Neonatal hyperbilirubinemia – Severe (NHS3 2025—2027)

CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM
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REPORTING INFORMATION
(To be completed by the CPSP)

Report number:	
Month of reporting:	
Province:	
Today's date:	

Please complete the following sections for the case identified above. If the information asked for below is not readily available, please leave it blank. Strict confidentiality of information will be assured.

CASE DEFINITION FOR NEONATAL HYPERBILIRUBINEMIA – SEVERE (2025–2027)

Infants with unconjugated hyperbilirubinemia born at ≥ 35 weeks gestation and aged ≤ 60 days who have had either:
1) Peak serum total bilirubin >425 μmol/L
OR
2) Neonatal exchange transfusion

Exclusion criteria
Infants who have had exchange transfusion for documented Rh isoimmunization

SECTION 1 – PATIENT DEMOGRAPHIC INFORMATION

A) Infant

1.1 Month/year of birth: _____ /_______ (MM / YYYY)

1.2 Age at presentation with bilirubin >425 µmol/L: ______hours

1.3 Sex assigned at birth: ❍ Male ❍ Female ❍ Intersex ❍ Unknown

1.4 Province/territory of infant's birth: ____________________

1.5 Location of birth (Select ONE):

❍ Planned home birth
❍ Birthing centre
❍ Emergency birth outside of hospital
❍ Hospital where severe hyperbilirubinemia was diagnosed/managed
❍ Hospital other than where severe hyperbilirubinemia was initially diagnosed/managed
❍ Other, specify: _______________________________

1.6 Does the infant have provincial, territorial, or federal healthcare coverage? ❍ Yes ❍ No ❍ Unknown

1.6.1 If *No*, why? ❍ Still pending ❍ Parents are foreign residents/not Canadian residents ❍ Unknown

B) Mother

1.7 Mother's province/territory of residence: _________________________

1.8 Age at delivery: _______years

1.9 Does your institution collect patient- or family-identified race/ethnicity data (can be documented in antenatal care record, neonatal intensive care unit admission, or any part of intake)? ❍ Yes ❍ No ❍ Unknown

1.9.1 If *Yes,* which one of the following best describes the mother's self-identified population group? (Select ONE)

❍ Arab
❍ Japanese
❍ First Nations
❍ Southeast Asian (e.g., Vietnamese, Cambodian, Laotian)
❍ Black
❍ Korean
❍ Inuit
❍ South Asian (e.g., East Indian, Pakistani, Sri Lankan)
❍ Chinese
❍ Latin American
❍ Métis
❍ West Asian (e.g., Iranian, Afghan)
❍ Filipino
❍ White
❍ Unknown/did not ask
❍ Other, specify: ____________________

1.10 Gravida: _____ Para: _____

1.10.1 Number of abortions: _____ ❍ Unknown
1.10.2 Number of abortions that were spontaneous: _____ ❍ Unknown
1.10.3 Number of abortions that were therapeutic: _____ ❍ Unknown

1.11 Maternal hepatitis B surface antigen (HBsAg) status: ❍ Positive ❍ Negative ❍ Unknown

SECTION 2 – FAMILY HISTORY

2.1 Consanguinity: ❍ Yes ❍ No ❍ Unknown
 2.1.1 If *Yes*, specify: ___________________________

2.2 Previous early infant death(s): ❍ Yes ❍ No ❍ Unknown
 2.2.1 If *Yes*, specify reason(s): _____________________________________ ❍ Unknown

2.3 Previous sibling(s) with neonatal jaundice: ❍ Yes ❍ No ❍ Unknown
 2.3.1 If *Yes*, specify reason(s): _____________________________________ ❍ Unknown
 2.3.2 Treatment: Phototherapy: ❍ Yes ❍ No ❍ Unknown
 2.3.3 Treatment: Exchange transfusion: ❍ Yes ❍ No ❍ Unknown

2.4 Family history or previous sibling diagnosed with glucose-6-phosphate dehydrogenase (G6PD) deficiency: ❍ Yes ❍ No ❍ Unknown
 2.4.1 If *Yes*, specify the relationship to infant (e.g., sibling, cousin): ________________________
 2.4.2 G6PD quantitative levels: ❍ Average ❍ Low ❍ Very low ❍ Unknown

2.5 Other neonatal hemolytic disease: ❍ Yes ❍ No ❍ Unknown
 2.5.1 If *Yes*, specify sibling/family member: ___________________________

2.6 Was the mother born in Canada: ❍ Yes ❍ No ❍ Unknown
 2.6.1 If *No,* number of years since the mother immigrated to Canada: ___________years ❍ Unknown

2.7 Does the mother speak the language of the healthcare institution (English or French)? ❍ Yes ❍ No

SECTION 3 – MEDICAL HISTORY

3.1 Gestational age of infant at birth: ______weeks completed

3.2 Type of delivery: ❍ Vaginal ❍ Instrumental – Forceps ❍ Vacuum ❍ Caesarean section

3.3 APGAR score at: 1 minute: _______ 5 minutes: _______ 10 minutes: _______

3.4 Birth weight: _______grams Length: _______cm Head circumference: _______cm

3.5 Feeding (Select all that apply): ❑ Breast ❑ Bottle ❑ NPO (nothing by mouth)

3.6 Readmission: ❍ Yes ❍ No ❍ Unknown
 3.6.1 If *Yes*: Age at readmission: _______hours
 Weight at readmission: _______grams

