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>60.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices in MDT</td>
<td></td>
<td>Wilcoxon rank sum test W = 286</td>
<td>0.12*</td>
</tr>
<tr>
<td>Yes</td>
<td>182.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>121.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepts referral from family doctor</td>
<td></td>
<td>Wilcoxon rank sum test W =193</td>
<td>0.19*</td>
</tr>
<tr>
<td>Yes</td>
<td>182.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>106.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catchment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within city only</td>
<td>91.2</td>
<td>Kruskal-Wallis chi-squared = 3.21</td>
<td>0.36</td>
</tr>
<tr>
<td>Within regional health authority</td>
<td>182.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>182.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>182.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province of practice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Columbia</td>
<td>243.2</td>
<td>Kruskal-Wallis chi-squared = 13.61</td>
<td>0.19*</td>
</tr>
<tr>
<td>Alberta</td>
<td>91.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>182.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>410.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Brunswick</td>
<td>136.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other§</td>
<td>152.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis; MDT = multidisciplinary team; § “Other” is the median wait time for provinces with one respondent (Manitoba, Saskatchewan, Nova Scotia, Newfoundland and Labrador, Yukon, and Nunavut) that have been collapsed in the displayed results to prevent identification of individual respondents’ wait times.

Variables were tested for multicollinearity to ensure that variables included in the model were independently associated with the dependent variable. Type of assessor was significantly associated with assessment time (Kruskal-Wallis chi-squared = 5.59; degrees of freedom [d.f.] = 2; p=0.003), with the median general paediatrician assessment time (90 minutes) reported as half that of developmental paediatricians (180 minutes). Type of assessor was also significantly...
associated with whether the participant accepted referrals from family doctors, with 91% of general paediatricians accepting these referrals, versus 67% of developmental paediatricians and none of the other clinicians (Fisher’s exact test p = 0.0004). Type of assessor was additionally associated with whether the participant practiced in a MDT, with a higher proportion of developmental paediatricians practicing in MDTs compared to general paediatricians and other clinicians (62% versus 47% and 50%, respectively; Fisher’s exact test p = 0.0004). Practicing in an MDT was significantly associated with province of practice, with 100% of respondents from BC and Quebec reporting practicing in an MDT versus 30% in Ontario (Fisher’s exact test p = 0.01). Practicing in an MDT was also significantly associated with accepting referrals from family doctors, with 69% of MDTs accepting family doctor referrals compared with 86% for those not practicing in MDTs (Fisher’s exact test p = 0.01). None of the variables with significant multicolinearity were tested together in the models.

All regression analyses were performed with an ln transformed Time 1. The first variable tested in the model was assessment time, which was significantly positively associated with wait time to first visit (β = 0.004, t = 3.21, p = 0.002). Assessment time remained significant when controlling for whether the participant was part of an MDT (β = 0.004, t = 3.06, p = 0.004), but in this model, being in a MDT was not significantly associated with wait time to first visit (β = 0.32, t = 1.19, p = 0.24). Assessment time also remained significant when controlling for accepting referrals from family doctors (β = 0.004, t = 3.21, p = 0.002), though accepting these referrals itself was not significantly associated with the outcome measure (β = 0.32, t = 1.32, p = 0.19). Assessment time did not remain significant when controlling for province (β = 0.003, t = 1.93, p = 0.06), but was marginally significant in a model controlling for both province and accepting family doctor referrals (β = 0.003, t = 2.03, p = 0.05).

The model was then tested with type of assessor, which was significant only for the small group of “Other” clinicians when compared with developmental paediatricians (β = -1.2, t = -2.05, p = 0.045). The “Other” clinician group was no longer significant after controlling for province. In this model, participants practicing in Quebec had a significantly higher wait time when compared with Alberta (β = 0.96, t = 2.12, p = 0.04). When province of practice was tested on its own (no longer controlling for type of assessor), this comparison remained significant (β = 1.16, t = 2.58,
p = 0.01). Neither MDT nor accepting referrals from family doctors were significantly associated with Time 1 when tested alone in the model.

Based on the above process of variable selection, the final model included only assessment time as an explanatory variable of interest (Table 19). Analyses of the residuals confirmed that they were normally distributed (sum of residuals = 0; Shapiro Wilk W = 0.97, p = 0.17; Q-Q plot displayed in Figure 3). Evaluations for homoscedasticity in the model showed constant variance between residuals and fitted values (Figure 4) but did show evidence of heteroscedasticity when evaluating the plot of residuals against assessment time (Figure 5). Eleven influential observations were identified and removed from the data set, and the model was re-run. The $R^2$ for the full data set model was 0.16, with an adjusted $R^2$ of 0.15, indicating that approximately 15% of the variance in the model can be explained by assessment time. For the model without influential observations, the $R^2$ was 0.16, with an adjusted $R^2$ of 0.14.

The Duan smearing estimator was used to back-transform the regression results to obtain adjusted wait times. The calculated smearing estimators for the full set model and model with influential observations removed were 1.33 and 1.2, respectively. Adjusted back-transformed mean wait times for first visit with 95% confidence intervals based on assessment time are listed in Table 20. The mean adjusted wait time for Time 1 was 211 days (95% confidence interval [CI] 172, 258). When the assessment time was 60 minutes, the associated wait time for Time 1 was 130 days (95% CI 93.5, 179.7); compared with this value, an assessment time of 180 minutes added 80 days of wait time (mean 210.6 days; 95% CI 171.1, 259.3). As assessment time increased, there was a progressively larger increase in wait time. Removal of influential observations decreased the adjusted Time 1 wait times, indicating that influential observations tended to be associated with longer wait times. Adjusted values for the full data set are plotted in Figure 6.
Table 19: Regression model for wait time to first visit

<table>
<thead>
<tr>
<th>Variable</th>
<th>Co-efficient (s.d.)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Full data set</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>4.41 (0.23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ln assessment time (minutes)</td>
<td>0.004 (0.001)</td>
<td>3.21</td>
<td>0.002</td>
</tr>
<tr>
<td><strong>Influential observations removed</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>4.43 (0.23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ln assessment time (minutes)</td>
<td>0.004 (0.001)</td>
<td>2.85</td>
<td>0.007</td>
</tr>
</tbody>
</table>

ln = natural logarithm
Figure 3: Q-Q plot evaluating normality of residuals from ln-transformed Time 1 regression model

\[ \ln = \text{natural logarithm, Q-Q = quantile-quantile; the model presented includes assessment time as the explanatory variable; data from the ln-transformed are plotted on the vertical axis and compared with data from a standard normal population on the horizontal axis. The solid line represents a normally distributed sample.} \]
Figure 4: Plot of residuals against fitted values (Time 1 analysis)

Residuals are plotted on the vertical axis against fitted values from the model plotted on the horizontal axis. The solid line is the regression line between the fitted values and residuals.
Figure 5: Plot of residuals against assessment time (Time 1 analysis)

Residuals are plotted on the vertical axis against assessment time plotted on the horizontal axis. The solid line is the regression line between assessment time and the residuals.
Table 20: Mean adjusted wait times for first visit by assessment time

<table>
<thead>
<tr>
<th>Assessment time (min)</th>
<th>Mean wait time (days)</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
<th>Assessment time (min)</th>
<th>Mean wait time (days)</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>60</td>
<td>129.6</td>
<td>93.5</td>
<td>179.7</td>
<td>60</td>
<td>124.4</td>
<td>90.4</td>
<td>171.1</td>
</tr>
<tr>
<td>90</td>
<td>146.3</td>
<td>111.5</td>
<td>191.9</td>
<td>90</td>
<td>138.2</td>
<td>106.4</td>
<td>179.4</td>
</tr>
<tr>
<td>120</td>
<td>165.2</td>
<td>131.5</td>
<td>207.5</td>
<td>120</td>
<td>153.4</td>
<td>123.9</td>
<td>190</td>
</tr>
<tr>
<td>180</td>
<td>210.6</td>
<td>171.1</td>
<td>259.3</td>
<td>180</td>
<td>189.2</td>
<td>157.4</td>
<td>227.5</td>
</tr>
<tr>
<td>240</td>
<td>268.5</td>
<td>202.2</td>
<td>356.6</td>
<td>240</td>
<td>240.9</td>
<td>183.2</td>
<td>316.7</td>
</tr>
<tr>
<td>300</td>
<td>342.4</td>
<td>228.5</td>
<td>513</td>
<td>300</td>
<td>287.9</td>
<td>197.3</td>
<td>420.1</td>
</tr>
</tbody>
</table>

CI = confidence interval; min = minutes
Figure 6: Predicted wait time for first visit based on assessment time

This figure shows the predicted wait time for the first visit of the diagnostic assessment based on assessment time. Assessment time in minutes is plotted on the horizontal axis and wait time for first visit in days on the vertical axis. The blue line represents the mean predicted value, with the shaded zone representing the 95% confidence interval.
7.2 Determinants of wait time from first visit to communication of the diagnosis to the family (Time 2)

Bivariate analyses were performed to attempt to identify significant associations between the hypothesized covariates and Time 2 (Tables 21 and 22). Of the hypothesized variables, only practicing in an MDT was significantly associated with Time 2, with shorter Time 2 wait times reported by respondents practicing in MDTs.

MDT was inputted as an explanatory variable in the regression model; however, models using Time 2 as the dependent variable could not be transformed to meet the assumptions of linearity. As such, no regression analyses were performed for Time 2.

Table 21: Bivariate analyses of associations between putative continuous variables and Time 2

<table>
<thead>
<tr>
<th>Variable</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practice factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on assessment</td>
<td>Spearman rank correlation coefficient</td>
<td>0.27</td>
</tr>
<tr>
<td></td>
<td>( r_s = 0.15 )</td>
<td></td>
</tr>
<tr>
<td>Demographic factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in practice</td>
<td>Spearman rank correlation coefficient</td>
<td>0.47</td>
</tr>
<tr>
<td></td>
<td>( r_s = -0.10 )</td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of \( p < 0.2 \) to be included in regression analysis
Table 22: Bivariate analyses of associations between categorical putative variables and Time 2

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median wait time (days)</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices in MDT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21.0</td>
<td>Wilcoxon rank sum test $W = 491.5$</td>
<td>0.05*</td>
</tr>
<tr>
<td>No</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catchment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within city only</td>
<td>28.0</td>
<td>Kruskal-Wallis chi-squared = 4.45</td>
<td>0.21</td>
</tr>
<tr>
<td>Within regional health authority</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>24.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of assessor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Paediatrics</td>
<td>28.0</td>
<td>Kruskal-Wallis chi-squared = 1.05</td>
<td>0.59</td>
</tr>
<tr>
<td>General Paediatrics</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepts referral from family doctor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28.0</td>
<td>Wilcoxon rank sum test $W = 266$</td>
<td>0.88</td>
</tr>
<tr>
<td>No</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province of practice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Columbia</td>
<td>42.0</td>
<td>Kruskal-Wallis chi-squared = 12.60</td>
<td>0.25</td>
</tr>
<tr>
<td>Alberta</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>28.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>38.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Brunswick</td>
<td>56.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other§</td>
<td>14.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of $p < 0.2$ to be included in regression analysis; MDT = multidisciplinary team; § “Other” is the median wait time for provinces with one respondent (Manitoba, Saskatchewan, Nova Scotia, Newfoundland and Labrador, Yukon, and Nunavut) that have been collapsed in the displayed results to prevent identification of individual respondents’ wait times.
7.3 Determinants of total wait time

Bivariate analyses were first performed to determine the putative demographic and practice factors associated with total wait time (time from referral to communication of the diagnosis in days). The results are presented below in Tables 23 and 24.

