

PREGNANCY & **CHILDBIRTH DATA COLLECTION REFERENCE GUIDE**

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We are thrilled that you are interested in measuring outcomes for women during Pregnancy & Childbirth according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

© 2016 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more standard outcome sets.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Standard Sets, comprehensive yet parsimonious sets of outcomes and case-mix variables we recommend all providers track.

Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary is included in the appendix.

Working Group Members for Pregnancy and Childbirth

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Pregnancy & Childbirth in partnership with ICHOM and under the leadership of Dr. Arie Franx, Professor of Obstetrics and the Division President and Medical Manager of the Division of Women and Babies at the University Medical Center, Utrecht.

Austra	

Tessa Kowaliw Rod Petersen

Italy

Anna Maria Speciale

Malaysia

J Ravichandran R Jeganathan Shamala Devi Karalasingam

Netherlands

Gouke Bonsel Arie Franx Floris Groenendaal Irwin Reiss Marije Lamain-de Ruiter

South Africa

Stefan Gebhardt

Sweden

Isis Amer-Wahlin

United Kingdom

Matthew Coleman James Duffy

United States

Allyson Brooks
Tracy Flanagan
Meridith Greene
Elliott Main
Marlin Mills
Malini Nijagal
Michelle Owens
Carol Sakala
Rachel Thompson

Supporting Organizations

The Pregnancy & Childbirth Standard Set is made possible through the support of the following sponsors:

Thank you.









Conditions Covered for Pregnancy & Childbirth

We developed this set with the aim of measuring the outcomes that matter most to women during pregnancy and childbirth. However, we recognize the significant practical constraints on doing so given the variety of care providers and settings in which women seek care throughout this care cycle and the variety of interventions and management options available. Therefore, the set was designed to provide valid and beneficial outcomes data for a wide range of interventions and care settings.

The Pregnancy & Childbirth Standard Set includes outcomes to evaluate maternity care for all women during pregnancy, labor and delivery, and up to six month postpartum. The Standard Set also includes a list of case-mix factors to allow for comparisons of outcomes across this broad patient population.

Conditions All women during: Pregnancy Labor and delivery Up to six months postpartum	
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ICHOM Standard Set for Pregnancy & Childbirth

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Demographic Factor	S			
	Age	Age at delivery	42 days postpartum	Administrative data
All women	Education level	Level of education completed		
All women	Race/ethnicity	Race/ethnicity as defined locally	Entry to Patient-repor prenatal care	
	Social Support	Assessed with the SIMSS		
Obstetric and Medic	al History			
	Parity	Parity greater than o		
All women	Obstetric history	History of pre-term birth, hemorrhage, cesarean delivery or stillbirth	Entry to prenatal care	Patient-reported
	Medical history	Diagnosis of diabetes, hypertension or a mental health condition prior to pregnancy		
	Multiple gestations	Number of gestations in current pregnancy		
	Body height	Height	_	
	Body weight	Weight prior to pregnancy		
	Substance use	Tobacco use during pregnancy or substance use complicating the puerperium	42 days	Administrative
	Congenital anomaly	Diagnosis of a congenital anomaly within 28 days of birth	postpartum	data

Treatment Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
All women	Facility type	Type of facility at which birth occurred	42 days	Administrative
	Route of delivery	Type of delivery	postpartum –	data

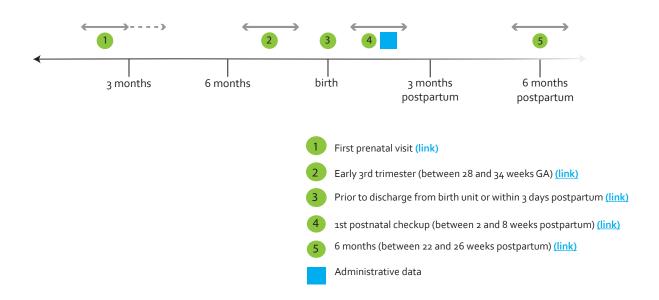
Outcomes

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Survival				
All women	Maternal death Still birth Neonatal death	WHO definition	42 days postpartum	Administrative data
Severe Maternal Mo				
	Maternal need for intensive care	ICU admission	1.2 days nostnartum	
	Maternal length of stay	Number of consecutive days in the hospital from delivery to discharge		
All women	Late maternal complication	Admission or re-admission within the first 42 days postpartum for childbirth related complications		Administrative data
	Transfusion	Any transfusion of red blood cells within the first 42 days postpartum		
Neonatal Morbidity				
All women	Spontaneous pre- term birth	Live birth at <37+ o weeks gestation occurring after spontaneous labor or rupture of membranes	– 42 days postpartum Administr data	Administrative
	latrogenic pre- term birth	Cesarean or labor induction before <37 weeks + o gestation excluding those occurring after spontaneous labor or rupture of membranes		
	Oxygen dependence	Administration of O2 by any route for greater than 24 hours through 28 days of life		data
	Neonate length of stay	Number of consecutive days in hospital from birth through 28 days of life		
	Birth injury	As defined by the California Maternal Quality Care Collaborative		
Patient-reported hea				
	Health related quality of life	Tracked via the PROMIS Global10	Entry to prenatal care 3rd trimester	
All women	Incontinence	Tracked via either the ICIQ- SF or Wexner	Postpartum check-up 6 months postpartum	Patient- - reported
	Pain with intercourse	Tracked via PROMIS SFFAC102	Entry to prenatal care Postpartum check-up 6 months postpartum	reported

