Provincial Council *for* Maternal *and* Child Health
building a brighter future

Neonatal Follow-Up Program

Implementation Toolkit

Table of Contents

Background

Throughout the province, the role of the Neonatal Follow-Up Program (NFUP) is crucial for continued monitoring and early intervention to promote optimal outcome in high risk infants from Neonatal Intensive Care Units (NICUs), as well to evaluating the impact of care for these infants. In 2012/2013 there were 24 NFUP Clinics in Ontario that cumulatively enrolled 3,000 new NICU graduates. Despite the prevalence and importance of NFUP clinics however, there has not been a comprehensive and critical examination of the system and its impacts.

In 2013 the Provincial Council for Maternal and Child Health convened a panel of experts, the ‘Neonatal Follow-Up Clinics Work Group’, to examine the current state of NFUP clinics in Ontario and to make recommendations to best address the needs of the population. The work group’s final report found that the clinics operate independently from one other, resulting in a largely uncoordinated system of care. The impact of this results in discrepancies in quality of care, gaps in care coverage, and health inequities resulting from barriers such as patient travel costs.

In December 2015 the ‘Neonatal Follow-Up Clinics Implementation Committee’ was convened to implement the recommendations from the Final Report of the ‘Neonatal Follow-Up Clinics Work Group’. The Committee developed an action plan to identify tangible steps to implement the recommendations and developed a series of tools to help coordinate and standardize care across the province.

The Neonatal Follow-Up Program

The Neonatal follow-up clinics are collectively referred to as the Neonatal Follow-Up Program (NFUP). The intention of this is to reflect that these clinics do not operate in silos, but rather, are part of a larger, provincial, collaborative system. The ultimate goal of this work is to develop a cohesive system of neonatal follow-up that includes collaboration amongst the clinics and other relevant care providers, placing families at the centre of care. Instead of the clinics working in isolation of each other, this work aims to leverage and pool system resources and standardize key functions to ensure that children across the province have equitable access to high quality care.

A further aim of the NFUP is to improve communication with all health care providers involved in the care of babies and children seen by NFUP clinics. There is not a great of deal awareness among community health care providers regarding what the clinics do, how to refer a child, and the potential for collaboration. A goal of this work is to ensure better communication and a better coordinated system of care for children and their families.

About the NNFU Implementation Tools

This Implementation Toolkit is designed to help Ontario's NFUP clinics implement the tools created by the Neonatal Follow-Up Implementation Committee. The following table lists the tools covered in the toolkit. Each tool can be accessed by visiting http://www.pcmch.on.ca/ontario-neonatal-follow-program/.

Tool	Description
Levels of Neonatal Follow-Up Reference Sheet	A reference sheet outlining the neonatal follow-up levels of care, including admission criteria, goals, and recommended resources.
Patient Flow Charts	A series of flow charts that depict the most common referral processes for children with motor, behavior, cognitive and social issues.
Shared Care Form	A form designed to be used between two neonatal follow-up clinics to facilitate information sharing between clinics in order to improve the coordination of care for patients and families.
List of Assessment Tools	A list of commonly used assessment tools organized by developmental domain, administration time, qualifications required to administer and strengths/limitations, to assist clinicians in selecting an appropriate assessment tool to meet the specific goals/touch points of clinic visits.
Post-natal Screening Forms	A set of three mental health screening tools to screen for postpartum in mothers, and anxiety or depression in other caregivers.
Letter to Health Care Providers and Physicians	A letter/bulletin directed to community health care providers and physicians to bring awareness of the role of the Neonatal Follow-Up Program, why it is important and how external providers can work with clinics to ensure that babies get proper, comprehensive care.
Resources for Parents and Families	Materials for parents and families to educate them about neonatal follow-up clinics and what to expect as well as information about their child's development.

