

## Innovation of High-risk Infants Follow-up Surveillance System in Iran

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### ABSTRACT

**Background:** Early childhood development is one of the most social determinants of health that must be notified in order to reducing social gap and inequity. In spite of increasingly developing intensive neonatal care wards and decreasing neonatal mortality rate, there is no follow-up surveillance system to identify high-risk infants (HRI) and their health problems for timely intervention after discharge. This study was carried out to design and pilot high-risk infant follow-ups (HRIFs) surveillance system, in Alzahra Hospital, a tertiary level center of Tabriz University of Medical Sciences (TUOMS), in 2012–2013.

**Methods:** In this qualitative research after studying international documents, consensus about criteria of HRIs accomplished by focus group discussion. Then, Delphi agreement technique was used to finalizing assessment timetable. In the second phase, we piloted the designed surveillance system in Alzahra Hospital, a tertiary level center of TUOMS. Pilot study was implemented by follow-up team organized in designed model at the first phase of the study. Then, the findings of the pilot study were being assessed by an expert panel. If the members agreed on made decisions, they were being placed on the agenda of the national committee of development care of newborns for final approval.

**Results:** High-risk infants follow-up surveillance system was designed in following steps: Defining of evidence-based criteria of HRIs, organizing the follow-up team, regulating the organs and neurodevelopment assessment timetable, publishing a health certificate notebook for HRIs, and designing Access database software for data collection, report and evaluation.

**Conclusions:** We designed and piloted HRIFs surveillance system, so this system was institutionalized in Alzahra Hospital, finally. It can be prepared to apply in the whole country, after detecting the quantitative outcomes and developing the program in East Azarbijan.

**Keywords:** Follow-up, high-risk infants, Iran, surveillance system

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### INTRODUCTION

Early childhood development (ECD) is one of the most social determinants of health that must be notified in order to reducing social gap and inequity. Physical, social/emotional, and language/cognitive domains of ECD contribute to the health and play a key role in health equity, across the lifelong.<sup>[1,2]</sup>

The quality of person's life depends on her/his abilities. This theory was developed by Martha Nussbaum, who uses this theory to address "social justice." The theory indicates on a minimal level of social justice requires "the availability of main capabilities to all."<sup>[3]</sup> Scientists point out that development can be enhanced through intervention programs involving improved parenting skills, nutritional supplementation and quality of child care arrangements.<sup>[4,5]</sup>

Preterm infants biologically have significantly higher rates of functional limitations and are at risk for developmental delays. These delays and complications can be reduced through high-risk infant follow-up (HRIF) program.<sup>[6]</sup> By definition, high-risk infant (HRI) includes any neonate, regardless of birth weight, size, or gestational age, who has a greater than average chance of morbidity or mortality, especially within the first 28 days of life. Risk factors include preconception, prenatal, natal, or postnatal conditions or circumstances that interfere with the normal birth process or impede adjustment to extra-uterine growth and development.<sup>[5]</sup>

High-risk infants needs special care by physicians and nurses during hospitalization and after discharge. HRIF program bridges care pre- and post-neonatal Intensive Care Unit (NICU) discharge to assure that infants with special needs reach optimal health and developmental levels. Progressing in the follow-up program for detection of HRIs along with care taking, give a mechanism for monitoring and evaluation of the quality of care in NICU.<sup>[7]</sup> One of the most important components of postdischarge management in HRIs is long-term assessment, care and education through a follow-up system. Nurses as one member of professional team, are ideal for identifying HRIs, individualizing discharge education and assuring follow-up referrals.<sup>[8]</sup>

By introducing advanced technology and programs for taking care of premature infants, neonatal and infant mortality rate has been reduced and survival among graduates of NICUs has been increased.<sup>[9]</sup> Because of increased risk of disabilities and development delays, most programs have focused their resources on long-term follow-up of the most vulnerable group with birth weight <1500 g.<sup>[10]</sup>

Regarding to extension of NICU wards in Iran, ethically, it seems to be necessary to create a follow-up surveillance system for HRIs since the number of these infants is increasing. After creating an action model for HRIF Program by Heidarzadeh, *et al.* in 2012,<sup>[11]</sup> the next question was about how the surveillance system could be designed and implemented. Therefore, present study was carried out with the aim of designing and

piloting HRIFs surveillance system based on the action model, more than a service package, for its reformation and implementation in whole country, in Iran, in 2013.

## METHODS

This qualitative study has been done by the Neonatal Health Department of the Iran's Deputy of Public Health in cooperation with pediatrics health research center of Tabriz University of Medical Sciences (TUOMS). We applied international document study include current program for NICU graduated infants of California and Iowa (USA), Australia in developed countries and India in developing countries for compiling the first draft.<sup>[4]</sup> Then, consensus about the criteria and definition of HRI has been accomplished by focus group discussion. The participants were 12 persons of academic staff of different courses such as neonatology, endocrinology, lung, gastroenterology, neurology, psychology, neurodevelopment, and rehabilitation, and also physicians of the governmental and private sectors.

After drawing the assessment timetable, Delphi agreement technique was used to finalizing the time of visits and screening tests. The participants were executive managers and academic staff of different courses. For conformability of the study, we considered bracketing, member check, triangulation, and peer review.

In the second phase, we piloted the designed surveillance system in Alzahra Hospital, a tertiary level center of TUOMS. Pilot study was implemented by follow-up team organized in designed model, at the first phase of the study. If the parents did not tend to contribute to this health service, they were asked to complete a consent form. Then, the findings of pilot study were being assessed by expert panel consisted from 5 persons: A neonatologist as program manager, executive manager of the TUOMS, a pediatrician, a neurodevelopment specialist, head of the department of neonatal health of the Health Ministration and National expert staff of the program. If the members agreed on made decisions, they were being placed on the agenda of the national committee of development care of newborns for final approval.