Breastfeeding				
All women	Success with breastfeeding	Exclusive or partial breastfeeding	Birth Postpartum check-up 6 months postpartum	Patient-
	Confidence with breastfeeding	Option to track via the BSES-SF	3 rd trimester Birth Postpartum check-up	reported
Role Transition				
	Mother-infant attachment	Tracked via the MIBS	Birth Postpartum check-up	- Patient-
All women	Confidence with role as a mother	Woman's confidence in caring for her baby	Entry to prenatal care Postpartum check-up 6 months postpartum	reported
Mental Health				
All women	Postpartum depression	Assessed via the PHQ-2 with	Entry to prenatal care 3rd trimester Postpartum check-up 6 months postpartum	Patient- reported
		Optional follow-up with the EPDS	Postpartum check-up 6 months postpartum	
Satisfaction with car	e			
All women	Satisfaction with the results of care	N/A	3rd trimester Postpartum check-up 6 months postpartum	Patient- reported
Healthcare responsive	veness			
All women	Confidence as an active participant in healthcare decisions Confidence in healthcare providers	N/A	3rd trimester Postpartum check-up 6 months postpartum	Patient- reported
Birth experience	p. 0 114 C13			
All women	Birth experience	Assessed via the BSS_R	Postpartum check-up	Patient- reported

Follow-Up Timeline and Sample Questionnaires

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample patient questionnaires may be found in the legend below.



As presented above, data is collected either via patient-report or abstracted from administrative record. In cases in which there is no administrative record of events, data can be collected from a clinician attending the birth.

Data collection begins when a woman enters prenatal care. In many cases this is within the first trimester but may be considerably later in some care systems. If entry to prenatal care occurs close to or within the 3rd trimester, we recommend combining time points 1 and 2. In the case of a loss or termination of the pregnancy prior to 20 weeks but after the beginning of data collection, no further data collection should be pursued.

With the exception of time point 5 and collection of administrative data, the collection of all patient-reported data is timed to coincide with standard points at which women present for care. As some of the data collect from women at these times is clinically relevant, we recommend that women complete the patient-reported surveys prior presenting for care. Patient-portals or ePROM tools are ideal for this kind of data collection. Data can also be collected via pen and paper at the office prior to being seen.

Finally, we recognize that collection of data across the range of time points above will often require a coordinated effort between distinct care providers. Due to structural differences across care systems, we leave it to each implementing organization to determine how best to structure this coordinated effort.

Collecting Patient-Reported Outcome Measures

Survey(s) Used	Licensing Information	Scoring Guide
PROMIS-10 and PROMIS item bank questions	Free for use in clinical practice and a license is not required. Information about available translations can be found here: http://www.nihpromis.org/measures/translations	The scoring guide for the PROMIS-10 can be found at: https://www.assessmentcenter.net/documents/Scoring%20 PROMIS%20Global%20short%20 form.pdf Please see the Assessment Center for information on individual item bank items.
International Consultation on Incontinence Questionnaire - Urinary Incontinence Short Form (ICIQ-UI SF)	Free for use in clinical practice, routine outcomes measurement, and clinical research but requires permission for use from the developer. Please visit the following webpage to obtain persmission and an official copy of the instrument or to inquire about translations: http://www.iciq.net/userpolicy.html	Please visit the following webpage to obtain a scoring guide: http://www.iciq.net/userpolicy.html
Wexner	Free for use. No license is required.	Please see Table 2 of Vaizey et al. (1999) Prospective comparison of faecal incontinence grading systems. Gut 44:77-80.
Breastfeeding Self-Efficacy Scale - Short Form (BSES-SF)	Free for use in clinical practice, routine outcomes measurement, and clinical research but requires permission from the developer. Please contact Dr. Cindy-Lee Dennis (cindylee.dennis@utoronto.ca) to obtain persmission and an official copy of the instrument or to inquire about translations.	Please see Dennis, C-L. (2003) The Breastfeeding Self-Efficacy Scale: Psychometric assessment of the short form. Journal of Obstetric, Gynecologic, and Neonatal Nursing, 32, 734-744. More information on this instrument can be found at: http://www.cindyleedennis.ca/research/#1-breastfeeding
Mother-to-Infant Bonding Scale (MIBS)	Free for use in clinical practice, routine outcomes measurement, and clinical research but requires permission from the developer. Please contact Dr. Alyx Taylor (alyx.taylor@kcl.ac.uk) to obtain persmission and an official copy of the instrument or to inquire about translations.	The complete scoring guide as well as information on clinical interpretation can be found at: http://www.ncbi.nlm.nih.gov/pubmed/15868385
Patient Health Questionnaire-2 (PHQ-2)	Free for use. No license is required.	Scoring and clinical interpretation can be found at: http://www.cqaimh.org/pdf/tool_phq2.pdf