Levels of Neonatal Follow-Up Reference Sheet

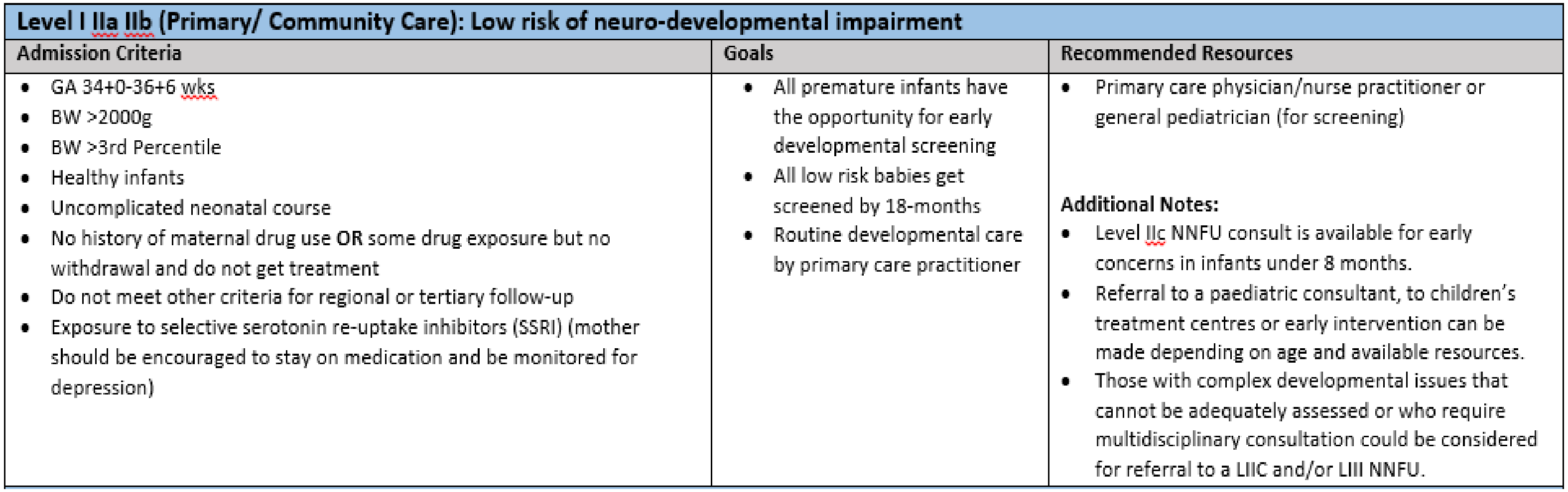
About the Tool

This reference sheet outlines the neonatal follow-up levels of care, including admission criteria, goals, and recommended resources. Neonates admitted to neonatal follow-up have well documented risks to their development and may present with subtle findings indicative of future developmental challenges. Generally, the risk correlates to the extent of dysmaturation and gestational age as well as severity of illness, which is why it is important to ensure that levels of neonatal follow-up are paired with NICU levels of care. Through proactive monitoring geared to the extent of risk (aligned with NICU levels of care), early signs can be identified and coaching and intervention can then be provided to parents to redirect the trajectory to one of greater self-regulation and success

Purpose

To provide details on the different levels of care and ensure that babies receive care at the appropriate level.

Example



Level I IIa IIb (Primary/ Community Care): Low risk of neuro-developmental impairment		
Admission Criteria	**Goals**	**Recommended Resources**
• GA 34+0-36+6 wks • BW >2000g • BW >3rd Percentile • Healthy infants • Uncomplicated neonatal course • No history of maternal drug use **OR** some drug exposure but no withdrawal and do not get treatment • Do not meet other criteria for regional or tertiary follow-up • Exposure to selective serotonin re-uptake inhibitors (SSRI) (mother should be encouraged to stay on medication and be monitored for depression)	• All premature infants have the opportunity for early developmental screening • All low risk babies get screened by 18-months • Routine developmental care by primary care practitioner	• Primary care physician/nurse practitioner or general pediatrician (for screening) **Additional Notes:** • Level IIc NNFU consult is available for early concerns in infants under 8 months. • Referral to a paediatric consultant, to children's treatment centres or early intervention can be made depending on age and available resources. • Those with complex developmental issues that cannot be adequately assessed or who require multidisciplinary consultation could be considered for referral to a LIIC and/or LIII NNFU.