Table 23: Bivariate analyses of associations between continuous putative variables and total wait time

<table>
<thead>
<tr>
<th>Variable</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Practice factors</td>
<td></td>
</tr>
<tr>
<td>Time spent on assessment</td>
<td>Spearman rank correlation coefficient</td>
<td>0.02*</td>
</tr>
<tr>
<td>(minutes)</td>
<td>( r_s = 0.31 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Demographic factors</td>
<td></td>
</tr>
<tr>
<td>Years in practice</td>
<td>Spearman rank correlation coefficient</td>
<td>0.34</td>
</tr>
<tr>
<td></td>
<td>( r_s = -0.13 )</td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis
### Table 24: Bivariate analyses of associations between categorical putative variables and total wait time

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median wait time (days)</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of assessor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Paediatrics</td>
<td>203.4</td>
<td>Kruskal-Wallis chi-squared = 3.66</td>
<td>0.16*</td>
</tr>
<tr>
<td>General Paediatrics</td>
<td>227.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>88.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepts referral from family doctor</td>
<td>212.8</td>
<td>Wilcoxon rank sum test W=200</td>
<td>0.24</td>
</tr>
<tr>
<td>Yes</td>
<td>212.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>176.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices in MDT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>271.2</td>
<td>Wilcoxon rank sum test W = 308.5</td>
<td>0.25</td>
</tr>
<tr>
<td>No</td>
<td>199.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catchment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within city only</td>
<td>196.4</td>
<td>Kruskal-Wallis chi-squared = 2.85</td>
<td>0.42</td>
</tr>
<tr>
<td>Within regional health authority</td>
<td>271.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>196.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>196.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province of practice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Columbia</td>
<td>285.2</td>
<td>Kruskal-Wallis chi-squared = 13.67</td>
<td>0.19*</td>
</tr>
<tr>
<td>Alberta</td>
<td>149.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>203.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>445.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Brunswick</td>
<td>262.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other§</td>
<td>221.8</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis; § “Other” is the median wait time for provinces with one respondent (Manitoba, Saskatchewan, Nova Scotia, Newfoundland and Labrador, Yukon, and Nunavut) that have been collapsed in the displayed results to prevent identification of individual respondents’ wait times.

Time spent on assessment was significantly associated with total wait time ($r_s = 0.31$, $p = 0.02$), indicating a longer wait time for respondents who conducted longer diagnostic assessments. Of the categorical variables, the type of assessor was significant with the small group of two “Other” clinicians having the lowest total wait time. General paediatricians had a longer median total wait time compared with developmental paediatricians, which was contrary to the hypothesis that more specialized assessors would have a longer wait time. The differences in total wait times between provinces met the significance threshold for inclusion in the model,
with a wide range of values between provinces. Though not reaching statistical significance, median wait times were longer for those accepting referrals from family doctors, those practicing in MDTs, and those with a catchment that included the regional health authority.

Variables were then tested for multicollinearity to ensure that variables included in the model were independently associated with the dependent variable. As determined for Time 1, type of assessor was significantly associated with assessment time. As a result, these variables were not tested together in the models.

All models required ln transformation of total wait time. The first variable tested in the model was assessment time, which was significantly associated with total wait time (β = 0.004, t = 3.25, p = 0.002). Assessment time remained marginally significant when controlling for province (β = 0.003, t = 1.99, p = 0.05), but province itself was not significantly associated with total wait time (partial F test = 0.88, p = 0.56).

The model was then tested with type of assessor, which was not significantly associated with wait time. Province was also tested on its own in the model, with the only significant result being the higher wait time when comparing Quebec and Alberta (β = 0.97, t = 2.47, p = 0.02). This comparison remained significant when controlling for type of assessor (β = 0.83, t = 2.1, p = 0.04).

Based on the above process of variable selection, the final model included only assessment time as a determinant of total wait time (Table 25). Evaluation of the residuals confirmed that the model met the assumptions of linearity (sum of residuals = 0; Shapiro Wilk test W = 0.97, p = 0.12; Q-Q plot displayed in Figure 7). Evaluations for homoscedasticity in the model showed constant variance between residuals and fitted values (Figure 8) and between residuals and assessment time (Figure 9). Thirteen influential observations were identified and removed from the data set, and the model was re-run. The R² for the full data set model was 0.17, with an adjusted R² of 0.15, indicating that approximately 15% of the variance in the model can be explained by assessment time. For the model without influential observations, the R² was 0.19, with an adjusted R² of 0.17.

The Duan smearing estimator was used to back-transform the ln wait time regression results to obtain wait times in minutes. The calculated smearing estimators for the full set model and
model with influential observations removed were 1.23 and 1.14, respectively. Predicted back-transformed mean wait times for first visit with 95% confidence intervals based on assessment time are listed in Table 26. The mean adjusted total wait time was 254.2 days (95% confidence interval 213.8, 302.4). When the assessment time was 60 minutes, the associated wait time was slightly less than six months (mean 178.3 days; 95% CI 134.8, 235.9); compared with this value, an assessment time of 180 minutes added nearly 100 days of wait time (mean 271.6 days; 95% CI 227.3, 324.5). As assessment time increased, there was a progressively larger increase in wait time. Removal of influential observations decreased the adjusted total wait times, indicating that influential observations tended to be for respondents with longer wait times. Adjusted values for the full data set are plotted in Figure 10.

Table 25: Regression model for total wait time

<table>
<thead>
<tr>
<th>Variable</th>
<th>Co-efficient (s.d.)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Full data set</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>4.77 (0.19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ln assessment time (minutes)</td>
<td>0.0035 (0.0012)</td>
<td>3.25</td>
<td>0.002</td>
</tr>
<tr>
<td><strong>Influential observations removed</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>4.73 (0.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ln assessment time (minutes)</td>
<td>0.0033 (0.0011)</td>
<td>3.06</td>
<td>0.004</td>
</tr>
</tbody>
</table>

ln = natural logarithm
Figure 7: Q-Q plot evaluating normality of residuals from ln-transformed total wait time regression model

In = natural logarithm, Q-Q = quantile-quantile; the model presented includes assessment time as the explanatory variable; data from the ln-transformed model are plotted on the vertical axis and compared with data from a standard normal population on the horizontal axis. The solid line represents a normally distributed sample.
Residuals are plotted on the vertical axis against fitted values from the model plotted on the horizontal axis. The solid line is the regression line between the fitted values and residuals.
Figure 9: Plot of residuals against assessment time (total wait time analysis)

Residuals are plotted on the vertical axis against assessment time plotted on the horizontal axis. The solid line is the regression line between the fitted values and residuals.
Table 26: Mean adjusted total wait times by assessment time

<table>
<thead>
<tr>
<th>Assessment time (min)</th>
<th>Mean wait time (days)</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
<th>Assessment time (min)</th>
<th>Mean wait time (days)</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>60</td>
<td>178.3</td>
<td>134.8</td>
<td>235.9</td>
<td>60</td>
<td>156.9</td>
<td>117.6</td>
<td>209.4</td>
</tr>
<tr>
<td>90</td>
<td>198.1</td>
<td>157</td>
<td>249.9</td>
<td>90</td>
<td>173.4</td>
<td>136.9</td>
<td>219.6</td>
</tr>
<tr>
<td>120</td>
<td>220.1</td>
<td>181</td>
<td>267.5</td>
<td>120</td>
<td>191.5</td>
<td>157.9</td>
<td>232.2</td>
</tr>
<tr>
<td>180</td>
<td>271.6</td>
<td>227.3</td>
<td>324.5</td>
<td>180</td>
<td>233.7</td>
<td>199.2</td>
<td>274.3</td>
</tr>
<tr>
<td>240</td>
<td>335.2</td>
<td>263</td>
<td>427.4</td>
<td>240</td>
<td>285.3</td>
<td>228.8</td>
<td>355.7</td>
</tr>
<tr>
<td>300</td>
<td>413.7</td>
<td>292.7</td>
<td>584.9</td>
<td>300</td>
<td>348.2</td>
<td>251.3</td>
<td>482.3</td>
</tr>
</tbody>
</table>

CI = confidence interval; min = minutes
Figure 10: Predicted total wait time based on assessment time

This figure shows the predicted total wait time from referral to completion of the ASD diagnostic assessment based on assessment time. Assessment time in minutes is plotted on the horizontal axis and wait time in days on the vertical axis. The blue line represents the mean adjusted value, with the shaded zone representing the 95% confidence interval.
7.4 Predictors of meeting Canadian wait time targets

Logistic regression analyses were performed based on whether the participants’ reported wait times met the targets as outlined in the Miriam Foundation guideline (2008). This guideline recommends a maximum wait time of three months for Time 1, two months for Time 2 and five months total wait time.

7.4.1 Predictors of first visit within three months of referral (Time 1)

Bivariate analyses were performed to identify which of the hypothesized factors were significantly associated with the first visit occurring within three months. These results are displayed in Tables 27 and 28. Assessment time was significantly associated with meeting the Time 1 target, with a one hour shorter median assessment time for those that met the target versus those that did not. The type of assessor was also significantly associated with meeting the Time 1 target, with 100% of other clinicians and 47% of general paediatricians meeting the target, versus just 14% of developmental paediatricians. Practicing in an MDT and accepting referrals from family doctors tended to have lower proportions of respondents meeting the target, but these failed to reach statistical significance for inclusion in the model.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median of those meeting target</th>
<th>Median of those not meeting target</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practice factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on assessment (minutes)</td>
<td>90</td>
<td>150</td>
<td>Wilcoxon rank sum test = 518</td>
<td>0.003*</td>
</tr>
<tr>
<td>Demographic factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in practice</td>
<td>16</td>
<td>20</td>
<td>Wilcoxon rank sum test = 353</td>
<td>0.97</td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis
Table 28: Bivariate analyses of putative categorical variables against Time 1 of three months or less

<table>
<thead>
<tr>
<th>Variable</th>
<th>n meeting target</th>
<th>n not meeting target</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of assessor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Paediatrics</td>
<td>3</td>
<td>18</td>
<td>Fisher’s exact test</td>
<td>0.007*</td>
</tr>
<tr>
<td>General Paediatrics</td>
<td>15</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices in MDT</td>
<td></td>
<td></td>
<td>Chi-squared = 1.32</td>
<td>0.25</td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepts referral from family</td>
<td></td>
<td></td>
<td>Fisher’s exact test</td>
<td>0.32</td>
</tr>
<tr>
<td>doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
<td>29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catchment</td>
<td></td>
<td></td>
<td>Fisher’s exact test</td>
<td>0.50</td>
</tr>
<tr>
<td>Within city only</td>
<td>8</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within regional health authority</td>
<td>6</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>4</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>2</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province of practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Columbia</td>
<td>0</td>
<td>3</td>
<td>Fisher’s exact test</td>
<td>0.30</td>
</tr>
<tr>
<td>Alberta</td>
<td>6</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>10</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>0</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Brunswick</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other§</td>
<td>2</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis; § “Other” contains all provinces with one respondent (Manitoba, Saskatchewan, Nova Scotia, Newfoundland and Labrador, Yukon, and Nunavut) and has been collapsed in the displayed results to prevent identification of individual responses; Y = yes; N = no

Variables were tested for multicolinearity. Assessment time and type of assessor were significantly associated (Kruskal-Wallis chi-squared = 5.59; p = 0.003), and these variables were not tested together in the model.

Assessment time was the first variable tested in the model. It was significantly associated with meeting the wait time target (Wald Z = –2.77, p = 0.006), with the result indicating that a longer
assesssment time was associated with lower odds of Time 1 being three months or less. Type of assessor was also tested in the model, but did not reach significance (chi-squared = 5.48, d.f. = 2, p = 0.06). The comparison between general paediatricians and developmental paediatricians was significant (Wald Z = 2.32, p = 0.02), with general paediatricians having higher odds of meeting the wait time target (odds ratio [OR] = 5.29; 95% confidence interval 1.3, 21.6).