Edinburgh Postnatal Depression Scale (EPDS)	Free for use. No license is required. Users may reproduce the scale without permissions provided they repect copyright (which remains with the British Journal of Psychiatry) by quoting the names of the authors, the title and the source of the paper in all reproduced copies.	The scoring guide and clinical interpretation can be found in Cox JL et al (1987) Detection of postnatal depression development of the 10-item Edinburgh Postnatal Depression Scale.
Birth Satisfaction Scale - Revised (BSS-R)	Free for use in clinical practice, routine outcomes measurement, and clinical research but requires permission from the developer. Please contact Prof Caroline J. Hollins Martin (c.hollinsmartin@ napier.ac.uk) to obtain persmission and an official copy of the instrument or to inquire about translations.	Scoring and interpretation are published in Hollins Martin CJ et al (2014) Development and psychometric properties of the Birth Satisfaction Scale - Revised (BSS-R). Midwifery 30: 610-619

The Growing ICHOM Community

By implementing the ICHOM Standard Sets, you become part of an expanding, international community of innovative health care providers dedicated to improving value for patients. To learn more about how ICHOM can assist your organization in implementing outcome measurement, contact us at implement@ichom.org, or visit http://www.ichom.org/measure.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Pregnancy and Childbirth Standard Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. We are happy to provide an Excel version of this data dictionary for technical use.

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

Variable ID: N/A CASE-MIX VARIABLES

Variable: Patient ID

Definition: Indicate the patient's medical record number

Supporting Definition: This number will not be shared with ICHOM. In the case patient-level data is

submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating

institution.

Inclusion Criteria: All women

Timing: On all forms

Reporting Source: Administrative or clinical

Type: Numerical

Response Options: According to institution

Demographic

Variable ID: AGE Variable: Age

Definition: Age at time of delivery

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Numerical

Response Options: Numerical value

Variable ID: EDUCATION
Variable: Education level

Definition: Please indicated the highest level of schooling completed.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Single answer

Response Options o = None

1 = Primary 2 = Secondary 3 = Tertiary (university or equivalent)

Variable ID: RACE_ETHNIC Variable: Race/ethnicity

Definition: Varies by country and should be determined by country (not for cross country

comparison)

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care
Reporting Source: Patient-reported

Type: Single answer

Response Options: N/A

Variable ID: SIMSS

Variable: Social Support

Definition: How many people do you have near you that you can readily count on for help in

time of difficulty such as to watch over children or pets, give rides to the hospital or

store, or help when you are sick?

Supporting Definition: The SIMSS

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Single answer

Response Options: o = o

1 = 1 2 = 2 - 5 3 = 6 - 10

Obstetric and medical history

Variable ID: PARITY Variable: Parity

Definition: Have you given birth before? This includes both vaginal births and Cesarean

sections (operations to remove your baby from your abdomen). Please do not count miscarriages or births that happened before 20 weeks (5 months) of

pregnancy.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Single answer

Response Options: o = No

1 = Yes

Variable ID: OBHX

Variable: Obstetric history

Definition: If you have been pregnant before, have you experienced any of the following in

previous pregnancies? Please mark all that apply.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Multiple answers

Response Options: o = This is my first pregnancy

1 = A baby born early, more than 3 weeks before his or her due date

2 = Bleeding so much during pregnancy, birth, or after giving birth that you needed

to be given blood

3 = A cesarean section (operation to remove your baby through your abdomen)

4 = Loss of a pregnancy after 20 weeks (5 months) of pregnancy

Variable ID: MEDHX
Variable: Medical history

Definition: BEFORE you got pregnant, did a doctor, nurse, or other health worker tell you that

you had any of the following health conditions? Please mark all that apply.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Multiple answers

Response Options: o = None

1 = Diabetes

2 = High blood pressure or hypertension

3 = A mental health disorder such as depression, anxiety, bipolar disorder or

schizophrenia

Variable ID: MULTGEST

Variable: Multiple gestations **Definition:** Are you pregnant with:

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = One baby

2 = Two babies (twins)

3 = Three or more babies (triplets or higher)

Variable ID: HEIGHT
Variable: Body height
Definition: How tall are you?

Supporting Definition: Indicate height in centimeters or inches. Also indicate units of height. Height and

weight are used to calculate BMI.