Patient Flow Charts

About the Tool

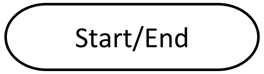
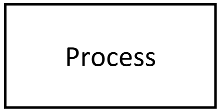
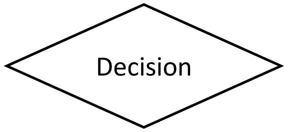
This tool includes a series of flow charts that depict the most common referral processes for children with motor, behavior, cognitive and social issues. Although individual exceptions may occur, the goal of this tool is to help standardize care and processes so that all children across the province receive the same standard of care.

Purpose

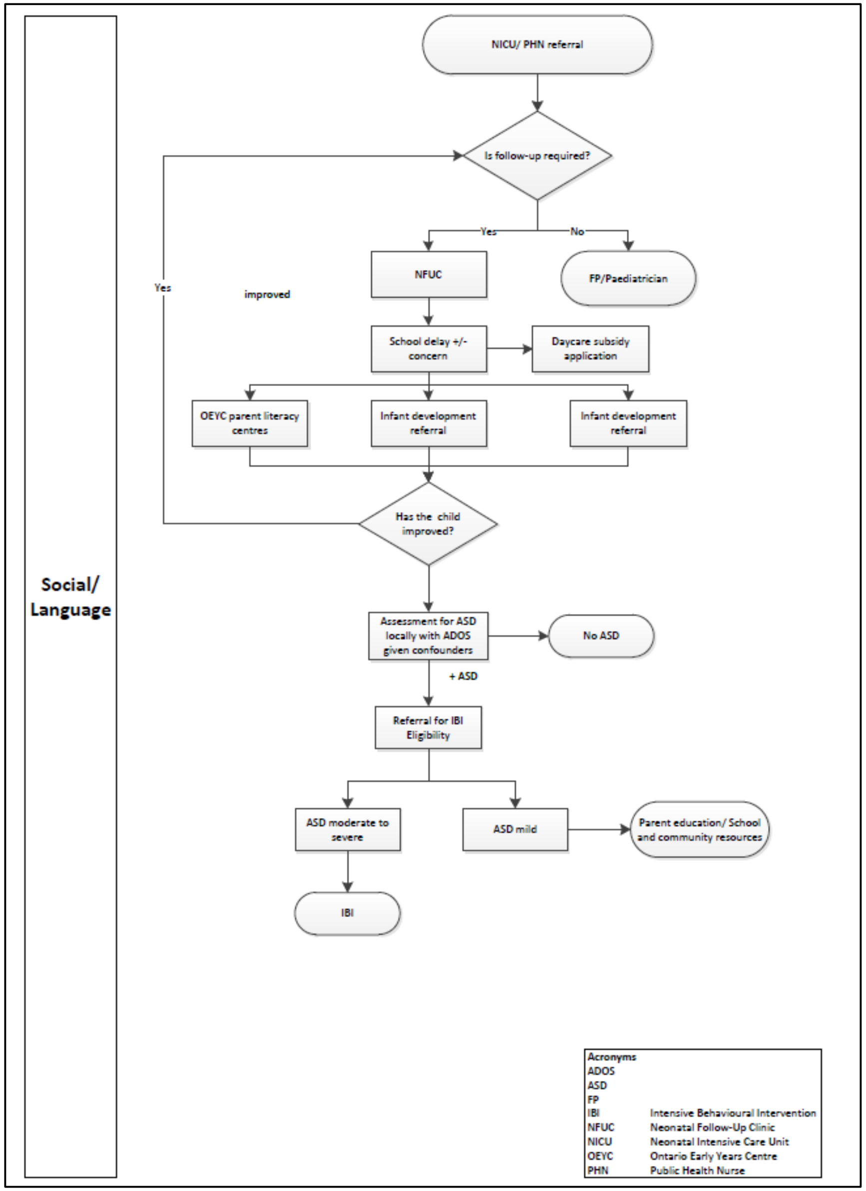
To illustrate the most common referral processes for children with motor, behaviour, cognitive and social issues in NFUP clinics.

