



Riayati

Newborn Screening Results Specifications

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Document History

Change / Version No.	Date Change Approved	Description of Changes (including section numbers)	Impacted Supporting Document(s)	Supporting Document Change / Version No.	Authors
V0.1	01/03/2024	Initial Draft	N/A	N/A	MOHAP
V0.2	16/01/2025	Document updated	N/A	N/A	MOHAP

Table 1 Document Version History

Document Acceptance and Sign-Off	Signature	Date

Table 2 Document Acceptance and Sign-Off

After this document is accepted by the approvers, the approved version becomes the baseline. All changes to the baseline version will be as per the change control procedure outlined in the Program Charter. Riayati CCB is responsible for approving any changes to this document.

1 Introduction

1.1 Document Purpose

The purpose of this document is to provide healthcare facilities with clear specifications and guidelines on the proper procedures for sharing newborn screening results. These guidelines aim to ensure a standardized and efficient process, promoting accurate and timely communication of crucial information related to newborn screening outcomes.

1.2 Intended Audience

The intended audience for this newborn screening results specification document typically includes hospital administration, quality team, co-ordinators, healthcare professionals, hospital staff involved in newborn care, laboratory personnel responsible for conducting screening tests, and any other relevant stakeholders engaged in the process of newborn screening. This document aims to provide clear guidelines and instructions to ensure a consistent and accurate approach to sharing newborn screening results.

1.3 Objective

The primary objective is to align healthcare facilities with the directives set forth by the Ministry of Health and Prevention (MOHAP) in the UAE. In adherence to the recommendations outlined by MOHAP's Public Health Department and Digital Health Department, all applicable healthcare facilities are mandated to share newborn screening test results with the Riayati NUMR. This commitment to sharing critical health information ensures a comprehensive and unified approach to newborn care, promoting efficient data exchange and contributing to improved health outcomes.

By implementing these guidelines, we aim to establish a standardized and systematic process for the communication of newborn screening results. This not only facilitates compliance with regulatory requirements but also enhances the overall quality of healthcare services. The objective is to create a seamless integration between healthcare facilities and the Riayati NUMR, fostering a collaborative environment that prioritizes the well-being of newborns and supports a unified healthcare infrastructure in line with national health initiatives.

1.4 Newborn Screening

1.4.1 Newborn Screening Tests

Newborn screening tests are a series of medical tests performed shortly after a baby is born to identify certain disorders that may not be apparent at birth but could cause significant health issues if not addressed promptly. These tests aim to detect conditions that, if identified early, allow for timely intervention and treatment. The specific tests conducted can vary by region and healthcare policies, but common newborn screening tests often include:

- **Neonatal Screening Blood Tests (Metabolic Screen):** These tests screen for disorders, such as phenylketonuria (PKU), Congenital hypothyroidism, and sickle cell disease...
- **Newborn Hearing Screening:** This is a simple and painless test that can identify any hearing issues early on, allowing for timely intervention and support.
- **Critical Congenital Heart Defect Screening (CCHD):** Critical Congenital Heart Disease (CCHD) screening uses pulse oximetry to detect heart defects that might not be apparent at birth.

The purpose of these screenings is to find health issues that, if not treated, could cause developmental delays, learning disabilities, or serious health problems. Finding and treating these issues early greatly improves the chances of a better and healthier life for the baby.

1.4.2 The newborn screening test is done within the first 24 to 48 hours after birth. For more details, check the "National Newborn Screening Laboratory Guideline 2023" from MoHAP.Specifications

To establish a consistent and standardized approach for facilities to report newborn screening with Riayati NUMR, we have formulated the following guidelines.

(Disclaimer: The guidelines provided here are intended solely to share newborn screening results with Riayati NUMR. These guidelines do not apply to other regulatory submissions including Riayati PO.)