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Numeric value

Response Options: Numeric value of height in metric or imperial system

Variable ID: HEIGHTUNIT
Variable: Body height units
Definition: Height units

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = centimeters

2 = inches

Variable ID: WEIGHT
Variable: Body weight

Definition: How much did you weigh IMMEDIATELY before your pregnancy?

Supporting Definition: Indicate weight in kilograms or pounds. Also indicate units of weight. Height and

weight are used to calculate BMI.

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Numeric value

Response Options: Numeric value of weight in metric or imperial system

Variable ID: WEIGHTUNIT
Variable: Body weight units
Definition: Weight units

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = kilograms

2 = pounds

Variable ID: SUBUSETOB

Variable: Substance use tobacco

Definition: Tobacco use during pregnancy

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Options: o = No

1 = Yes

Variable ID: SUBUSEDRUG
Variable: Substance use drug

Definition: Drug use complicating the puerperium

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Options: o = No

1 = Yes

Variable ID: SUBUSEALC

Variable: Substance use alcohol

Definition: Alcohol use complicating the puerperium

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Options: o = No

1 = Yes

Variable: CONANOMALY
Variable: Congenital anomaly

Definition: Diagnosis of a neonate with any of the following within 28 days of birth:

Anencephaly, Spina bifida occulta, Meningo(myelo)cele,

Hydrocephaly/holoprosencephaly without neural tube defect, Encephalocele, Neuromuscular abnormalities, Transposition of the great arteries, Tetralogy of

Fallot, Hypoplastic left heart, Coarctation of the aorta, Complex cardiac malformation, Choanal atresia, Congenital malformation trachea, Lung hypoplasia, Hydro/Chylothorax, Congenital diaphragmatic hernia, Extrophia vesicase, Bilateral renal agenesis, Gastroschisis, Omphalocele, Trisomy 13, Trisomy

To The Control of the

18, Trisomy 21, Congenital malignancy, Other

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Options: o = No

ı = Yes

Treatment Variables

Treatment variables

Variable ID: FACTYPE
Variable: Facility type

Definition: Indicate where the birth took place: **Supporting Definition:** Using local NICU level definitions

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Options: o = Birth at home or birth center

1 = Birth at a hospital with a level 1 or 2 NICU2 = Birth at a hospital with a level 3 NICU or higher

Variable ID: DEVTYPE

Variable: Route of delivery

Definition: Indicate the route of birth:

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Options: o = Spontaneous vaginal delivery

1 = Forceps or vacuum vaginal delivery

2 = Delivery by cesarean section

Outcomes

Survival

Variable ID: MATERNALDEATH
Variable: Maternal death

Definition: Death of a female from any cause related to or aggravated by pregnancy or its

management (excluding accidental or incidental causes) during pregnancy and childbirth or within 42 days of pregnancy termination, irrespective of site or

duration of the pregnancy*

Supporting Definition: *This outcome should be tracked by all providers but will not be used for

comparisons between providers or provider organizations

Inclusion Criteria: All women

Timing: 42 days postpartum **Reporting Source:** Administrative

Type: Date

Response Options: DD/MM/YYYY

Variable ID: STILLBIRTH Variable: Stillbirth

Definition: Pregnancy loss at or after 28+0 weeks gestation or a birthweight of greater or

equal to 1000 grams

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Date

Response Options: DD/MM/YYYY

Variable: NEODEATH
Variable: Neonatal death

Definition: Death of a live born neonate up to 28 days of life

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum **Reporting Source:** Administrative

Type: Date

Response Options: DD/MM/YYYY

Severe maternal morbidity

Variable ID: ICUADMIT

Variable: Maternal need for intensive care

Definition: Admission to an ICU or a unit that provides 24-hour medical supervision and is able

to provide mechanical ventilation or continuous vasoactive drug support at any point during pregnancy through 42 days postpartum for pregnancy or childbirth

related complications.

OR

Transfer to another facility for intensive care.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single answer

Response Option: o = No

1 = Yes

Variable ID: MLOS

Variable: Maternal length of stay

Definition: Number of consecutive days in the hospital from delivery to discharge

Supporting Definition: Recorded as date of delivery and date of discharge

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Date

Response Options: DD/MM/YYYY delivery

DD/MM/YYYY discharge

Variable ID: READMIT

Variable: Late maternal complication

Definition: Admission to a hospital within the first 42 days postpartum for childbirth related

complications.*

Supporting Definition: *Excludes initial hospitalization for childbirth

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single Answer

Response Options: o = No

1 = Yes

Variable ID: TRANS

Variable: Transfusion

Definition: Any transfusion of red blood cells within the first 42 days postpartum