The final model contained assessment time as the only significant factor associated with meeting the target (Table 29). The results showed significantly decreased odds of meeting the Time 1 target with each additional minute of assessment (OR 0.16, 95% CI 0.04, 0.58). Five influential observations were identified and removed; the results for the regression analysis without influential observations are also presented in Table 29. The results from this analysis show even lower odds of meeting the Time 1 target per additional minute of assessment (OR 0.06, 95% CI 0.01, 0.39). A plot of the probability of first visit within three months against the assessment time (full data set) is presented in Figure 11. For the full data set model, the $R^2$ was 0.24, indicating that 24% of the variance was explained by assessment time.

The concordance index for the full data set model was 0.74, indicating that the model is approaching good ability to discriminate between participants that did or did not meet the wait time target. Somer’s $D_{xy}$ was 0.48, indicating a low correlation between predicted probabilities and observed events. The Brier’s score was 0.19, indicating relatively low reliability. The gamma score was 0.55, suggesting some overfitting is present, despite the inclusion of only one covariate. This is likely attributable to the sample size of 55 participants. Using bootstrapping and calibration, the intercept of the calibrated model changed by 2.6% and the regression coefficient changed by 111%, indicating a large difference between the observed and the bias-corrected models.
Table 29: Logistic regression model for first clinic visit within three months

<table>
<thead>
<tr>
<th>Variable</th>
<th>Co-efficient (s.d.)</th>
<th>Wald Z</th>
<th>p</th>
<th>OR</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Full data set</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>1.48 (0.74)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment time (minutes)</td>
<td>-0.014 (0.005)</td>
<td>-2.77</td>
<td>0.006</td>
<td>0.16</td>
<td>0.04</td>
<td>0.58</td>
</tr>
<tr>
<td><strong>Influential observations removed</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>2.27 (0.99)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment time (minutes)</td>
<td>-0.023 (0.008)</td>
<td>-2.91</td>
<td>0.004</td>
<td>0.06</td>
<td>0.01</td>
<td>0.39</td>
</tr>
</tbody>
</table>

CI = confidence interval; OR = odds ratio; s.d. = standard deviation
Figure 11: Probability of first clinic visit within three months based on assessment time

This figure shows the probability of the first visit of the diagnostic assessment occurring within three months based on assessment time. Assessment time in minutes is plotted on the horizontal axis and probability on the vertical axis. The blue line represents the mean predicted value, with the shaded zone representing the 95% confidence interval.
7.4.2 Predictors of communication of the diagnosis to the family within two months of first visit (Time 2)

Bivariate analyses were performed to identify which of the hypothesized factors were significantly associated with Time 2 of two months or less. These results are displayed in Tables 30 and 31. Contrary to the results for Time 1, the time spent on assessment had a paradoxically higher median among those who met the Time 2 target, though this was not statistically significant. Catchment was the only variable that met significance criteria for testing in the model, with a lower proportion of respondents with regional health authority catchments meeting the Time 2 target (68%) compared with other catchments (80% for within-city, 100% for within province, and 100% for no defined catchment). When tested in the model, however, catchment was not a significant predictor of meeting this wait time target (chi-squared = 0.65, p = 0.88).

Table 30: Bivariate analyses of putative continuous variables against Time 2 of two months or less

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median of those meeting target</th>
<th>Median of those not meeting target</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on assessment (minutes)</td>
<td>150</td>
<td>135</td>
<td>Wilcoxon rank sum test $W=191.5$</td>
<td>0.73</td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in practice</td>
<td>20</td>
<td>10</td>
<td>Wilcoxon rank sum test $=210.5$</td>
<td>0.95</td>
</tr>
</tbody>
</table>
### Table 31: Bivariate analyses of putative categorical variables against Time 2 of two months or less

<table>
<thead>
<tr>
<th>Variable</th>
<th>n meeting target</th>
<th>n not meeting target</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catchment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within city only</td>
<td>12</td>
<td>3</td>
<td>Fisher’s exact test</td>
<td>0.07*</td>
</tr>
<tr>
<td>Within regional health authority</td>
<td>13</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>14</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>7</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of assessor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Paediatrics</td>
<td>18</td>
<td>2</td>
<td>Fisher’s exact test</td>
<td>0.51</td>
</tr>
<tr>
<td>General Paediatrics</td>
<td>25</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepts referral from family doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>35</td>
<td>8</td>
<td>Fisher’s exact test</td>
<td>0.67</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices in MDT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25</td>
<td>4</td>
<td>Fisher’s exact test</td>
<td>0.72</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province of practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Columbia</td>
<td>3</td>
<td>0</td>
<td>Fisher’s exact test</td>
<td>0.72</td>
</tr>
<tr>
<td>Alberta</td>
<td>9</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>23</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Brunswick</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other§</td>
<td>5</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis; § “Other” contains all provinces with one respondent (Manitoba, Saskatchewan, Nova Scotia, Newfoundland and Labrador, Yukon, and Nunavut) and has been collapsed in the displayed results to prevent identification of individual responses; Y = yes; N = no

#### 7.4.3 Factors significantly associated with total wait time of five months or less

Bivariate analyses were performed to identify which of the hypothesized explanatory variables were significantly associated with a total wait time five months or less. These results are displayed in Tables 32 and 33. Assessment time was significantly associated with meeting the
total wait time target, with those meeting the target reporting an assessment time that was one hour shorter than those who did not meet the target. Type of assessor was significantly associated with meeting the total wait time target, with higher proportions of general paediatricians (41%) and other clinicians (100%) meeting the target compared with developmental paediatricians (14%). None of the other variables reached significance for inclusion in the model, though there was a trend toward a lower proportion of those practicing in MDTs meeting the total wait time target (24%, versus 42% for those not in MDTs).

Table 32: Bivariate analyses of putative continuous variables against total wait time of five months or less

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median of those meeting target</th>
<th>Median of those not meeting target</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent on assessment</td>
<td>90</td>
<td>150</td>
<td>Wilcoxon rank sum test = 494</td>
<td>0.004*</td>
</tr>
<tr>
<td>(minutes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in practice</td>
<td>13</td>
<td>20</td>
<td>Wilcoxon rank sum test W=373</td>
<td>0.48</td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis
Table 33: Bivariate analyses of putative categorical variables against total wait time of five months or less

<table>
<thead>
<tr>
<th>Variable</th>
<th>n meeting target</th>
<th>n not meeting target</th>
<th>Test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of assessor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Paediatrics</td>
<td>3</td>
<td>18</td>
<td>Fisher’s exact test</td>
<td>0.05*</td>
</tr>
<tr>
<td>General Paediatrics</td>
<td>13</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices in MDT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>22</td>
<td>Chi-squared = 1.31</td>
<td>0.25</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepts referrals from family doctor</td>
<td></td>
<td></td>
<td>Chi-squared = 0.16</td>
<td>0.69</td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catchment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within city only</td>
<td>6</td>
<td>9</td>
<td>Fisher’s exact test</td>
<td>0.93</td>
</tr>
<tr>
<td>Within regional health authority</td>
<td>6</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within province/territory</td>
<td>4</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No defined catchment</td>
<td>2</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province of practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Columbia</td>
<td>0</td>
<td>3</td>
<td>Fisher’s exact test</td>
<td>0.42</td>
</tr>
<tr>
<td>Alberta</td>
<td>5</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>9</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quebec</td>
<td>0</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Brunswick</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other§</td>
<td>2</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* = variable meets cutoff of p < 0.2 to be included in regression analysis; § “Other” contains all provinces with one respondent (Manitoba, Saskatchewan, Nova Scotia, Newfoundland and Labrador, Yukon, and Nunavut) and has been collapsed in the displayed results to prevent identification of individual responses; Y = yes; N = no

Assessment time and type of assessor were known to be significantly associated and these variables were not tested together in the model. Assessment time was the first variable tested in the model. It was significantly associated with meeting the wait time target, with longer assessment times having lower odds of meeting the target (Wald Z = – 2.75, p = 0.006). Type of assessor was also tested in the model, but did not reach significance (chi-squared = 3.92, d.f. = 2, p = 0.14). The comparison between general paediatricians and developmental paediatricians was
marginally significant (Wald Z = 1.96, p = 0.05), with general paediatricians having higher odds of meeting the wait time target (OR = 4.11; 95% confidence interval 1, 16.8).

The final model contained assessment time as the only significant factor (Table 34). The results showed significantly decreased odds of meeting the total wait time target with each additional minute of assessment (OR 0.14, 95% CI 0.03, 0.57). Four influential observations were identified and removed from the data set. The regression analysis for the data set without influential observations is also presented in Table 34 and shows lower odds of meeting the total wait time with each additional minute of assessment (OR 0.06, 95% CI 0.01, 0.39) when compared with the full data set model. A plot of the probability of total wait time of five months or less against the assessment time (full data set) is presented in Figure 12.

For the full data set model, the $R^2$ for this model was 0.25, indicating that 25% of the variance was explained by assessment time. The c-index for the model was 0.74 indicating that the model is approaching good discriminative ability for participants that did or did not meet the wait time target. Somer’s $D_{xy}$ was 0.48, showing a low correlation between predicted probabilities and observed events. The Brier’s score was 0.18, indicating suboptimal reliability. The gamma score was 0.55, indicating some overfitting, likely attributable to the sample size of 55 participants. The intercept of the calibrated model changed by 9% and the regression co-efficient changed by 157%, indicating a sizable difference between the observed and the bias-corrected models.
Table 34: Logistic regression model for total wait time of five months or less

<table>
<thead>
<tr>
<th>Variable</th>
<th>Co-efficient (s.d.)</th>
<th>Wald Z</th>
<th>p</th>
<th>OR</th>
<th>Lower 95%</th>
<th>Upper 95%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Full data set</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>1.41 (0.77)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment time (minutes)</td>
<td>-0.015 (0.005)</td>
<td>-2.75</td>
<td>0.006</td>
<td>0.14</td>
<td>0.03</td>
<td>0.57</td>
</tr>
<tr>
<td><strong>Influential observations removed</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>2.27 (0.99)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment time (minutes)</td>
<td>-0.023 (0.008)</td>
<td>-2.91</td>
<td>0.004</td>
<td>0.06</td>
<td>0.01</td>
<td>0.39</td>
</tr>
</tbody>
</table>

CI = confidence interval; OR = odds ratio; s.d. = standard deviation
Figure 12: Probability of first clinic visit within three months based on assessment time

This figure shows the probability of completion of the diagnostic assessment within five months of referral based on assessment time. Assessment time in minutes is plotted on the horizontal axis and probability on the vertical axis. The blue line represents the mean predicted value, with the shaded zone representing the 95% confidence interval.
8 Discussion

This chapter will review the results of the systematic review of guidance documents for ASD diagnosis, the policy scan detailing Canadian and UK ASD diagnostic practices, and the reported practice patterns of Canadian paediatricians as they relate to ASD diagnosis, including the analyses to identify determinants of wait times for ASD diagnosis. It will then relate these findings to what is currently known in the scientific literature. A discussion of implications for clinicians, decision makers, and families will follow. Limitations of the work will be discussed, followed by overall conclusions.