3.7 Neurological signs:

	Yes	No	Unknown		Yes	No	Unknown
Poor sucking	❍	❍	❍	Arching of neck (retrocollis)	❍	❍	❍
Arching of back (opisthotonus)	❍	❍	❍	Increased muscle tone	❍	❍	❍
Decreased muscle tone	❍	❍	❍	Seizures	❍	❍	❍

 Level of consciousness: ❍ Unconscious ❍ Sleeping ❍ Lethargic ❍ Normal

3.8 Medication exposure of the infant: ❍ Yes ❍ No ❍ Unknown
 3.8.1 If *Yes,* indicate mode of exposure: ❍ In utero ❍ Breast milk ❍ Other, specify: ____________ ❍ Unknown
 3.8.2 If *Yes*, indicate name of medication(s): _________________ ❍ Unknown

3.9 Medication exposure of the mother (prenatally and inter-partum): ❍ Yes ❍ No ❍ Unknown
 3.9.1 If *Yes,* indicate which trimester gestation: ❍ First trimester ❍ Second trimester ❍ Third trimester ❍ Unknown

3.10 Infection in the neonatal period: ❍ Yes ❍ No ❍ Unknown
 3.10.1 If *Yes*, specify infection type: _________________________

SECTION 4 – LABORATORY DATA AT PRESENTATION OF CONDITION

4.1 Maternal blood group: ABO: ____ Rh: ____ Maternal antibodies: ________

4.2 Infant blood group: ABO: ____ Rh: ____ Coombs: Direct: ____ Indirect: ____

4.3 Hemoglobin (HB): _____ Hematocrit (HCT): _____ White blood cell (WBC): _____ Platelets: ______
 Smear: _______________________ Serum sodium: _____
 Blood urea nitrogen (BUN): _____ Creatinine: _____

4.4 Total bilirubin levels:

Clinical event or test	Test performed	Total bilirubin level (µmol/L)	Age (hours)
Bilirubin level obtained in the first 24 hours after birth	❍ Yes ❍ No ❍ Unknown ❍ Not applicable		
Peak bilirubin before any hyperbilirubinemia therapy e.g., phototherapy, exchange transfusion, IVIG	❍ Yes ❍ No ❍ Unknown ❍ Not applicable		
Bilirubin immediately before phototherapy started	❍ Yes ❍ No ❍ Unknown ❍ Not applicable		
Bilirubin immediately before exchange transfusion started	❍ Yes ❍ No ❍ Unknown ❍ Not applicable		
Bilirubin immediately before IVIG started	❍ Yes ❍ No ❍ Unknown ❍ Not applicable		

4.4.1 Does your institution have a policy on bilirubin testing? ❍ Yes ❍ No ❍ Unknown

4.5 G6PD results: ❍ Positive ❍ Negative ❍ Unknown ❍ Not performed
4.5.1 If *Positive*, quantitative level: ❍ Average ❍ Low ❍ Very Low

4.6 Osmotic fragility: ❍ Yes ❍ No ❍ Unknown ❍ Not performed
4.6.1 If *Yes*: ❍ Normal ❍ Abnormal

4.7 Which guidelines for the management of hyperbilirubinemia do you follow? (Select ONE)
❍ 2007 Canadian Paediatric Society (CPS) guidelines ❍ 2025 adapted CPS guidelines (anticipated spring 2025)
❍ 2004 American Academy of Pediatrics (AAP) guidelines ❍ 2022 adapted AAP guidelines
❍ Other, specify: ___________________________

SECTION 5 – TREATMENT AND OUTCOME

5.1 Age at phototherapy initiation: ______hours Phototherapy duration: ______hours
5.2 Exchange transfusion: ❍ Yes ❍ No ❍ Unknown
5.2.1 If *Yes,* age at initiation of exchange transfusion: ______hours
5.3 IVIG administration: ❍ Yes ❍ No ❍ Unknown
5.4 Other transfusions: ❍ Yes ❍ No ❍ Unknown
5.5 Seizures: ❍ Yes ❍ No ❍ Unknown
5.6 Infant status: ❍ Still in hospital ❍ Discharged home ❍ Died ❍ Transferred to another centre
5.6.1 If the infant *Died*: Age at death: _______hours
5.6.2 Cause of death: ____ ❍ Unknown
5.6.3 Autopsy report: ❍ Yes ❍ No ❍ Pending
5.7 Neurological status at discharge/current status if still in the hospital: (Select all that apply)
❑ Normal ❑ Unknown ❑ Hearing loss ❑ Vision loss ❑ Motor impairment ❑ Seizures
5.8 Brain MRI completed: ❍ Yes ❍ No ❍ Unknown
5.8.1 If *Yes*, basal ganglia changes consistent with bilirubin encephalopathy: ❍ Yes ❍ No
5.8.2 Other findings: ____

SECTION 6 – FURTHER INFORMATION

6.1 Are you willing to be contacted by the Canadian Paediatric Surveillance Program (CPSP) for further information on this questionnaire? ❍ Yes ❍ No

SECTION 7 – REPORTING PHYSICIAN

7.1 What is your practice setting? (Select all that apply):

a) ❑ Urban ❑ Suburban ❑ Rural/Remote	b) ❑ Academic ❑ Non-academic	c) ❑ Tertiary hospital ❑ Community hospital ❑ Other, specify: ________________________

First name________________________________ Surname____

Address____

City______________________________________ Province___________________________ Postal code______________

Telephone number______________________________________ Fax number____________________________________

E-mail____ Date completed_________________________________

Thank you for completing this form.