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single Answer

Response Options: o = No

1 = Yes

Neonatal morbidity

Variable ID: SPRETERM

Variable: Spontaneous pre-term birth

Definition: Live birth at <37+ o weeks gestation occurring after spontaneous labor or rupture

of membranes

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Date

Response Options: DD/MM/YYYY

Variable ID: IPRETERM

Variable: latrogenic pre-term birth

Definition: Cesarean or labor induction betfore <37+ o weeks gestation excluding those

occurring after spontaneous labor or rupture of membranes

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single Answer

Response Options: o = No

1 = Yes

Variable ID: OXYGEN

Variable: Oxygen dependence

Definition: Administration of O₂ by any route for greater than 24 hours at any point during

the first 28 days of life

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single Answer

Response Options: o = No

1 = Yes

Variable ID: NLOS

Variable: Neonate length of stay

Definition: Number of consecutive days in hospital from birth through 28 days of life

Supporting Definition: Recorded as date of birth and date of discharge

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Date

Response Options: DD/MM/YYYY birth

DD/MM/YYYY discharge

Variable ID: BIRTHINJ Variable: Birth injury

Definition: Subdural and cerebral hemorrhage, massive epicranial subaponeurotic

hemorrhage, other injuries to skeleton due to birth trauma, injury to spine and spinal cord due to birth trauma, injury to brachial plexus due to birth trauma, other cranial and peripheral nerve injuries due to birth trauma in single liveborn neonates

Supporting Definition: Record of ICD 10 codes P10 - P14

Inclusion Criteria: All women

Timing: 42 days postpartum

Reporting Source: Administrative

Type: Single Answer

Response Options: o = No

1 = Yes

Patient-reported health status

Variable ID: Globalo1

Variable: Question 1 of PROMIS-10 **Definition:** In the past few weeks...

In general, would you say your health is:...

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: Globalo2

Variable: Question 2 of PROMIS-10

Definition: In the past few weeks...

In general, would you say your quality of life is:...

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: Globalo3

Variable: Question 3 of PROMIS-10 **Definition:** In the past few weeks...

In general, how would you rate your physical health?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: Globalo4

Variable: Question 4 of PROMIS-10 **Definition:** In the past few weeks...

In general, how would you rate your mental health, including your mood and your

ability to think?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: Globalo5

Variable: Question 5 of PROMIS-10 **Definition:** In the past few weeks...

In general, how would you rate your satisfaction with your social activities and

relationships?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair

1 = Poor

Variable ID: Globalo6

Variable: Question 6 of PROMIS-10 **Definition:** In the past few weeks...

In general, please rate how well you carry out your usual social activities and roles.

(This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc).

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: Globalo7

Variable: Question 7 of PROMIS-10 **Definition:** In the past few weeks...

To what extent are you able to carry out your everyday physical activities such as

walking, climbing stairs, carrying groceries, or moving a chair?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 5 = Completely

4= Mostly 3 = Moderately 2 = A little 1 = Not at all

Variable ID: Globalo8

Variable: Question 8 of PROMIS-10

Definition: In the past 7 days...

How often have you been bothered by emotional problems such as feeling anxious,

depressed or irritable?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always Variable ID: Globalo9

Variable: Question 9 of PROMIS-10

Definition: In the past 7 days...

How would you rate your fatigue on average?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = None

2 = Mild 3 = Moderate 4 = Severe 5 = Very severe

Variable ID: Global10

Variable: Question 10 of PROMIS-10

Definition: How would you rate your pain on average?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No pain

1 = 1 2 = 2

3 = 3

4 = 4

5 = 5

6 = 6

7 = 7

8 = 8

9 = 9

10 = Worst imaginable pain

Variable ID: INCONTSCREEN

Variable: Incontinence screening question

Definition: In the past month, have you leaked urine, leaked stool or passed gas by accident?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Yes, I leaked urine

2 = Yes, I leaked stool or passed gas by accident

3 = No, I did not leak urine, leak stool, or pass gas by accident

Variable ID: Ulo1*

Variable: Question 1 of the ICIQ-SF **Definition:** How often do you leak urine?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 1 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = never

1 = about once a week or less often2 = two or three times a week

3 = about once a day 4 = several time a day 5 = all the time

Variable ID: Ulo2*

Variable: Question 2 of the ICIQ-SF

Definition: We would like to know how much urine you think leaks. How much urine do you

usually leak (whether you wear protection or not)?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 1 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = none

2 = a small amount4 = a moderate amount6 = a large amount

Variable ID: Ulo3*

Variable: Question 3 of the ICIQ-SF

Definition: Overall, how much does leaking urine interfere with your everyday life? Please

select a number between o (not at all) and 10 (a great deal).

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 1 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single answer

Response Options: o = Not at all

10 = A great deal

Variable ID: Ulo4*

Variable: Question 4 of the ICIQ-SF

Definition: When does urine leak?(Please tick all that apply to you).