8.1 Key study findings

The systematic review of guidance documents revealed substantial variability in both the quality of guidance documents for ASD diagnosis as well as in the content of their recommendations. Of the three highest ranked documents, two were from governments (the NICE and BC guidelines; the ASHA guideline, now rescinded, was the second highest ranked). The included guidance documents varied in their suggested use of diagnostic tools and personnel in the diagnostic assessment. Even when limiting to the three highest ranked documents, there were differing recommendations regarding the use of MDTs (required in the NICE and BC documents; “ideal” in the ASHA guidelines, which also permitted SLPs to independently diagnose ASD) and the use of tools (ADOS and ADI-R required in the BC guideline; no specific tools recommended in the ASHA and NICE guidelines). This variation is likely attributable to the paucity of empirical evidence available to support the various components of the ASD diagnostic assessment. The low degree of evidence was addressed only in the NICE guideline; other documents supported their diagnostic assessment recommendations with clinical consensus (the AACAP practice parameter), with references to other guidance documents (the BC guideline), or by excluding recommendations for the diagnostic assessment from graded recommendations (the AAN practice parameter). Few documents dealt with health systems issues related to diagnosis, particularly those published by professional associations. Those that did provide recommended maximum wait times provided little guidance as to how these could be achieved.

The policy scan of provincial, federal, and national UK diagnostic practices also showed a high degree of variability between jurisdictions with regard to ASD diagnosis and management. In the policy scan, recommended practices for ASD diagnosis were effectively requirements that had to
be met to receive publicly funded interventions. The provinces differed greatly with no discernable patterns among required tools or personnel, or with respect to acceptance of provisional diagnosis for services, direct provision of EIBI versus provision of funding to families to contract EIBI providers, or the ministry/ministries responsible for funding the interventions. Often, the ministry/ministries charged with delivering interventions differed from the ministry involved in the diagnostic assessment (which was most often the provincial health ministry). The variation in policies for ASD diagnosis suggests that the ways in which the diagnostic assessment informs intervention strategies have not been fully elucidated beyond simply determining eligibility for costly interventions.

There was little federal input for ASD diagnosis in Canada when compared with the UK, which is likely due to the differing health care structures (with more centralized health care policy-making in the UK). In contrast to the provincial policies, the UK guidance document focused predominantly on assessment, as there is no provision of ASD services at a national level in the UK.

Policies and guidance documents related to ASD diagnosis were all examined through the Triple-I framework of ideas, interests, and institutions (MacLean & Wood, 2010). Important ideas relating to ASD diagnosis clinical guidance included the differing value of evidence versus clinical consensus, the emphasis on early identification, the necessity of MDT assessment, and the distinction between the results of tools and broader clinical judgment. Interests influencing the development of diagnostic guidance included professional associations (who have shaped conceptions of ASD as a medical, psychological, communication, or behavioral disorder) and institutions concerned with limiting eligibility for costly interventions. Families and autistic self-advocates have provided relatively little input to the diagnostic process. Institutions have also contributed to the landscape of ASD diagnosis, particularly as the diagnostic assessment occurs within the health sector, with the family often transitioning to an alternative sector for intervention.

The survey of Canadian paediatrician practices with regard to ASD diagnosis similarly showed great variability. This variation is not surprising giving the differing recommendations described above in both the guidance documents and the policy scan. Many paediatricians conducted developmental consultations (with associated wait times and billing costs) but did not provide
ASD diagnoses in their practices. Paediatricians that did diagnose ASD reported differing practice patterns with regard to accepting primary care referrals, the number of visits required to make a diagnosis, the length of the visits, participation in a MDT, use of diagnostic tools, use of regional resources to support the assessment, additional tests ordered with a diagnosis, and compensation (through reported billing codes).

There were no two identically composed MDTs across the country, which may be reflective of the lack of uniformity in recommendations in guidance documents and policies regarding the necessary personnel for ASD diagnostic assessment. While this has not been previously described in ASD MDTs, one qualitative study of psychiatric MDTs in Ireland similarly found no consensus among 32 participants regarding the composition of their MDTs (Deady, 2012). The author found MDTs to be fluid concepts (as opposed to structured and unchanging) that were influenced by the biases of the MDT members. He warns that policies based on concepts such as MDT assessment can vary considerably in their application in clinical practice, which may also help to explain the significant variability in ASD diagnostic MDTs in Canada.

Average wait times were long, with an adjusted mean total wait from referral to diagnosis of over 250 days. Wait times had a very wide range with a positive skew, indicating that a small proportion of respondents had very long wait times.

The linear regression analyses to identify determinants of paediatrician-reported wait times consistently showed that a longer assessment time was significantly associated with longer wait times for the first visit of the diagnostic assessment (Time 1) and for the total wait from referral to diagnosis. Physicians with longer assessment times will likely have fewer available clinic slots and as a result will see fewer patients, leading to longer wait times. Practicing in a MDT was correlated with a shorter time between the first visit and communication of the diagnosis to the family (Time 2) in a bivariate analysis, which was an unanticipated finding and may represent a more structured clinic scheduling process for these teams.

The logistic regressions identified a trend of general paediatricians having higher odds of meeting wait time targets when compared with more specialized developmental paediatricians. This finding suggests that general paediatricians may be able to provide more timely diagnostic assessments for ASD, though it does not address the accuracy or quality of these assessments. Results also showed that many paediatricians in the sample consulted on patients with
developmental concerns but did not diagnose ASD; paediatricians who could instead provide a diagnosis at that intermediate juncture between primary care and subspecialist assessment may eliminate months of wait time for the diagnosis.

8.2 Comparison of study findings and existing research

This is the first study to evaluate guidance documents relating to all aspects of the ASD diagnostic assessment, though one previous review evaluated guidance document recommendations related to diagnostic tools. In 2013, CADTH published a Rapid Response Report on screening and diagnostic tools for ASD with a review of current guidance documents (Canadian Agency for Drugs and Technology in Health, 2013). Four guidelines were included in the review, three of which were included in this review (the fourth was a guideline from New Zealand, falling outside of the scope of this review). The CADTH review also identified discrepancies in the recommendations between guidelines as they pertained to the use of screening and diagnostic tools. The review presented here shows the lack of consistency in recommendations pertaining to all aspects of the diagnostic assessment, including whether ASD must be diagnosed by a MDT, the composition of the MDT, and the timeframe for completion of the assessment.

The survey reported here is the first to examine detailed self-reported practice patterns for ASD diagnosis, as well as to link these with self-reported wait times for assessment. The practice patterns did not always align with recommendations from the guidance documents, a finding that was also seen in a large US survey of 646 paediatricians’ practice patterns for developmental screening. A survey conducted in 2002 found that despite an AAP guideline recommending universal developmental screening with a standardized tool, only 23% reported consistent adherence to this recommendation (Sand, 2005). The authors concluded that even in the presence of clear guideline recommendations, the systems of care encouraging developmental detection were difficult to establish. Given that clear recommendations related to developmental screening have poor adherence, it is not surprising to find such wide variability in ASD diagnostic practices given the discrepant recommendations for assessment found in ASD diagnosis guidance documents.
There are relatively few studies evaluating the link between practice patterns and wait times for outpatient consultation. Jaakkimainen et al. (2014) linked electronic medical records and health administrative databases to evaluate patient and provider determinants of wait times for specialist consultations. The only provider characteristics associated with wait times were family practice location (with rural having a longer wait time) and family practice size (with more rostered patients being associated with a longer wait time). These observations are across the Canadian health system and are difficult to apply to a specific condition like ASD, particularly with regard to the impact of individual clinicians’ assessment decisions on wait times.

The present study was one of the first to examine the associations between wait times and clinicians’ chosen elements of assessment. Only one other study was identified that looked at the impact of clinical decision making on outpatient consultation wait times. The Practice Audit in Gastroenterology wait times program performed chart audits on over 5,000 referrals and found significant variation in wait times between provinces (Armstrong, 2008). It also examined the impact of clinical decision making (the decision to perform colonoscopies for average-risk patients) on total wait times (consultation plus endoscopy) and found longer wait times for those endorsing this practice (99 days versus 66 days; no test of statistical significance performed).

The authors posit that increased emphasis on and funding for colorectal screening may have influenced primary care physicians to refer average risk patients to gastroenterologists for colonoscopy, increasing wait times across the system. Increased funding for developmental screening (such as the 18-month enhanced developmental screening in Ontario; Ontario Ministry of Child and Youth Services, 2011c) may have had a similar effect for ASD diagnostic wait times, with a trade-off of more cases being identified but in a less timely manner.

The present study contributed to the literature on ASD diagnostic assessment by summarizing and critically appraising both the quality and content of the many clinical guidance documents related to ASD diagnosis and by analyzing ASD diagnostic practice patterns of Canadian paediatricians. These findings have important implications for all ASD stakeholders.
8.3 Clinical and policy implications

8.3.1 Implications for clinicians

There are multiple guidance documents for ASD diagnosis with varying recommendations, and clinicians therefore cannot be faulted for the wide variation in practice. Further, it remains unclear as to how the guidance documents reflect the practice realities of ASD clinicians, particularly those practicing outside of tertiary care institutions. Any guidance document aiming to reduce practice variation must consider how to construct and maintain these systems of care, as described by Sand and colleagues in their discussion of barriers to developmental screening (Sand, 2005).

The results of the regression analyses show that clinical decisions in the assessment process have an important impact on wait times. Assessment time was consistently positively associated with the wait time to first visit of the assessment as well as total wait time from referral to diagnosis. These results suggest that assessors must make careful decisions regarding necessary elements of the ASD diagnostic assessment, as there may be a resultant diagnostic delay, putting the child at risk for suboptimal developmental outcomes.

There are also intriguing findings about the types of clinicians that should be involved in the diagnostic assessment. Of those that diagnosed ASD in the survey, nearly half indicated that they did not participate in an MDT, which was inconsistent with the recommendations of many of the guidance documents. The lack of uniformity in the composition of MDTs across the country suggests a lack of clarity on the information to be collected and analyzed in the assessment, and how that information is operationalized for intervention. The difference in odds of meeting wait time targets between general paediatricians and developmental paediatricians adds further to the suggestion by Anagnostou et al. (2014) that general paediatricians can and should be a part of a system of ASD diagnostic assessments.

Finally, the finding of a wide range of reported wait times between the first clinic visit and the completion of the assessment deserves mention. Practicing in a MDT was associated with a lower wait time during this period and may be related to the ways in which assessments are scheduled with teams versus solo practitioners. This period may represent a particularly stressful time for families as they likely know their child is being assessed for ASD but do not have the
diagnosis required (in most provinces) to access intervention. Clinicians must be cognizant of all components of wait times for diagnosis, and further work should attempt to identify and mitigate determinants of this component of the wait time for an ASD diagnosis.

8.3.2 Implications for decision makers and guidance document developers

These results also have significant implications for decision makers and guidance document developers, both in governments and in professional associations. The recommendations and requirements for ASD diagnosis produced by these groups have significant implications on assessment time and wait times for diagnosis and should be considered in light of the available evidence.

Governments must consider the impact of policies and systems of care on wait times for diagnostic assessment. High-level decisions such as the variation in payer for intervention and the decision to deliver an intervention service versus providing funding to families to pay for intervention directly may contribute to some of the variation seen in the survey results. Unfortunately, the sample size from this survey was not sufficient to identify significant associations between provincial policies and wait times. In the scientific literature, Ontario and Nova Scotia are the only provinces with published outcomes from their respective intervention programs (Freeman & Perry, 2010; I. M. Smith et al., 2010), providing little effectiveness data to compare outcomes between systems.

In the development of future ASD guidance documents, professional associations must evaluate the systems implications of their recommendations, including wait times, costs, and access to diagnosis and interventions. As evidenced by the low Applicability domain scores from the AGREE-2 in the systematic review, many of the guidance documents neglected these important considerations in their recommended practices. The results of the regression analyses suggest that future guidelines should include recommendations for wait times (including the wait time from first clinic visit to completion of the assessment), as well as for the assessment time, which is a significant determinant of wait time.