How to Use the Tool

Follow the arrows along the chart to the next step. The following table below explains the flow chart symbols.

	Where the flow begins and ends.
	Illustrates a process, action or operation.
	Represents a question asked in the flow process. The result will usually be two arrows that lead to the appropriate process point based on the decision made.

Example



Acronyms	
ADOS	
ASD	
FP	
IBI	Intensive Behavioural Intervention
NFUC	Neonatal Follow-Up Clinic
NICU	Neonatal Intensive Care Unit
OEYC	Ontario Early Years Centre
PHN	Public Health Nurse

Shared Care Form

About the Tool

In a shared care model, care for the patient is shared between a Level II and a Level III NFUP clinic. The criteria and guiding principles for a shared care model, listed below, are intended to promote patient-centred care, enhanced compliance to the NFUP visit schedule, enhancement of the patient/family experience through easier visits and consistency of messaging, avoidance of redundancy, and best use of available resources. This form can be used to facilitate information sharing between two clinics to improve the coordination of care for patients and families.

Purpose

To facilitate information sharing between clinics in order to improve the coordination of care for patients and families.

How to Use the Tool

1. Double click the header at the top of the page to insert the name. Please be sure to include the child's name in the header of the form to ensure that the various pages of the record are kept together.
2. Complete the appropriate fields in the form below for every visit a child has at your clinic.
3. Fax the completed form to the partner clinic to update their records accordingly. Be sure to get the family's consent before sharing any information with another clinic.

Example

The following two columns are guidelines only. Include any additional goals or coaching and interventions in the comments column.

Neonatal Follow-Up Program Recommended Visit Schedule			Level II Center	Level III Center	Comments/ Concerns
Visit Timing (Approximate date)	Goals (Circle areas of concern)	Coaching and Intervention Goals			
4 – 8 weeks post-discharge	• Attachment • Regulation (feeding, sleeping) • Positioning (safety and beginning of intervention) • Maternal/family health wellbeing/depression/anxiety and link to primary care if needed	Coaching: • Signs and symptoms of depression and help available • Safe sleep • Normalizing infant’s need for external support for regulation • Developmental cues for feeding	☐	☐	

Approvals

Level III: Click here to enter text.	Level III Approval: Signature	Level III Fax Number: Click here to enter text.
Level II: Click here to enter text.	Level II Approval: Signature	Level II Fax Number: Click here to enter text.
Family consents to sharing information between clinics: Signature		

Obtaining family support is important before sharing any information with another clinic.

Fax the completed form to the partner clinic after every visit to ensure that records are continuously kept up to date.

List of Assessment Tools

About the Tool

The following menu of assessment tools are recommended for use to address the specific goals of each NFUP visit. The menu was collated to provide the best assessments available for the specified goal and allows the individual NFUP clinic and clinicians to select the tools to be used in their particular setting/circumstance with attention to the specific goal/touch point of the visit.

Note, this is not an exhaustive list of assessment tools and are not targeted to premature babies.

Purpose

To assist care providers to select an appropriate assessment tool to meet the specific goals/touch points of NFUP visits.