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 1 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Never - urine does not leak

1 = Leaks before you can get to the toilet
2 = Leaks when you cough or sneeze
3 = Leaks when you are asleep

4 = Leaks when you are physically active/exercising

5 = Leaks when you have finished urinating and are dressed

6 = Leaks for no obvious reason

7 = Leaks all the time

Variable ID: Alo1*

Variable: Question 1 of Wexner

Definition: How often do you have accidents to solid, well-formed stool?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 2 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Never

1 = Less than once per month

2 = Less than once/week & greater than once/month3 = Less than once/day & greater than once/month

4 = Once a day or more than once a day

Variable ID: Alo2*

Variable: Question 2 of Wexner

Definition: How often do you have accidents to liquid stool/diarrhea?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 2 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Never

1 = Less than once per month

2 = Less than once/week & greater than once/month3 = Less than once/day & greater than once/month

4 = Once a day or more than once a day

Variable ID: Alo3*

Variable: Question 3 of Wexner

Definition: How often does the gas escape without your knowledge or control?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 2 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Never

1 = Less than once per month

2 = Less than once/week & greater than once/month3 = Less than once/day & greater than once/month

4 = Once a day or more than once a day

Variable ID: Alo4*

Variable: Question 4 of Wexner

Definition: How often do you wear a pad/depends or change underwear?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 2 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Never

1 = Less than once per month

2 = Less than once/week & greater than once/month3 = Less than once/day & greater than once/month

4 = Once a day or more than once a day

Variable ID: Alo5*

Variable: Question 5 of Wexner

Definition: How much do the above answers alter your lifestyle or activities?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 2 on INCONTSCREEN

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Never

1 = Less than once per month

2 = Less than once/week & greater than once/month3 = Less than once/day & greater than once/month

4 = Once a day or more than once a day

Variable ID: PROMIS_SFFAC102
Variable: Pain with intercourse

Definition: In the past 30 days, how much has pain affected your satisfaction with your sex

life?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Have not had pain in the past 30 days

1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Breastfeeding

Variable ID: BFINTENT

Variable: Intension to breast feed

Definition: Do you plan to breastfeed your baby when he or she is born?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 3rd trimester

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No

1 = Yes

Variable ID: BFCONFID

Variable: Confidence with breast feeding*

Definition: How confident do you feel about breast feeding?

Supporting Definition: N/A

Inclusion Criteria: *women scoring a 1 on BFINTENT in 3rd trimester OR 1 or 2 on BFSUCCESS at

birth, postpartum check-up, or 6 month postpartum

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Somewhat confident

4 = Confident 5 = Very confident

Variable ID: BFSUCCESS

Variable: Success with breastfeeding

Definition: Please indicate how you are feeding your baby:

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Birth

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = My baby has received only breast milk in the past 7 days.

2 = My baby has received a combination of breast milk, formula, or water in the

past 7 days.

3 = My baby has received only formula, water, or other liquids but not breast milk

in the past 7 days.

Variable ID: BSESo1*

Variable: Question 1 of BSES-SF

Definition: I can always determine that my baby is getting enough milk.

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident 3 = Sometimes confident

4 = Confident

5 = Very confident

Variable ID: BSES02*

Variable: Question 2 of BSES-SF

Definition: I can always successfully cope with breastfeeding like I have with other challenging

tasks.

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident 5 = Very confident

Variable ID: BSESo3*

Variable: Question 3 of BSES-SF

Definition: I can always breastfeed my baby without using formula as a supplement.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident5 = Very confident

Variable ID: BSESo4*

Variable: Question 4 of BSES-SF

Definition: I can always ensure that my baby is properly latched on for the whole feeding.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident
5 = Very confident

Variable ID: BSESo5*

Variable: Question 5 of BSES-SF

Definition: I can always manage the breastfeeding situation to my satisfaction.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident 5 = Very confident

Variable ID: BSESo6*

Variable: Question 6 of BSES-SF

Definition: I can always manage to breastfeed even if my baby is crying.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident 5 = Very confident

Variable ID: BSESo7*

Variable: Question 7 of BSES-SF

Definition: I can always keep wanting to breastfeed.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident
5 = Very confident

Variable ID: BSESo8*

Variable: Question 8 of BSES-SF

Definition: I can always comfortably breastfeed with my family members present.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident5 = Very confident

Variable ID: BSESo9*

Variable: Question 9 of BSES-SF

Definition: I can always be satisfied with my breastfeeding experience.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident5 = Very confident

Variable ID: BSES10*

Variable: Question 10 of BSES-SF

Definition: I can always deal with the fact that breastfeeding can be time-consuming.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident 3 = Sometimes confident

4 = Confident 5 = Very confident

Variable ID: BSES11*

Variable: Question 11 of BSES-SF

Definition: I can always finish feeding my baby on one breast before switching to the other

breast.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident 3 = Sometimes confident

4 = Confident5 = Very confident

Variable ID: BSES12*

Variable: Question 12 of BSES-SF

Definition: I can always continue to breastfeed my baby for every feeding.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident 3 = Sometimes confident

4 = Confident5 = Very confident

Variable ID: BSES13*

Variable: Question 13 of BSES-SF

Definition: I can always manage to keep up with my baby's breastfeeding demands.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident 3 = Sometimes confident

4 = Confident5 = Very confident

Variable ID: BSES14*

Variable: Question 14 of BSES-SF

Definition: I can always tell when my baby is finished breastfeeding.