Both governments and professional associations will need to assess their attitudes toward variability in ASD diagnostic assessments. ASD itself is associated with significant variability in
clinical presentation and developmental trajectory, and it may be that a one-size-fits-all approach to diagnostic assessment does not provide sufficient flexibility to accommodate for this variation. For instance, children with a more severe presentation of ASD may not require multiple assessors and diagnostic tools to confer a diagnosis with acceptable accuracy. In such cases, inflexible recommendations and requirements for assessment may add inefficiency to an already strained system. All stakeholders in ASD diagnosis responsible for creating policies or guidance documents should consider the tradeoffs between allowing less specialized clinicians to perform ASD diagnostic assessments in some cases (with a higher odds of meeting wait time targets, as this research suggests) or guaranteeing a high quality assessment for all children with ASD and accepting the risk of a longer wait time and the accompanying potential for suboptimal developmental outcomes.

8.4 Implications for families with a child with suspected ASD

Families consistently report a high level of distress associated with the ASD diagnostic assessment period (Goin-Kochel et al., 2006; Gray, 1993; Howlin & Moore, 1997). Families going through this process have different options for diagnostic assessment based on the jurisdiction in which they live. In Ontario, for instance, the primary care physician may identify concerns and refer to a general paediatrician, who may then offer the family the choice of waiting for a subspecialist diagnosis versus performing the diagnostic assessment in his or her practice. Families in Ontario may also pay for a privately funded diagnostic assessment by a psychologist, which would allow them earlier access to the queue for EIBI. In BC, the referral process is more strictly defined, though parents also have the option of pursuing a private diagnostic assessment (British Columbia Ministry of Child and Family Development, 2010). As such, the options available to families are not only influenced by jurisdiction, but also by the financial means available to the family.

Despite the disparities in diagnostic processes between jurisdictions, parent advocacy groups have paid relatively little attention to the assessment and diagnostic process, with much of the effort going into securing public funding for interventions (Broderick, 2009; Court of Appeal for British Columbia, 2007; The Supreme Court of British Columbia, 2007). In a recent qualitative study of ASD policy in Canada, parents described that after they received the diagnosis, they quickly shifted to a feeling of “panic” about securing interventions for their child (Shepherd,
2015). As a result, little advocacy may be directed toward the process that brought families to the diagnosis of ASD. Still, the journey leading to diagnosis should not go unexamined, as a prolonged wait time for diagnosis results in children seeking intervention at an older age, which only serves to heighten parental anxiety about accessing early intervention.

### 8.5 Study limitations

This work has some important limitations. First, the systematic review of guidance documents was limited to professional associations, Canadian jurisdictions, and the UK. As a result, some guidance documents (particularly those from other countries) were not included. This decision was taken to prioritize Canadian practices for ASD and to provide a high quality international comparator (the UK NICE guideline). The results are therefore not exhaustive of international guidance for ASD diagnostic assessments. Even with these limits, there was a high degree of variability in the quality and content of the included documents.

Only one reviewer filtered the retrieved documents and performed the quality appraisal and content analysis. As a result, there is the potential for bias in the systematic review results.

The policy scan of Canadian provinces and national practices produced only one clear guidance document (the BC guideline), and as a result, the remaining descriptions of ASD diagnostic systems and policies were assembled based on documents obtained in online searches. There may be additional policies relating to ASD diagnosis and intervention that are not posted online and thus were not included in this policy scan. It is also possible that the information presented here does not provide an accurate view of how these systems function in the real world, information that would be valuable in assessing the potential gap between policy and practice.

The survey had representation from across Canada and a response rate similar to the NPS. Comparison with demographic data from the NPS suggested that the results are generalizable to paediatricians across Canada, with two important exceptions. First, the proportion of females to males was higher in the study sample, which may reflect a bias toward more females with an interest in ASD. Second, due to the voluntary nature of the survey, there is a strong potential of volunteer bias with respondents more likely to have an interest in ASD. As such, the total sample results should not be considered indicative of the proportion of paediatricians that diagnose ASD.
Wait times in the survey were self-reported by clinicians, leading to the potential for bias. Participants may have been biased to either report shorter wait times to promote a positive view of their own performance, or may have reported longer wait times in an attempt to garner more support for developmental services from decision-makers. To minimize the possibility of recall bias, participants were asked to report their current wait time, as opposed to estimating an average over a period of time. Participants were also notified in the information letter that the survey would ask about wait times to allow them to collect this information in advance. Many institutions are required to report on their wait times, and it is likely that the paediatricians working in institutions would have access to this information. Further, paediatricians in community practice have close access to their office staff to provide this information. Still, there is a possibility of recall bias for those less familiar with their wait times.

The total number of respondents limited the statistical analysis of results, particularly the regression analyses for those that diagnosed ASD. With a larger sample size and more statistical power, additional determinants of wait times may have been identified. The study sample did not include psychologists and psychiatrists, who may also be involved in the diagnosis of ASD and whose practice patterns may influence systems for ASD diagnosis.

8.6 Future research

This work has identified a number of future areas that require further study. A study using participants with suspected ASD as the units of data collection (instead of clinicians) would provide more statistical power and may allow for further identification of elements of the diagnostic assessment that act as determinants of wait times. This could be achieved prospectively, as occurred with the Practice Audit in Gastroenterology study described above, or retrospectively, using health administration databases. The latter may pose a challenge for data collection at a national level due to the considerable variation in diagnostic systems between provinces.

At a broader level, further research is needed to identify more efficient assessment practices for ASD. This could involve evaluating diagnostic accuracy between MDT assessments using the ADI-R and ADOS and abbreviated specialist assessments. This study also identified that less specialized assessors (general paediatricians) had a higher odds of meeting wait time targets, and targeted use of this group may help to expand ASD diagnostic capacity. Future research should
evaluate the diagnostic accuracy of this group when compared to a full MDT assessment with standardized tools, as well as evaluating families’ perceptions of the quality of the assessment. Some children with a more complex presentation will require a more in-depth assessment, and responsiveness in the system could be informed by delineating which cases are suited for abbreviated or less specialized assessment, and which require a more rigorous assessment.

8.7 Conclusions

Clinical guidance documents for ASD diagnostic assessment published by governments, professional associations, and non-governmental organizations vary considerably in their quality and in the content of their recommendations. Many guidance documents had questionable rigor of development and limited applicability. Government systems and policies for ASD diagnosis also differed across Canada and in comparison with the UK. Guidelines, policies, and systems are all influenced by ideas about ASD, the interests of stakeholders, and institutions providing diagnostic and intervention services.

A survey of ASD diagnostic practices of Canadian paediatricians also showed differing practices. Many paediatricians that did not diagnose ASD still saw developmental consultations, adding an additional time cost to families on the diagnostic journey. Among those that diagnosed ASD, practices regarding the use of tools and personnel showed no consensus among assessors. Assessment time was a significant determinant of wait time and a predictor of meeting wait time targets, with general paediatricians having a higher probability of meeting wait time targets compared with developmental paediatricians. Further work is needed to identify more efficient assessment strategies that preserve reasonable accuracy and quality while allowing families to access both a diagnosis and intervention in a timely manner.
Appendices

Appendix A: Data Extraction Sheet - Government

☐ Federal  ☐ Provincial (which province): ________________________________

Name of document: _____________________________________________________________

Date of document: ______________________   Retrieval date: __________________________

1. Does the document mention a targeted age for diagnosis? Y/N  Age: _____

2. What are the strategies employed to meet this target?
   a. Screening
   b. Increased capacity for subspecialist diagnosis
   c. Increased capacity for diagnosis among generalists
   d. Other (specify): ______________________________

3. Does the document mention a targeted time from referral to diagnosis? Y/N

4. What are the strategies employed to meet this target?
   a. Increased capacity for tertiary centre diagnosis
   b. Increased capacity for community subspecialist diagnosis
   c. Increased capacity for community generalist diagnosis
   d. Other (specify): ______________________________

5. Does the document mention which professional(s) can provide a diagnosis of ASD? Y/N

6. If so, which professionals?
   a. Developmental Paediatrician
   b. General Paediatrician
   c. Neurologist
   d. Family Physician
   e. Psychiatrist
   f. Child Psychiatrist
   g. Clinical Psychologist
   h. Speech-Language Pathologist
   i. Occupational Therapist
   j. Other (specify): ______________________________

7. Are multiple professional assessments necessary? Y/N

8. Which professionals?
   a. Developmental Paediatrician
   b. General Paediatrician
   c. Neurologist
   d. Family Physician
   e. Psychiatrist
   f. Child Psychiatrist
   g. Clinical Psychologist
9. Are there guidelines for which tool(s) must be completed for a diagnosis of ASD? Y/N

10. If so, which one(s)?
   a. Autism Diagnostic Observation Schedule (ADOS)
   b. Autism Diagnostic Interview – Revised (ADI-R)
   c. Childhood Autism Rating Scale (CARS)
   d. Other (specify): __________________________

11. Does the document have clearly stated eligibility criteria for provincially funded ABA/IBI?
   i. Is there an upper age limit? Y/N
      1. If yes, age: ___________
   ii. Is provisional diagnosis acceptable for waitlist entry? Y/N
   iii. Is definitive diagnosis required for waitlist entry? Y/N
   iv. Do certain professionals have to be involved in the diagnosis? Y/N
      1. Which ones?
         a. Developmental Paediatrician
         b. General Paediatrician
         c. Family Physician
         d. Psychiatrist
         e. Child Psychiatrist
         f. Clinical Psychologist
         g. Speech-Language Pathologist
         h. Occupational Therapist
         i. Other (specify): __________________________
   v. Do certain tools have to be used in the diagnosis? Y/N
   vi. Which ones?
      1. ADOS
      2. ADI-R
      3. CARS
      4. Other (specify): __________________________
Appendix B: Data Extraction Sheet – Professional Association

Name of Professional Association: _____________________________________________

Guideline date: ____________________  Retrieval date: _______________________

1. Who is the guideline’s target audience?
   a. Paediatricians
   b. Developmental Paediatricians
   c. Neurologists
   d. Psychiatrists
   e. Child Psychiatrists
   f. Clinical Psychologists
   g. Speech-Language Pathologists
   h. Occupational Therapists

2. Does the guideline mention a targeted age for diagnosis? Y/N  Age: ____

3. What are the strategies employed to meet this target?
   a. Screening
   b. Increased capacity for subspecialist diagnosis
   c. Increased capacity for diagnosis among generalists
   d. Other (specify):____________________________

4. Does the guideline mention a targeted time from referral to diagnosis? Y/N  Time: ____

5. What are the strategies employed to meet this target?
   a. Increased capacity for tertiary centre diagnosis
   b. Increased capacity for community subspecialist diagnosis
   c. Increased capacity for community generalist diagnosis
   d. Other (specify):____________________________

6. Does the guideline mention which professional(s) can provide a diagnosis of ASD? Y/N

7. If so, which professionals?
   a. Developmental Paediatrician
   b. General Paediatrician
   c. Neurologist
   d. Psychiatrist
   e. Child Psychiatrist
   f. Clinical Psychologist
   g. Speech-Language Pathologist
   h. Occupational Therapist
   i. Other (specify):

8. Are multiple professional assessments necessary? Y/N

9. Which professionals?
   a. Developmental Paediatrician
   b. General Paediatrician
   c. Neurologist
   d. Psychiatrist
   e. Child Psychiatrist
f. Clinical Psychologist
g. Speech-Language Pathologist
h. Occupational Therapist
i. Other (specify): __________________________

10. Are there guidelines for which tool(s) must be completed for a diagnosis of ASD? Y/N
11. If so, which one(s)?
   a. Autism Diagnostic Observation Schedule (ADOS)
   b. Autism Diagnostic Interview – Revised (ADI-R)
   c. Childhood Autism Rating Scale (CARS)
   d. Other (specify): __________________________
Appendix C: Approval from CPS Section Executives for survey distribution

Jaime McCormick [jaimem@cps.ca]

In response to the message from Melanie Penner, 11/11/2014
To: Melanie Penner

You replied on 11/27/2014 7:38 AM.
Good Morning Melanie,

My name is Jaime and I have taken on Laura Cox’s position. I am following up in regards to the request for the survey distribution. The sections, Community Paediatrics, Developmental Paediatrics and Mental Health, are willing to have this survey distributed to their members. Once the survey is ready, we will distribute it on your behalf.