How to Use the Tool

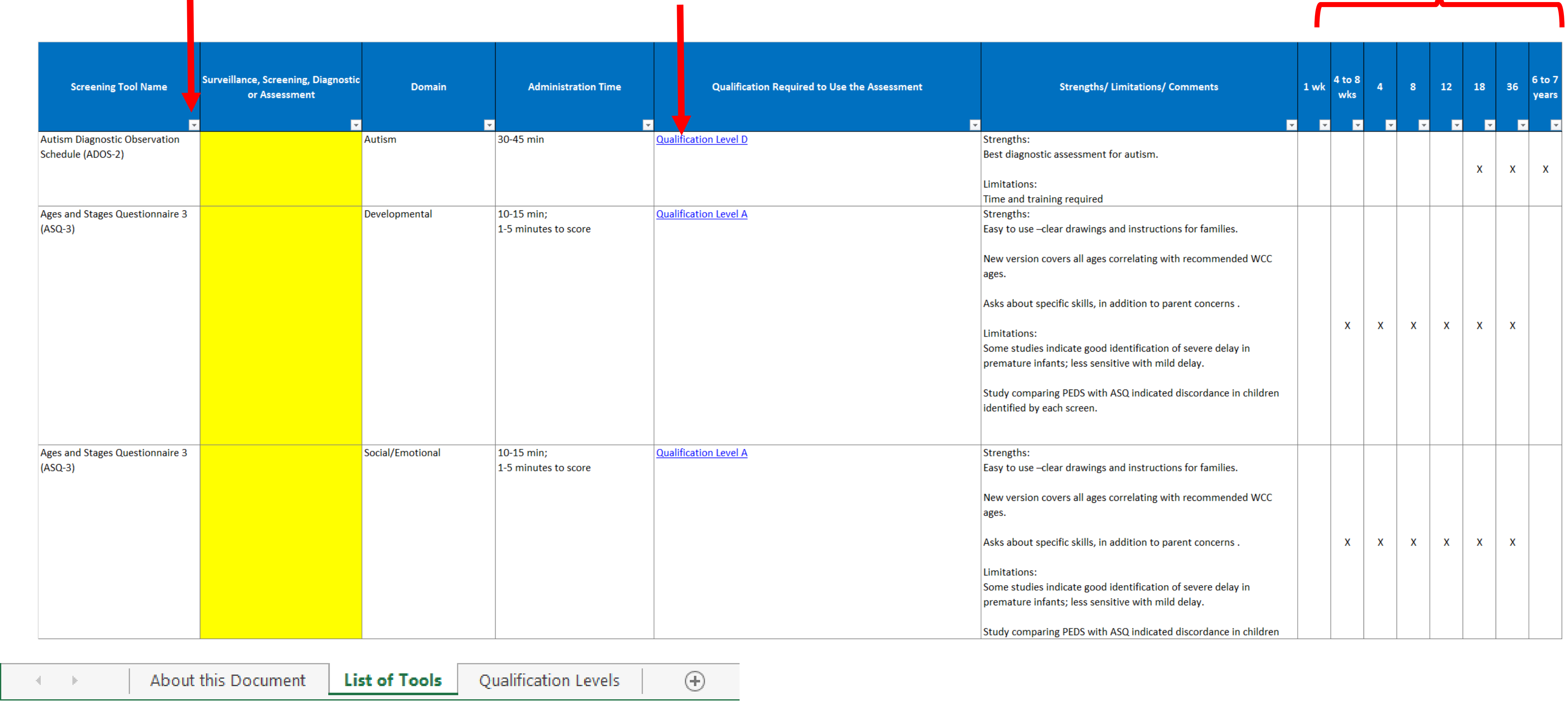
Identify what you want to test and what resources are available in your clinic. Use the list to select the tool that is suited to both criteria.

Example

Click on the arrow box above each column to sort the tools

Click on the link to see the required qualifications

Recommended visit schedule



Screening Tool Name	Surveillance, Screening, Diagnostic or Assessment	Domain	Administration Time	Qualification Required to Use the Assessment	Strengths/ Limitations/ Comments	1 wk	4 to 8 wks	4	8	12	18	36	6 to 7 years
Autism Diagnostic Observation Schedule (ADOS-2)		Autism	30-45 min	Qualification Level D	Strengths: Best diagnostic assessment for autism. Limitations: Time and training required						X	X	X
Ages and Stages Questionnaire 3 (ASQ-3)		Developmental	10-15 min; 1-5 minutes to score	Qualification Level A	Strengths: Easy to use –clear drawings and instructions for families. New version covers all ages correlating with recommended WCC ages. Asks about specific skills, in addition to parent concerns . Limitations: Some studies indicate good identification of severe delay in premature infants; less sensitive with mild delay. Study comparing PEDS with ASQ indicated discordance in children identified by each screen.		X	X	X	X	X	X	
Ages and Stages Questionnaire 3 (ASQ-3)		Social/Emotional	10-15 min; 1-5 minutes to score	Qualification Level A	Strengths: Easy to use –clear drawings and instructions for families. New version covers all ages correlating with recommended WCC ages. Asks about specific skills, in addition to parent concerns . Limitations: Some studies indicate good identification of severe delay in premature infants; less sensitive with mild delay. Study comparing PEDS with ASQ indicated discordance in children		X	X	X	X	X	X	

Click on a tab to view a different page

Tip: If you cannot see the full list of tools, ensure that you have not selected a filter option for any of the columns.