Supporting Definition: N/A

Inclusion Criteria: *Optional, may present if respondent scores a 3 or lower on BFCONFID

Timing: 3rd trimester

Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Sometimes confident

4 = Confident 5 = Very confident

Role transition

Variable ID: ROLECONF

Variable: Confidence in role

Definition: How confident do you feel about looking after your baby?

Supporting Definition: Add "when he or she is born" for entry to prenatal care questionnaire

Inclusion Criteria: All women

Timing: Entry to prenatal care

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all confident

2 = Not very confident3 = Somewhat confident

4 = Confident 5 = Very confident

Variable ID: MIBS1

Variable: Question 1 of MIBS

Definition: These questions are about your feelings for your child in the first few weeks. Some

adjectives are listed below which describe some of the feelings mothers have towards their baby in the FIRST WEEKS after the birth* / in the FIRST FEW WEEKS

after the birth**. Please make a tick against each word in the box that best

describes how you feel NOW* / felt in the FIRST FEW WEEKS**.

Loving

Supporting Definition: *delete if administering tool in post-partum period

**delete if administering tool at birth

Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little

3 = Not at all

Variable ID: MIBS2

Variable: Question 2 of MIBS

Definition: Resentful

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Variable ID: MIBS₃

Variable: Question 3 of MIBS **Definition:** Neutral or felt nothing

Supporting Definition: N/A **Inclusion Criteria:** All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Variable ID: MIBS4

Variable: Question 4 of MIBS

Definition: Joyful **Supporting Definition:** N/A

Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Variable ID: MIBS₅

Variable: Question 5 of MIBS

Definition: Dislike
Supporting Definition: N/A
Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Variable ID: MIBS6

Variable: Question 6 of MIBS

Definition: Protective

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Variable ID: MIBS7

Variable: Question 7 of MIBS **Definition:** Disappointed

Supporting Definition: N/A
Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Variable ID: MIBS8

Variable: Question 8 of MIBS

Definition: Aggressive

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Birth

Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very much

1 = A lot 2 = A little 3 = Not at all

Mental Health

Variable ID: PHQ1

Variable: Question 1 of PHQ-2

Definition: Over the past 2 weeks, how often have you been bothered by any of the following

problems?

Little interest or pleasure in doing things

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all

2 = Several days

3 = More than half the days

4 = Nearly every day

Variable ID: PHQ2

Variable: Question 2 of PHQ-2

Definition: Feeling down, depressed or hopeless

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Entry to prenatal care

3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 1 = Not at all

2 = Several days

3 = More than half the days 4 = Nearly every day

Variable ID: EPDS1*

Variable: Question 1 of the EPDS

Definition: As you are pregnant or have recently had a baby, we would like to know how you

are feeling. Please check the answer that comes closest to how you have felt IN

THE PAST 7 DAYS, not just how you feel today.

In the past 7 days:

I have been able to see the funny side of things

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-2

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = As much as I always could

1 = Not quite so much now2 = Definitely not so much now

3 = Not at all

Variable ID: EPDS2*

Variable: Question 2 of the EPDS

Definition: I have looked forward with enjoyment to things

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-3

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = As much as I ever did

1 = Rather less than I used to2 = Definitely less than I used to

3 = Hardly at all

Variable ID: EPDS3*

Variable: Question 3 of the EPDS

Definition: I have blamed myself unnecessarily when things when wrong

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-4

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, most of the time

1 = Yes, some of the time

2 = Not very often

3 = No, never

Variable ID: EPDS4*

Variable: Question 4 of the EPDS

Definition: I have been anxious or worried for no good reason

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-5

Timing: Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No, not at all

1 = Hardly ever 2 = Yes, sometimes 3 = Yes, very often

Variable ID: EPDS5*

Variable: Question 5 of the EPDS

Definition: I have felt scared or panicky for no very good reason

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-6

Timing: Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, quite a lot

1 = Yes, sometimes 2 = No, not much 3 = No, not at all

Variable ID: EPDS6*

Variable: Question 6 of the EPDS

Definition: Things have been getting on top of me

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-7

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, most of the time I haven't been able to cope at all