If you have any questions please do not hesitate to contact me or Jackie.

Kind regards,
Jaime

Jaime McCormick
Education Assistant, Canadian Paediatric Society
2305 St. Laurent Blvd, Ottawa, ON K1G 4J8
Tel: 613-526-9397 ext. 264 / Fax: 613-526-3332
www.cps.ca
Appendix D: Information letter for participants

(text of email sent to potential participants and included at beginning of survey)

Date: March 5, 2015

Dear Participant,

As part of my Masters degree, I am conducting research looking at the costs and wait times of different types of assessment approaches for Autism Spectrum Disorder (ASD). This information will provide much-needed evidence on cost-effective access to ASD diagnosis across Canada. To do this, I shall collect national data on ASD diagnostic practices and wait times.

I would like to invite you to take part in an online survey about your diagnostic practices and wait times. This survey has received approval from the Canadian Paediatric Society Developmental Paediatrics Section, Community Paediatrics Section and Mental Health Section for distribution to their members. Before agreeing to take part in this study, it is important that you understand how you will be involved.

The survey is available online through the link at the bottom of this page. I estimate that it will take 5-10 minutes to complete. The survey asks questions about whether you give a diagnosis of ASD in your practice, and if you do, what personnel, tests, and time you require in performing a diagnostic assessment and communicating the results. The survey will ask you about your clinical practice and your wait times for developmental assessment for ASD from the time you receive a referral (both the wait time for the first visit, as well as the wait time for subsequent visits), so it is important to know this information before starting the survey.
You will be able to stop the survey at any point and return to it at a later time. The survey website will provide you with a validation code if you want to stop the survey. You will require this validation code to return to your survey responses.

**Will anyone know what I say?**

I will collect data from the survey and store it in an electronic database on a secure, password-protected network at Sick Kids. Your name and any other information that could identify you WILL NOT be collected.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published. I must keep the research data we collect for 7 years as required by the Hospital for Sick Children.

**Do I have to do this?**

It’s okay if you decide not to take part. If you decide to take part, you can change your mind at any time. Whatever you decide will not affect your relationship with the Hospital for Sick Children.

**What are the risks and benefits?**

*Potential Risks:*

No identifying information about you will be collected, and there is no risk that your responses will be traced back to you. The questions should not make you feel uncomfortable, though you may stop at any point during the survey. The information you have already filled in will still be collected and analyzed. You will not waive your legal rights in the event of research-related harm if you decide to take part in this study.

*Benefits to individual participants:*

You will not benefit directly from participation.
Benefits to society:

This research project will provide information on the diagnostic practices of paediatricians and developmental paediatricians across Canada, as well as providing information on the wait times associated with different diagnostic approaches. This information will provide much-needed evidence on costs and wait time related to ASD diagnosis across Canada.

What if I have questions?

Please ask me to explain anything you don’t understand before completing the survey. If you have questions, you can contact me at 416-813-7654, extension 309431 (this is a study-specific voicemail) or at asd.diagnosisstudy@sickkids.ca. I will return your phone call/email within two business days.

The research team will prepare a one page summary of the research results and will send it to the Canadian Paediatric Society Developmental Paediatrics, Community Paediatrics and Mental Health section executives. Each section executive will then determine how to distribute study results to their respective membership at the end of the study.

If you have any questions about your rights as a research participant, please contact the Hospital for Sick Children Research Ethics Board at 416-813-8279.

Thank you for considering participation in this research study.

Yours truly,

Melanie Penner, MD FRCPC

Main Researcher

Child Health Evaluative Sciences Graduate Student – Sick Kids

BY FOLLOWING THE LINK BELOW, YOU AGREE THAT YOU HAVE READ THE INFORMATION FORM, UNDERSTAND THE STUDY, AND AGREE TO PARTICIPATE.

https://redcapexternal.research.sickkids.ca/surveys/?s=5EWHHibXme
Appendix E: National survey on diagnostic models and wait times for autism spectrum disorder

1. What is your age? _______
2. What is your sex? (M/F)
3. In which province/territory do you practice?
   a. Alberta
   b. British Columbia
   c. Manitoba
   d. New Brunswick
   e. Newfoundland & Labrador
   f. Nova Scotia
   g. Northwest Territories
   h. Nunavut
   i. Ontario
   j. Prince Edward Island
   k. Quebec
   l. Saskatchewan
   m. Yukon Territory
4. How large is your catchment area?
   a. Within-city only
   b. Within regional health authority
   c. Within province/territory
   d. No defined catchment
5. How many years have you been in paediatric practice? _______
6. What type of health professional are you?
   a. General paediatrician
   b. Developmental paediatrician
   c. Psychiatrist
   d. Psychologist
   e. Other
7. Do you have any formal training in child development or autism spectrum disorder (examples: subspecialty residency or fellowship in developmental paediatrics)? (Y/N)
   a. If Yes, please describe: _________________________________________
8. Do you give a diagnosis of autism spectrum disorder in your practice? (Y/N)
   IF YES, go to question 9
   IF NO, go to question 23
   a. (Only if participant selects general paediatrician for question 6 AND Yes to question 8) Of the cases with suspected autism spectrum disorder in your practice, for what percentage do you provide a definitive diagnostic assessment (versus referring for subspecialist assessment)? Select one:
      i. 0-25%
      ii. 26-50%
iii.  51-75%
iv.  76-100%

9. Do you accept referrals from family doctors for autism spectrum disorder diagnostic assessment (Y/N)?

10. How many clinic visits does it take you (on average) to perform an autism spectrum disorder diagnostic assessment and communicate the results?
   a.  1
   b.  2
   c.  3
   d.  4
   e.  5
   f.  More than 5

11. Which billing code(s) do you use for the first visit?
   a. Alberta
   b. BC – 00511
   c. BC – 00512
   d. BC – 00514
   e. BC – 00554
   f. Manitoba – 8540
   g. Manitoba – 8552
   h. Manitoba – 8404
   i. Manitoba – 8555
   j. New Brunswick – 14.1-93
   l. New Brunswick – 14.2-85
   m. New Brunswick – 14.2-86
   n. New Brunswick – 14.8C-91
   o. New Brunswick – 14.8-239
   p. New Brunswick – 14.8-194
   q. Newfoundland – 101
   r. Newfoundland – 102
   s. Newfoundland - 112
   t. Newfoundland – 113
   u. Newfoundland – 114
   v. Newfoundland – 115
   w. Newfoundland – 144
   x. Newfoundland – 181
   y. NWT – PA001
   z. NWT – PA007
   aa. NWT – PA016
   bb. Nova Scotia – 03.08
   cc. Nunavut – A-1
   dd. Nunavut – A-3
   ee. Ontario – A265
   ff. Ontario – A260
   gg. Ontario – A667
   hh. Ontario – K119
ii. Ontario – K122
jj. Ontario – K123
kk. PEI – 1160
ll. PEI – 1162
mm. PEI – 1110
nn. PEI – 1111
oo. PEI – 1112
pp. PEI – 2507
qq. PEI – 2586
rr. Quebec – 09127
ss. Quebec – 09165
tt. Quebec – 09129
uu. Quebec – 15164
vv. Saskatchewan – 14C
ww. Saskatchewan – 9C
xx. Saskatchewan – 11C
yy. Saskatchewan – 3C
zz. Yukon – 0510
aaa. Yukon – 0511
bbb. Yukon – 0512
ccc. Yukon – 0514
ddd. Yukon – 0550
eee. Yukon – 0551
fff. Yukon – 0554

12. (If the participant indicates two or more clinic visits) Which billing code(s) do you use for the second visit?
   a. Alberta – 3.0 PED CMXV30
   b. Alberta – 3.0 PED CMXV35
   c. BC – 00511
   d. BC – 00512
   e. BC – 00514
   f. BC – 00554
   g. Manitoba – 8540
   h. Manitoba – 8552
   i. Manitoba – 8404
   j. Manitoba – 8555
   k. New Brunswick – 14.1-93
   l. New Brunswick – 14.1-94
   m. New Brunswick – 14.2-85
   n. New Brunswick – 14.2-86
   o. New Brunswick – 14.8C-91
   p. New Brunswick – 14.8-239
   q. New Brunswick – 14.8-194
r. Newfoundland – 101
s. Newfoundland – 102
t. Newfoundland - 112
u. Newfoundland – 113
v. Newfoundland – 114
w. Newfoundland – 115
x. Newfoundland – 144
y. Newfoundland – 181
z. NWT – PA001
aa. NWT – PA007
bb. NWT – PA016
c. Nova Scotia – 03.08
dd. Nunavut – A-1
ee. Nunavut – A-3
ff. Ontario – A265
gg. Ontario – A260
hh. Ontario – A667
ii. Ontario – K119
jj. Ontario – K122
kk. Ontario – K123
ll. PEI – 1160
mm. PEI – 1162
nn. PEI – 1110
oo. PEI – 1111
pp. PEI – 1112
qq. PEI – 2507
rr. PEI – 2586
ss. Quebec – 09127
tt. Quebec – 09165
uu. Quebec – 09129
vv. Quebec – 15164
ww. Saskatchewan – 14C
xx. Saskatchewan – 9C
yy. Saskatchewan – 11C
zz. Saskatchewan – 3C
aaa. Yukon – 0510
bbb. Yukon – 0511
ccc. Yukon – 0512
ddd. Yukon – 0514
ee. Yukon – 0550
fff. Yukon – 0551
ggg. Yukon – 0554
hhh. Other (please list and indicate your province): ___________
iii. Other (please list and indicate your province): ___________
jjj. Other (please list and indicate your province): ___________
kkk. Don’t know
13. (If the participant indicates three or more clinic visits) Which billing code(s) do you use for the third visit?
   a. Alberta – 3.0 PED CMXV30
   b. Alberta – 3.0 PED CMXV35
   c. BC – 00511
   d. BC – 00512
   e. BC – 00514
   f. BC – 00554
   g. Manitoba – 8540
   h. Manitoba – 8552
   i. Manitoba – 8404
   j. Manitoba – 8555
   k. New Brunswick – 14.1-93
   l. New Brunswick – 14.1-94
   m. New Brunswick – 14.2-85
   n. New Brunswick – 14.2-86
   o. New Brunswick – 14.8C-91
   p. New Brunswick – 14.8-239
   q. New Brunswick – 14.8-194
   r. Newfoundland – 101
   s. Newfoundland – 102
   t. Newfoundland - 112
   u. Newfoundland – 113
   v. Newfoundland – 114
   w. Newfoundland – 115
   x. Newfoundland – 144
   y. Newfoundland – 181
   z. NWT – PA001
   aa. NWT – PA007
   bb. NWT – PA016
   cc. Nova Scotia – 03.08
   dd. Nunavut – A-1
   ee. Nunavut – A-3
   ff. Ontario – A265
   gg. Ontario – A260
   hh. Ontario – A667
   ii. Ontario – K119
   jj. Ontario – K122
   kk. Ontario – K123
   ll. PEI – 1160
   mm. PEI – 1162
   nn. PEI – 1110
   oo. PEI – 1111
   pp. PEI – 1112
   qq. PEI – 2507
   rr. PEI – 2586
   ss. Quebec – 09127
tt. Quebec – 09165
uu. Quebec – 09129
vv. Quebec – 15164
ww. Saskatchewan – 14C
xx. Saskatchewan – 9C
yy. Saskatchewan – 11C
zz. Saskatchewan – 3C
aaa. Yukon – 0510
bbb. Yukon – 0511
ccc. Yukon – 0512
ddd. Yukon – 0514
eee. Yukon – 0550
fff. Yukon – 0551
ggg. Yukon – 0554
hhh. Other (please list and indicate your province): _____________
iii. Other (please list and indicate your province): _____________
jjj. Other (please list and indicate your province): _____________
kkk. Don’t know