Post-Natal Screening Forms

About the Tool

A set of three mental health screening tools to screen for postpartum in mothers, and anxiety or depression in other caregivers.

- The ***Edinburgh Perinatal Depression Scale*** indicates how the mother has felt during the previous week. In doubtful cases it may be useful to repeat the tool after 2 weeks. The scale will not detect mothers with anxiety neuroses, phobias or personality disorders.
- The ***General Anxiety Disorder Scale (GAD-7)*** is a screening tool used to assess a client's general anxiety over a two week period.
- The ***Public Health Questionnaire-2 (PHQ-2)*** inquires about the frequency of depressed mood and anhedonia over the past two weeks.

The assessments are not meant to override clinical judgement and a careful clinical assessment should be carried out to confirm the diagnosis. Anyone who is identified as high risk should be referred to community resources as appropriate or referred for further assessment.

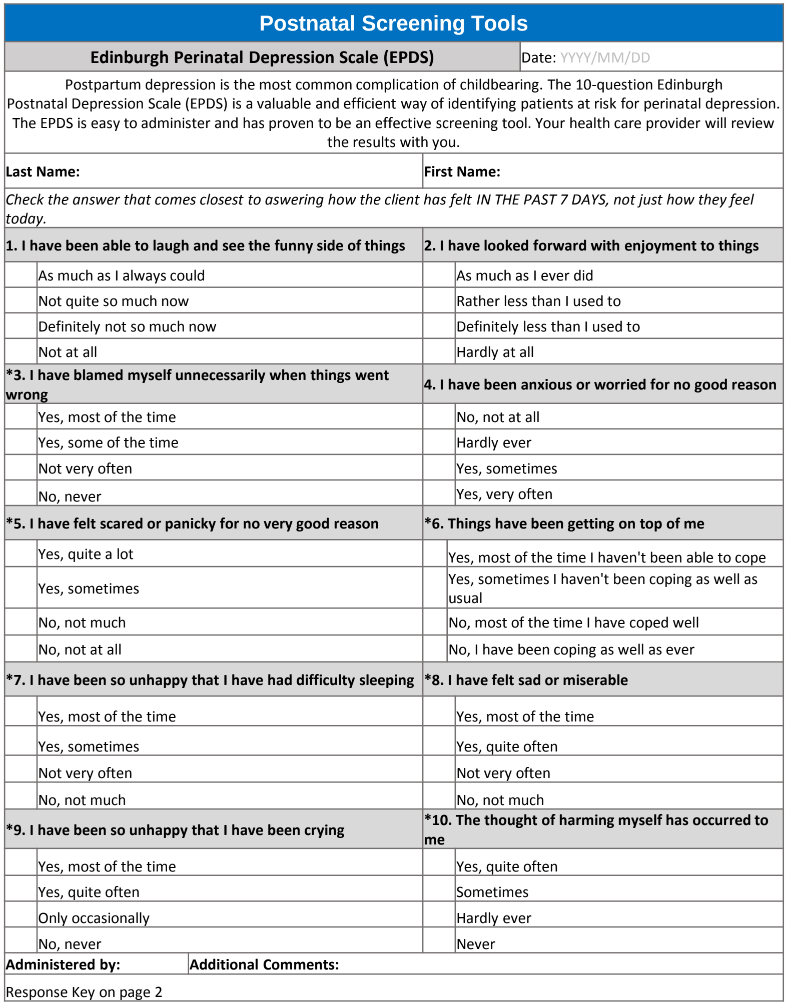
Purpose

To assist clinicians with screening parents and caregivers for mental health issues.