1 = Yes, sometimes I haven't been coping as well as usual

2 = No, most of the time I have coped quite well

3 = No, I have been coping as well as ever

Variable ID: EPDS7*

Variable: Question 7 of the EPDS

Definition: I have been so unhappy that I have difficulty sleeping

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-8

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, most of the time

1 = Yes, quite often 2 = Not very often 3 = No, not at all

Variable ID: EPDS8*

Variable: Question 8 of the EPDS

Definition: I have felt sad or miserable

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-9

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, most of the time

1 = Yes, quite often 2 = Not very often 3 = No, not at all

Variable ID: EPDS9*

Variable: Question 9 of the EPDS

Definition: I have been so unhappy that I have been crying

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-10

Timing: Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, most of the time

1 = Yes, quite often 2 = Only occasionally

3 = No, never

Variable ID: EPDS10*

Variable: Question 10 of the EPDS

Definition: The thought of harming myself has occurred to me

Supporting Definition: N/A

Inclusion Criteria: *Optional for women scoring a 3 or higher on the PHQ-11

Timing: Postpartum check-up 6 months postpartum

o months postparte

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Yes, quite often

1 = Sometimes 2 = Hardly ever 3 = Never

Satisfaction with care

Variable ID: CARESAT1

Variable: Satisfaction with care

Definition: How satisfied are you with the results of your care during your pregnancy?*

Supporting Definition: *change to "during your labor and the birth of your baby" or "in the months after

your baby was born" when presenting at the postpartum check-up and 6 months

postpartum

Inclusion Criteria: All women

Timing: 3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = Very unsatisfied

1 = Unsatisfied

2 = Neither satisfied nor dissatisfied

3 = Satisfied4 = Very satisfied

Healthcare Responsiveness

Variable ID: HCR1

Variable: Information and role in care 1

Definition: Thinking about your care during your pregnancy*...

Were you given information about your choices for maternity care?

Supporting Definition: *change to "during your labor and the birth of your baby" or "in the months after

your baby was born" when presenting at the postpartum check-up and 6 months

postpartum

Inclusion Criteria: All women

Timing: 3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No

1 = To some extent

2 = Yes

Variable ID: HCR2

Variable: Information and role in care 2

Definition: Were you given enough information to help you decide about your care?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No

1 = To some extent

2 = Yes

Variable ID: HCR3

Variable: Information and role in care 3

Definition: Were you given information at the right time to help you decide about your care?

Supporting Definition: N/A

Inclusion Criteria: All women
Timing: 3rd trimester

Postpartum check-up

6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No

1 = To some extent

2 = Yes

Variable ID: HCR4

Variable: Confidence in providers

Definition: Did you have confidence and trust in the staff caring for you?

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: 3rd trimester

Postpartum check-up 6 months postpartum

Reporting Source: Patient-reported

Type: Single Answer

Response Options: o = No

1 = To some extent

2 = Yes

Birth Experience

Variable ID: BSS_R1

Variable: Question 1 of the BSS-R

Definition: Please respond to the following statements:

I came through childbirth virtually unscathed.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R2

Variable: Question 2 of the BSS-R

Definition: I thought my labour was excessively long.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R3

Variable: Question 3 of the BSS-R

Definition: The delivery room staff encouraged me to take decisions about how I wanted my

birth to progress.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R4

Variable: Question 4 of the BSS-R

Definition: I felt very anxious during my labour and birth.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R5

Variable: Question 5 of the BSS-R

Definition: I felt well supported by staff during my labour and birth.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R6

Variable: Question 6 of the BSS-R

Definition: The staff communicated well with me during labour.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R7

Variable: Question 7 of the BSS-R

Definition: I found giving birth a distressing experience.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R8

Variable: Question 8 of the BSS-R

Definition: I felt out of control during my birth experience.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R9

Variable: Question 9 of the BSS-R

Definition: I was not distressed at all during labour.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

Variable ID: BSS_R10

Variable: Question 10 of the BSS-R

Definition: The delivery room was clean and hygienic.

Supporting Definition: N/A

Inclusion Criteria: All women

Timing: Postpartum check-up

Reporting Source: Patient-reported

Type: Single Answer

Response Options: 4 = Strongly Agree

3 = Agree

2 = Neither Agree or Disagree

1 = Disagree

o = Strongly Disagree

ICHOM Contact Information

Website	http://www.ichom.org
	Aurani Chuaah Cuita Haa
	14 Arrow Street, Suite #11
	Cambridge, MA 02138
Business Address	
	1 Eversholt Street
	London NW1 2DN, UK

Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.1	Data Dictionary	Item response correction for WEIGHTUNIT, UI02 and UI04
1.0.2	Data Dictionary	Inclusion criteria and timing of assessment modified for [BFCONFID], timing of assessment changed for [BFSUCCESS] and all items of the BSES assessment; 'Mental Health' title changed to 'Birth Experience'; Definition modified for [MIBS1], [MATERNALDEATH], [STILLBIRTH], [ICUADMIT], [READMIT], [SPRETERM], [IPRETERM], and [OXYGEN]
1.0.2	Timeline	Point 3: text changed from "At discharge" to "Prior to discharge"
1.0.2	Table	'Parity' moved under Obstetric and Medical History; 'Baseline' changed to 'Entry to prenatal care'; timing revised for 'Success with breastfeeding' and 'Confidence with breastfeeding'; differentiated timing for PHQ-2 and EPDS
1.0.3	Contact Information	Removed inactive email address: ichomteam@ichom.org

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