14. (If the participant indicates four or more clinic visits) Which billing code(s) do you use for the fourth visit?
   a. Alberta – 3.0 PED CMXV30
   b. Alberta – 3.0 PED CMXV35
   c. BC – 00511
   d. BC – 00512
   e. BC – 00514
   f. BC – 00554
   g. Manitoba – 8540
   h. Manitoba – 8552
   i. Manitoba – 8404
   j. Manitoba – 8555
   k. New Brunswick – 14.1-93
   l. New Brunswick – 14.1-94
   m. New Brunswick – 14.2-85
   n. New Brunswick – 14.2-86
   o. New Brunswick – 14.8C-91
   p. New Brunswick – 14.8-239
   q. New Brunswick – 14.8-194
   r. Newfoundland – 101
   s. Newfoundland – 102
   t. Newfoundland - 112
   u. Newfoundland – 113
   v. Newfoundland – 114
   w. Newfoundland – 115
   x. Newfoundland – 144
   y. Newfoundland – 181
   z. NWT – PA001
   aa. NWT – PA007
15. (If the participant indicates five or more clinic visits) Which billing code(s) do you use for the fifth visit?

a. Alberta – 3.0 PED CMXV30
b. Alberta – 3.0 PED CMXV35
c. BC – 00511
d. BC – 00512
e. BC – 00514
f. BC – 00554
g. Manitoba – 8540
h. Manitoba – 8552
i. Manitoba – 8404
j. Manitoba – 8555
k. New Brunswick – 14.1-93
l. New Brunswick – 14.1-94
m. New Brunswick – 14.2-85
n. New Brunswick – 14.2-86
o. New Brunswick – 14.8C-91
p. New Brunswick – 14.8-239
q. New Brunswick – 14.8-194
r. Newfoundland – 101
s. Newfoundland – 102
t. Newfoundland - 112
u. Newfoundland – 113
v. Newfoundland – 114
w. Newfoundland – 115
x. Newfoundland – 144
y. Newfoundland – 181
z. NWT – PA001
aa. NWT – PA007
bb. NWT – PA016
c. Nova Scotia – 03.08
dd. Nunavut – A-1
ee. Nunavut – A-3
ff. Ontario – A265
gg. Ontario – A260
hh. Ontario – A667
ii. Ontario – K119
jj. Ontario – K122
kk. Ontario – K123
ll. PEI – 1160
mm. PEI – 1162
nn. PEI – 1110
oo. PEI – 1111
pp. PEI – 1112
qq. PEI – 2507
rr. PEI – 2586
ss. Quebec – 09127
tt. Quebec – 09165
uu. Quebec – 09129
vv. Quebec – 15164
ww. Saskatchewan – 14C
xx. Saskatchewan – 9C
yy. Saskatchewan – 11C
zz. Saskatchewan – 3C
aaa. Yukon – 0510
bbb. Yukon – 0511
ccc. Yukon – 0512
ddd. Yukon – 0514
eee. Yukon – 0550
fff. Yukon – 0551
ggg. Yukon – 0554
hhh. Other (please list and indicate your province): ___________
iii. Other (please list and indicate your province): ___________
jjj. Other (please list and indicate your province): ___________
kkk. Don’t know

16. (If the participant indicates more than five clinic visits) Which billing code(s) do you use in most cases for subsequent ASD diagnostic visits?
   a. Alberta – 3.0 PED CMXV30
   b. Alberta – 3.0 PED CMXV35
   c. BC – 00511
   d. BC – 00512
   e. BC – 00514
   f. BC – 00554
   g. Manitoba – 8540
   h. Manitoba – 8552
   i. Manitoba – 8404
   j. Manitoba – 8555
   k. New Brunswick – 14.1-93
   l. New Brunswick – 14.1-94
   m. New Brunswick – 14.2-85
   n. New Brunswick – 14.2-86
   o. New Brunswick – 14.8C-91
   p. New Brunswick – 14.8-239
   q. New Brunswick – 14.8-194
   r. Newfoundland – 101
   s. Newfoundland – 102
   t. Newfoundland - 112
   u. Newfoundland – 113
   v. Newfoundland – 114
   w. Newfoundland – 115
   x. Newfoundland – 144
   y. Newfoundland – 181
   z. NWT – PA001
   aa. NWT – PA007
   bb. NWT – PA016
   cc. Nova Scotia – 03.08
   dd. Nunavut – A-1
   ee. Nunavut – A-3
   ff. Ontario – A265
   gg. Ontario – A260
   hh. Ontario – A667
   ii. Ontario – K119
   jj. Ontario – K122
   kk. Ontario – K123
   ll. PEI – 1160
17. How long is each clinic visit (on average)?
   a. 30 minutes or less
   b. 31-60 minutes
   c. 61-90 minutes
   d. 91-120 minutes
   e. 121-180 minutes
   f. > 180 minutes

18. Which tools do you use during the diagnostic assessment for autism spectrum disorder IN MOST CASES? Please check off the tool and indicate how many minutes it takes you to complete it (including scoring):
   a. Autism Diagnostic Interview – Revised: completion time (minutes) ____________
   b. Autism Diagnostic Observation Schedule – 2 ____________
   c. Social Responsiveness Scale: ______________
   d. Social Communication Questionnaire: ______________
   e. Vineland Adaptive Behaviour Scales 2nd ed.: ______________
   f. Mullen Scales of Early Learning: ______________
   g. Diagnostic Interview for Social and Communication Disorders: ______________
   h. Childhood Autism Rating Scale: ______________
   i. Other (specify): _________________________ (time) ____________________
   j. None

19. Do you conduct autism spectrum disorder diagnostic assessments as part of a multidisciplinary team (defined as an assessment in collaboration with at least one other
professional in a profession other than your own)? (Y/N) (if No, please skip to question 17)

20. For what per cent of cases do you provide diagnoses as part of a multidisciplinary team?
   a. 1-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

21. Which allied health professionals are available to your team? Include your role. Select all that apply.
   a. Psychology
   b. Speech-language pathology
   c. Occupational therapy
   d. Physiotherapy
   e. Social work
   f. Psychometry
   g. Clinical Genetics
   h. General Paediatrics
   i. Developmental Paediatrics
   j. Neurology
   k. Gastroenterology
   l. Behavioural Therapy
   m. Other: ____________________

22. Which professionals participate in the majority of the cases? Include your role. Select all that apply.
   a. Psychology
   b. Speech-language pathology
   c. Occupational therapy
   d. Physiotherapy
   e. Social work
   f. Psychometrist
   g. Clinical Genetics
   h. General Paediatrics
   i. Developmental Paediatrics
   j. Neurology
   k. Gastroenterology
   l. Behavioural Therapy
   m. Other: ____________________

23. For what per cent of cases do you consult with speech-language pathologists from outside of your institution (or use their assessment report) to help with your diagnosis (example: regional preschool Speech and Language Program)?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

24. For what per cent of cases do you consult with occupational therapists from outside of your institution (or use their assessment report) to help with your diagnosis?
   a. 0-25%
25. For what per cent of cases do you consult with early interventionists from outside of your institution (or use their assessment report) to help with your diagnosis?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

26. How many months is the current wait time (from the time your practice receives the referral) to be seen for the first visit of the diagnostic assessment? __________

27. How many weeks is the time period from your first clinic assessment visit to the communication of a diagnosis of autism spectrum disorder by you to the family? __________

28. Which of the following tests would you routinely offer when making a diagnosis of ASD? Select all that apply.
   a. Chromosomal microarray
   b. Fragile X testing
   c. Hearing assessment
   d. Vision assessment
   e. MECP2 for Rett Syndrome
   f. Metabolic screening
   g. MRI brain
   h. EEG
   i. Other________________________
   j. None

STOP POINT FOR PARTICIPANTS THAT DIAGNOSE ASD

29. How many weeks is the current wait time from receipt of a referral for a child with developmental concerns to you seeing the child in clinic? __________

30. How many minutes do you schedule for a first clinic visit for a child with developmental concerns?
   a. 15 minutes or less
   b. 16-30 minutes
   c. 31-45 minutes
   d. 46-60 minutes
   e. 61-75 minutes
   f. 76-90 minutes
   g. More than 90 minutes

31. Which billing code(s) do you use when seeing a child referred with developmental concerns?
   a. Alberta – 3.0 PED CMXV30
   b. Alberta – 3.0 PED CMXV35
   c. BC – 00511
   d. BC – 00512
   e. BC – 00514
   f. BC – 00554
   g. Manitoba – 8540
h. Manitoba – 8552  
i. Manitoba – 8404  
j. Manitoba – 8555  
k. New Brunswick – 14.1-93  
l. New Brunswick – 14.1-94  
m. New Brunswick – 14.2-85  
n. New Brunswick – 14.2-86  
o. New Brunswick – 14.8C-91  
p. New Brunswick – 14.8-239  
q. New Brunswick – 14.8-194  
r. Newfoundland – 101  
s. Newfoundland – 102  
t. Newfoundland - 112  
u. Newfoundland – 113  
v. Newfoundland – 114  
w. Newfoundland – 115  
x. Newfoundland – 144  
y. Newfoundland – 181  
z. NWT – PA001  
aa. NWT – PA007  
bb. NWT – PA016  
cc. Nova Scotia – 03.08  
dd. Nunavut – A-1  
ee. Nunavut – A-3  
ff. Ontario – A265  
gg. Ontario – A260  
hh. Ontario – A667  
i. Ontario – K119  
jj. Ontario – K122  
kk. Ontario – K123  
ll. PEI – 1160  
mm. PEI – 1162  
nn. PEI – 1110  
oo. PEI – 1111  
pp. PEI – 1112  
qq. PEI – 2507  
rr. PEI – 2586  
ss. Quebec – 09127  
tt. Quebec – 09165  
uu. Quebec – 09129  
vv. Quebec – 15164  
ww. Saskatchewan – 14C  
xx. Saskatchewan – 9C  
yy. Saskatchewan – 11C  
zz. Saskatchewan – 3C  
aaa. Yukon – 0510  
bbb. Yukon – 0511
ccc. Yukon – 0512
ddd. Yukon – 0514
eee. Yukon – 0550
fff. Yukon – 0551
ggg. Yukon – 0554

hhh. Other (please list and indicate your province): ___________

iii. Other (please list and indicate your province): ___________

jjj. Other (please list and indicate your province): ___________

kkk. Don't know

**STOP POINT FOR PARTICIPANTS THAT DO NOT DIAGNOSE ASD**
Appendix F: Reminder email sent after one week

Date: March 20, 2015

Dear Participant,

As part of my Masters degree, I am conducting research looking at the costs and wait times of different types of assessment approaches for Autism Spectrum Disorder (ASD). This information will provide much-needed evidence on cost-effective access to ASD diagnosis across Canada. To do this, I shall collect national data on ASD diagnostic practices and wait times

A detailed information letter as well as a link to the on-line survey was sent to you one week ago. Both the information letter and the survey are available at this address: https://redcapexternal.research.sickkids.ca/surveys/?s=5EWHHibXme.

You have two weeks remaining to complete the survey. I estimate that it will take 5-10 minutes to complete.

The survey will ask you about your clinical experience and wait times for developmental assessment for ASD. **Both the current wait time for the first visit, as well as the current wait time for subsequent visits will be needed, so it is important to know this information before starting the survey.** The survey will not ask for any identifying information, so no one will know what you say.