How to Use the Tool

1. These are self-reported tools. The mother/parent/caregiver is asked to check the response that comes closest to how she/he has been feeling.
2. All the items must be completed.
3. Answers should come from the mother/parent/caregiver.
4. The individual should complete the scale herself/himself, unless she/he has limited English or has difficulty with reading.
5. Refer to community or health services as appropriate.

Example



Postnatal Screening Tools

Edinburgh Perinatal Depression Scale (EPDS)	Date: YYYY/MM/DD

Postpartum depression is the most common complication of childbearing. The 10-question Edinburgh Postnatal Depression Scale (EPDS) is a valuable and efficient way of identifying patients at risk for perinatal depression. The EPDS is easy to administer and has proven to be an effective screening tool. Your health care provider will review the results with you.

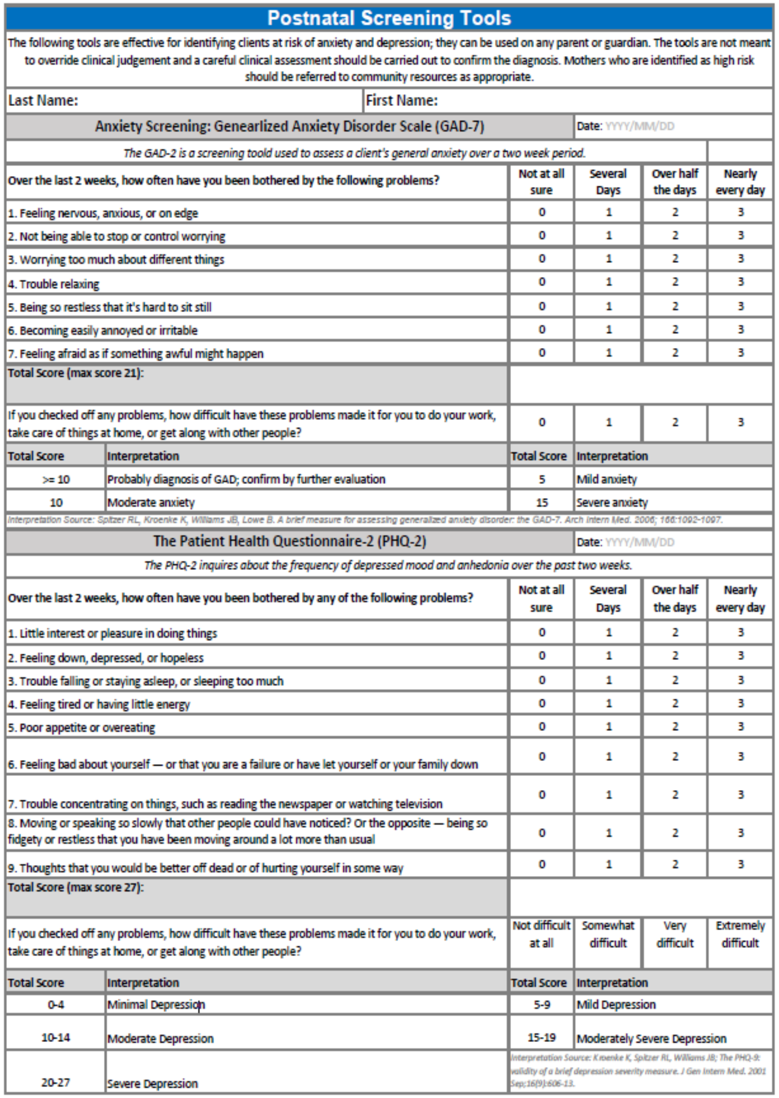
Last Name:	**First Name:**

Check the answer that comes closest to aswering how the client has felt IN THE PAST 7 DAYS, not just how they feel today.