1.4.2.1 Newborn Notification

- a. Upon the delivery of a newborn at the facility, it is imperative for the facility to promptly communicate this information to Riayati.
- b. This communication is facilitated by sharing an HL7 ADT Message, which includes the encounter details and sets the admission type flag to 'N' in PV1:4 field. For complete information see Riayati HL7 & CCD A Specifications documents.
- c. The admission type flag should exclusively be designated as 'N' for newborns and should be carry forwarded across all the HL7 Messages for this Patient Visit/Encounter.
- d. **Do not use the "N"** admission type flag for newborns born in an external facility.
- e. **Newborns should not be registered** as newborns if they visit healthcare facilities for services like immunization, phototherapy, NICU care, or other treatments before they are 28 days old, even if they were born in the same facility.

1.4.2.2 Results Notification

- a. Newborn Blood Spot Screening Results
 - i. Newborn blood spot screening investigation must be mandatorily ordered for all newborns.
 - ii. The newborn blood spot screening results must be shared as discrete values, following the specifications outlined below.
 - iii. The discrete data shared with the Riayati NUMR results must include, but is not limited to, the order details, specimen collection time, specimen dispatched time, specimen received time, result authorization time, and the performing location.
 - iv. The newborn blood spot screening report received from the performing lab must be uploaded along with the results and shared with MDM message.
 - v. If the screening test is not performed, the results must be shared with order status as "Cancelled" along with the Reason for not conducting the screening as Order Comments with the Riayati NUMR.
- b. Newborn CCHD Screening
 - i. Newborn CCHD screening must be mandatorily ordered for all newborns.

- ii. Once the CCHD screening test is completed, the procedure details must be shared with the Riayati NUMR.
- iii. Along with the procedure details, the observations must be shared as a Result Message with the following the specifications outlined below.
- iv. If the screening test is not performed, the results must be shared with order status as "Cancelled" along with the Reason for not conducting the screening as Order Comments with the Riayati NUMR.
- c. Newborn Hearing Screening
 - i. Newborn hearing screening must be mandatorily ordered for all newborns
 - ii. Once the Newborn hearing screening test is completed, the procedure details must be shared with the Riayati NUMR.
 - iii. Along with the procedure details, the observations must be shared as a Result Message with the following the specifications outlined below.
 - iv. If the screening test is not performed, the results must be shared with order status as "Cancelled" along with the Reason for not conducting the screening as Order Comments with the Riayati NUMR.
 - i.

1.5 Codes Sets

While sharing screening details below codes must be used as appropriate.

a. Newborn Blood Spot Screening

Type	Code System	Code	Test Name	Disorder
Order	RYT1153	NBSP	Newborn Blood Spot Screening Panel	-
Result	LOINC	57086-1	Congenital adrenal hyperplasia -17-OHP	Congenital adrenal hyperplasia (CAH)
Result	LOINC	54090-6	Congenital Hypothyroidism-TSH	Congenital Hypothyroidism
Result	LOINC	54078-1	Cystic Fibrosis IRT	Cystic Fibrosis
Result	LOINC	57087-9	Biotinidase Deficiency	Biotinidase Deficiency (BIOT)
Result	LOINC	54079-9	GALT	Galactosemia (Classic GALT Deficiency)
Result	LOINC	54081-5	Hemoglobin Disorders	Hematological Disorders



Result	LOINC	58091-0	G6PD Deficiency	Glucose-6-phosphate dehydrogenase (G6PD deficiency)
Result	LOINC	53261-4	Amino Acid Disorders	Amino Acidemia Disorders
Result	LOINC	57085-3	Organic Acid Disorders	Organic Acidemia Disorders
Result	LOINC	57084-6	Fatty Acid Oxidation Disorders	Fatty Acid Oxidation Disorders
Result Document	LOINC	57128-1	NBS Screening Report	Neonatal Screening Report

b. Newborn Hearing Screening

Type	Code System	Code	Test Name	Disorder
Order	CPT	92650	Auditory evoked potentials; screening of auditory potential with broadband stimuli, automated analysis	Newborn Hearing Screening
Result Document	LOINC	54111-0	Newborn Hearing Screening Report	Newborn Hearing Screening Panel

c. Critical Congenital Heart Defect Screening (CCHD)

Type	Code System	Code	Test Name	Disorder
Order	CPT	94761	Noninvasive ear or pulse oximetry for oxygen saturation; multiple determinations	Newborn CCHD Screening



Result Document	LOINC	73805-4	CCHD Newborn Screening Report	CCHD Newborn Screening Panel
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