Thank you for considering participating in this important project.

*Melanie Penner, MD FRCPC*

Main Researcher

Child Health Evaluative Sciences Graduate Student – Sick Kids
Appendix G: Reminder email sent after two weeks

Date: March 27, 2015

Dear Participant,

As part of my Masters degree, I am conducting research looking at the costs and wait times of different types of assessment approaches for Autism Spectrum Disorder (ASD). This information will provide much-needed evidence on cost-effective access to ASD diagnosis across Canada. To do this, I shall collect national data on ASD diagnostic practices and wait times.

A detailed information letter as well as a link to the on-line survey was sent to you two weeks ago. Both the information letter and the survey are available at this address:

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You have one week remaining to complete the survey. I estimate that it will take 5-10 minutes to complete.

The survey will ask you about your clinical experience and wait times for developmental assessment for ASD. Both the current wait time for the first visit, as well as the current wait time for subsequent visits will be needed, so it is important to know this information before starting the survey. The survey will not ask for any identifying information, so no one will know what you say.

Thank you for considering participating in this important project.

Melanie Penner, MD FRCPC

Main Researcher

Child Health Evaluative Sciences Graduate Student – Sick Kids
Appendix H: Research Ethics Board approval

Research Ethics Board (REB)

The membership and operations of the Hospital for Sick Children’s (SickKids’) Research Ethics Board (REB) are in compliance with: Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; the Medical Devices Regulations; the ICH Guideline for Good Clinical Practice Ed. Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, 2nd edition (TCPS 2); the Ontario Personal Health Information Protection Act, 2004; and other applicable regulations.

The REB has reviewed and approved the protocol, consent forms and other study documents listed below for this study which is to be conducted by the principal investigator named on this application. All clinical trials at SickKids are conducted by qualified investigators, as defined in the regulations. The approval and the views of this REB have been documented in writing, in accordance with the applicable legislations, regulations and guidelines.

Approval & Terms of Agreement

Investigators: Dr. Wendy Ungar, M. Pennner, E. Anagnostou
Study Title: Cost-Effectiveness Analysis of Access to Community Paediatric Practitioner Assessment for Autism Spectrum Disorder Compared to Multi-Disciplinary Team Assessment
REB File number: 1000847333 Level of Continuing Review: I B
Protocol Version Date: November 13, 2014
Consent & Assent Form Version Date(s):
Investigator's Brochure Version Date: N/A

I agree to carry out the proposed research involving human subjects in accordance with the above-noted guidelines and regulations (as applicable) and using only the REB-approved study protocol and consent/assent forms. I shall notify the division/department head and the REB prior to implementing any amendments in the protocol and consent/assent forms and of any deviations or any changes in study activity. I shall also notify the REB of any unexpected adverse events as per REB guidelines. As applicable, I certify that the research contract and corresponding protocol are consistent and will inform the contract manager of any protocol amendments as required.

I agree that, in accordance with the Personal Health Information Protection Act of Ontario, I am responsible for adhering to all conditions and restrictions imposed by the REB governing the use, security, disclosure, return and disposal of the research subjects’ personal health information. I am also responsible for reporting immediately any privacy breaches to the REB Chair and to Janice Campbell, the Sick Kids privacy officer. I will ensure that the personal health information is used, only as necessary, to fulfill the specific research objectives and related research questions described in this application and approved by the REB.

Signature of Principal Investigator __________________________ DATE_ November 19, 2014

I approve of this research protocol, agree to share responsibility for its proper conduct, and will ensure that the REB is notified of concerns, as appropriate.

Signature of Division/Department Head __________________________ DATE_ November 24, 2014

The REB of the Hospital for Sick Children has reviewed and approved the above-named research study.

Ronald M. Grant, M.D., REB Chair
555 University Avenue, Toronto, ON M5G 1X8
Tel: 416-813-6152 Fax: 416-813-6515 Email: ronald.grant@sickkids.ca

DATE OF APPROVAL_ November 24, 2014 EXPIRY DATE_ November 2015
Appendix I: Research Ethics Board approval of survey amendment

RESEARCH ETHICS BOARD AMENDMENT FORM
Form Version Date: October 29, 2013

PART 1: STUDY INFORMATION

1. PROJECT

REB file number
1 0 0 0 0 4 7 3 3 3

Complete project title
Cost effectiveness analysis of access to community paediatric practitioner assessment for autism spectrum disorder compared to multi disciplinary team assessment

Principal Investigator
Name: Wendy Ungar
Clinical department/division: No Clinical Appointment

Lay summary (max. 750 characters)
This project has two aims. The first aim is to examine the current guidelines suggesting how autism spectrum disorder (ASD) should be diagnosed. Government policies and professional association guidelines (for paediatricians, psychologists and other professionals involved in ASD diagnosis) will be evaluated for both their suggestions as well as the evidence base for those suggestions. The second aim of the project is to examine the costs of different diagnostic models for ASD compared with how quickly families can access these services. This analysis will focus on comparing access to assessment by solo physicians versus teams of specialized professionals. A survey of Canadian paediatricians will inform the analysis.

2. STUDY DETAILS

Research category and level of continuing review
Level of continuing review: 1  Research category: B

Study status
Not yet recruiting subjects

Study sponsor
Other - Melanie Penner’s salary from Clinician Investigator Program @ UofT

Project funding
- For each funding source provide the source name and type (granting agency, industry, non-profit, other hospital, etc.)

Salary support: Clinician Investigator Program, University of Toronto

PI: Wendy Ungar
Research Ethics Board Amendment Form

REB Number: 100047333
Page 1 of 5
Version Date: October 29, 2013
Was a waiver of consent granted for this study?

☐ Yes  ☐ No

Is this a Health Canada approved study?

☐ Yes  ☐ No

**PART 2: AMENDMENT DETAILS**

Science review may be needed for major amendments. If a science review was required, attach a copy of the completed science review form.

**3. TYPE OF AMENDMENT**

Indicate which of the following aspects of your study are being added, deleted, updated, changed or otherwise amended:

- ☐ Study procedures
- ☐ Data collection period
- ☐ Number of groups or arms
- ☐ Inclusion/Exclusion criteria
- ☐ Amount of funding available
- ☐ Patient risk or safety information
- ☐ Other

- ☐ Study sites
- ☑ Data being collected
- ☐ Sample size
- ☐ Recruitment process
- ☐ Amount of funding required
- ☐ Length of study
- ☐ Data sources
- ☐ Screening sample size
- ☐ Study sponsor
- ☐ Subject reimbursement
- ☐ Other

Indicate the documents that are being amended or added. Attach all indicated documents to this application with changes tracked (where applicable).

- ☐ Protocol
- ☐ Data collection form(s)
- ☐ Written materials for subjects
- ☐ Data Safety (DSMB) plan
- ☐ Other

- ☐ Informed consent/assent form(s)
- ☐ Investigator's brochure
- ☐ Questionnaire or survey
- ☐ Interview script
- ☐ Recruitment tools or documents
- ☐ Study budget
- ☐ Contract
- ☐ Other

Specify

Questionnaire for Physicians who Diagnose ASD

Is this amendment the result of an audit, adverse event or unanticipated problem?

☐ Yes  ☐ No

**4. STUDY CHANGES**

4a. Rationale for Changes

a) Describe the change(s) that you are proposing, making sure to reference what was in place previously (e.g. "we are changing the sample size from 19 to 25", rather than "we are increasing our sample size to 25")
Based on feedback we received from piloting our survey, we have clarified the wording of some of the questions. We are also now also asking about billing codes used for autism spectrum disorder (ASD) diagnostic assessments. The participant is first asked if he/she diagnoses ASD, and is then asked how many clinic visits it takes to complete the assessment. A list of potential billing codes (with three "Other" options with corresponding blank text fields) appears for each clinic visit. For instance, if the participant indicates that it takes him/her three clinic visits to complete an assessment, then the participant will be asked about the billing codes used for each of those three clinic visits.

b) Provide the rationale for each change

The wording clarification employed helps to ensure that participants are providing the desired information about what proportion of cases they choose to diagnose versus referring for subspecialist assessment. The billing codes were added based on feedback from the pilot process. These will provide useful information to inform the cost-effectiveness analysis by providing costs of each type of assessment. They will also provide useful information on how Canadian physicians are compensated (including provincial differences) for ASD assessment. Because some physicians may not do their own billing and may not know this information, questions about billing codes are not mandatory for survey completion.

4b. Impact on Subjects

What impact will this amendment have on research subjects?

This information may increase the time it takes to complete the survey by approximately two minutes (from an anticipated maximum of ten minutes).

Describe any changes to the potential risk to the subject

We do not anticipate any risks with these additional questions. The data will remain anonymous and billing patterns will not be traced back to individuals. Participants are unlikely to experience any feelings of discomfort with these questions, though if they do, they may choose not to answer.

Will current participants be informed of the change(s)?

☐ Yes  ☐ No

5. PRINCIPAL INVESTIGATOR ATTESTATION

I have read the information contained in this form. By signing below I agree that:
- I will inform my study team of all changes included in this amendment.
- I will only implement the changes described on this amendment form.
- I will ensure that, except in cases where the safety of the study participant is at risk, the changes will not be implemented until final REB approval has been received.

Wendy Ungar
Name of Principal Investigator

Signature of Principal Investigator

Date: Jan 14, 2015
**Department/Division Head**
The signatures of division or department heads who are named as investigators in this application are not accepted here; sign-off in such cases is done by an existing (e.g., not created specifically for this research project) deputy, or by the person to whom the Head reports for patient care matters.

**Science Review Board Chair**
If applicable - Any studies involving staff, subjects or data from the department of Haematology/Oncology requires approval from the Haematology/Oncology SRB.
### 7. APPROVAL FOR THIS AMENDMENT

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Appendix J: Renewed Research Ethics Board approval

RESEARCH ETHICS BOARD

October 06, 2015

Dr. Wendy Ungar
Child Health Evaluative Sciences
The Hospital for Sick Children

Dear Dr. Ungar:

Your study “Cost-Effectiveness Analysis of Access to Community Paediatric Practitioner Assessment for Autism Spectrum Disorder Compared to Multi-Disciplinary Team Assessment”

REB File No.: 1000047333

On behalf of the REB, I am writing to confirm that the above noted study was re approved by the REB via delegated review for a period effective from November 24, 2015 to November 24, 2016. The REB approved continuing review at level 1B. As necessary, the Research Quality and Risk Management Office will be contacting you to arrange follow up.

Please note that, in accordance with the Personal Health Information Protection Act of Ontario, you are responsible for adhering to all conditions and restrictions imposed by the REB governing the use, security, disclosure, return and disposal of the research subjects’ personal health information. You are also responsible for reporting immediately any privacy breaches to the REB Chair and to the SickKids privacy officer.

The SickKids REB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans, the Ontario Personal Health Information Protection Act, 2004, and ICH Good Clinical Practice Consolidated Guideline E6, Health Canada’s Regulations Amending the Food and Drug Regulations (1024 - Clinical Trials). Furthermore, all investigational drug trials at SickKids are conducted by Qualified Investigators.

Yours truly,

[Signature]

Elizabeth A. Stephenson, M.D., MSc., Interim REB Chair
555 University Avenue, Toronto, ON M5G 1X8
Tel: 416 813 8279  Fax: 416 813 6515

Co-Investigator(s): Melanie Penner, Evdokia Anagnostou
References


Government of Newfoundland and Labrador. (2014). Re: Your request for access to information under Part II of the Access to Information and Protection of Privacy Act (the Act), HCS 36 20141 C.F.R.


Williams, R., & Clinton, J. (2011). Getting it right at 18 months: In support of an enhanced well-baby visit. Paediatrics and Child Health, 16(10), 647-650.