1. I have been able to laugh and see the funny side of things		**2. I have looked forward with enjoyment to things**	
	As much as I always could		As much as I ever did
	Not quite so much now		Rather less than I used to
	Definitely not so much now		Definitely less than I used to
	Not at all		Hardly at all
***3. I have blamed myself unnecessarily when things went wrong**		**4. I have been anxious or worried for no good reason**	
	Yes, most of the time		No, not at all
	Yes, some of the time		Hardly ever
	Not very often		Yes, sometimes
	No, never		Yes, very often
***5. I have felt scared or panicky for no very good reason**		***6. Things have been getting on top of me**	
	Yes, quite a lot		Yes, most of the time I haven't been able to cope
	Yes, sometimes		Yes, sometimes I haven't been coping as well as usual
	No, not much		No, most of the time I have coped well
	No, not at all		No, I have been coping as well as ever
***7. I have been so unhappy that I have had difficulty sleeping**		***8. I have felt sad or miserable**	
	Yes, most of the time		Yes, most of the time
	Yes, sometimes		Yes, quite often
	Not very often		Not very often
	No, not much		No, not much
***9. I have been so unhappy that I have been crying**		***10. The thought of harming myself has occurred to me**	
	Yes, most of the time		Yes, quite often
	Yes, quite often		Sometimes
	Only occasionally		Hardly ever
	No, never		Never

Administered by:	**Additional Comments:**
Response Key on page 2	

Source: Cox, JL, holden, JM, Sagovsky, R (1987). Department of Psychiatry, University of Edinburgh.



Postnatal Screening Tools

The following tools are effective for identifying clients at risk of anxiety and depression; they can be used on any parent or guardian. The tools are not meant to override clinical judgement and a careful clinical assessment should be carried out to confirm the diagnosis. Mothers who are identified as high risk should be referred to community resources as appropriate.

Last Name:	First Name:

Anxiety Screening: Genearlized Anxiety Disorder Scale (GAD-7)	Date: YYYY/MM/DD

The GAD-2 is a screening toold used to assess a client's general anxiety over a two week period.

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several Days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Total Score (max score 21):				
If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	0	1	2	3

Total Score	Interpretation	Total Score	Interpretation
>= 10	Probably diagnosis of GAD; confirm by further evaluation	5	Mild anxiety
10	Moderate anxiety	15	Severe anxiety

Interpretation Source: Spitzer RL, Kroenke K, Williams JB, Lowe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006; 166:1092-1097.

The Patient Health Questionnaire-2 (PHQ-2)	Date: YYYY/MM/DD

The PHQ-2 inquires about the frequency of depressed mood and anhedonia over the past two weeks.

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all sure	Several Days	Over half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
Total Score (max score 27):				
If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult

Total Score	Interpretation	Total Score	Interpretation
0-4	Minimal Depression	5-9	Mild Depression
10-14	Moderate Depression	15-19	Moderately Severe Depression
20-27	Severe Depression	*Interpretation Source: Kroenke K, Spitzer RL, Williams JB; The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med. 2001 Sep;16(9):606-13.*	

Letter to Health Care Providers and Physicians

About the Tool

This letter is directed to community health care providers and physicians explaining the role of the NFUP and clinics.

Purpose

To make clinicians aware of the role of the NFUP, why it is important and how external providers can work with clinics to ensure that babies get proper, comprehensive care.

How to Use the Tool

Share the letter with any health provider or organization looking for more information about the NFUP.

Resources for Parents

About the Tools

Parents and families require access to information about the NFUP and their child's development in order to feel empowered to make the best possible decisions and participate in their child's care. To support them, an information package, brochure and visit schedule poster were developed. This information may be useful for parents in the NICU or when they first enter a NFUP.

Purpose

Information Package for Parents and Families	An informational booklet directed to parents and families to with answers to frequently asked questions about the NFUP and links to resources for key issues relevant to a baby's healthy development.
Brochure About the Neonatal Follow-Up Program	An informational brochure directed to parents and caregivers providing a brief summary of information regarding what the NFUP is, why it is important, the contact information of a family's clinic and space to write down details for a first appointment.
Visit Schedule Poster	A poster directed to parents and caregivers illustration the recommended visit schedule of the NFUP and some information on what to expect at each visit.

Provincial Council for Maternal and Child Health
555 University Ave
Toronto, ON
M5G 1X8

Telephone: (416) 813 – 8025
Fax: (416) 813 – 8026
Email: info@pcmch.on.ca