## RESULTS

### Designing the surveillance system

High-risk infant follow-ups surveillance system had designed as the followings:

1. Defining of evidence-based criteria of HRI; including criteria for HRI were determined and described [Table 1]. After admission the neonate

**Table 1: Criteria of HRIs**

Birth weight < 1500 g or gestational age < 32 weeks
Birth weight > 1500 g or gestational age > 32 weeks with the following conditions
IUGR
Antenatal or neonatal asphyxia (ABG of the cord or within the first hour: pH < 7 or Apgar score < 3 in 5 <sup>th</sup> min)
Continuous instability in neonatal period like hypoxemia or acidosis, hypoglycemia, or persistent hypotension and resistant to vasopressors
Persistent apnea requiring to medical treatment at discharge
Oxygen supplementation for more than 28 days during hospital admission or concomitant radiologic signs related to CLD
PPHN <sup>a</sup> diagnosed by echocardiography requiring treatment
Seizures
Intra cerebral insult including: IVH grade 2 or more, Periventricular leukomalacia, neurodevelopment disorders of CNS
RDS requiring mechanical ventilation for more than 2 h
Hypoglycemia: Two intervals blood sugar samples < 40 mg/dL and (50 after 24 h)
Polycythemia and partial exchange
Surgery during the neonatal period
Major anomalies
Infectious disease as TORCH syndrome
Neonates or mothers with systemic auto-immune disease
Proven sepsis and osteomyelitis
Intrauterine transfusion or hydrops fetalis
Other difficulties leading to CNS disorder as infection or hypotonia during discharge or hyper bilirubinemia at exchange transfusion level

HRIs=High-risk infants, IUGR=Intrauterine growth retardation, ABG=Arterial blood gas, CLD=Chronic lung disease, GERD=Gastroesophageal reflux disease, PPHN=Persistent pulmonary hypertension of the newborn, CNS=Central nervous system, IVH=Intraventricular hemorrhage, RDS=Respiratory distress syndrome

- at NICU ward and applying the necessary diagnosis, care, and treatment, one must determine if the infant is in the HRI group or not, according to the HRI defined criteria. In coordination to physician, the infant is checked according to HRI including criteria by the discharge nurse (DN); if the infant is in the HRI group then the corresponding procedure will be continued. Otherwise, the infant will be considered in low-risk group.
- Organizing follow-up team; following members defined for HRIF team:
    - Coordinator
    - Physician (neonatologist/fellow of neonatology/trained pediatrician)
    - DN
    - Follow-up clinic nurse (CN)
    - Data analyzer
    - Ophthalmologist
    - Audiologist
    - Neurodevelopment specialist.
  - Regulating the organs and neurodevelopment assessments timetable: We regulated organs and

neurodevelopment assessment time table based on age and probable involved organs [Table 2].

In the follow-up visit process; physical examination, detecting abnormal findings, planning necessary interventions, and other assessing based on suggested time table and also, determining the next referring time is done by a physician. A medical record includes follow-up forms, growth charts, and Ages and Stages Questionnaire (ASQ) test allocated to HRI at the follow-up clinic by CN.

Ages and Stages Questionnaire for the next calling are educated and delivered to the parents based on neurodevelopment time table. When ASQ as a screening test fails in a special field, or the parents worry or the physician finds any doubtful point in his/her investigation, Griffith's test as a more specific and extended neurodevelopment test is used to investigate more closely.

While coordinating with regionalization of perinatal care services, it was supposed to choose a pediatrician for each city in the province, with in level II center to attend a workshop, so that could be able to manage the follow-up visits.

Since the recall of the family is very important in the follow-up program, thus a process was designed for calling them in the case of not attending, after 3 days.

- A health certificate notebook was designed and printed for HRIs, which contains all important information and data include past medical history, clinical findings, laboratory results, radiology reports, developmental tests and growth charts from birth up to 5 years old, which is hold by the parents
- Access database software applied for data collection by considering all information about these infants including perinatal care, problems during NICU admission and data of follow-up visits, ASQ screening test, Griffith's test, and, etc
- Monitoring and evaluation the program can be done by data analyzing and interpretation.

### Pilot study

In the second phase, findings of the pilot study show that we would consider some additional columns for some additional visits in timetable. We found that ASQ is not enough for screening of these vulnerable infants; therefore, Bayley screening test was suggested by an expert panel to confirm. We also understand, it is necessary considering Bayley extended development test instead of Griffith's test for national implementation.

The HRIF certificate notebook was too long for physicians, and it must revised, so physician be able to observe the results of all visits in one view, and it is better adding to a supplemental guidance for parents.

**Table 2: Organs and neurodevelopment assessment time table**

Age	2 weeks	1 month	2 months	3 months	4 months	6 months	8 months	9 months	12 months	18 months	2 years	3 years	4 years	5 years
Growth indices														
Cardiac examination R/O CHD <sup>b</sup>														
Hypertension														
GERD <sup>c</sup>														
CLD <sup>d</sup>														
In all visits (based on corrected age for preterm infants)														
Hypothyroidism														
Osteopenia														
In all visits (based on history and symptoms)														
Nutritional assessment														
Nephrocalcinosis														
Tubular impairments														
Anemia														
DDH <sup>e</sup>														
Dental health														
ADHD <sup>f</sup>														
Autism														
Behavioral disorders														
Child abuse and neglect														
Sleep and feeding disorders														
IVH														
ROP <sup>g</sup>														
AABR <sup>h</sup> (hearing assessment)														
ASQ														
Griffith's test														

<sup>a</sup>Must be done in all patients; <sup>x</sup>Must be done in higher risk; <sup>o</sup>Objective by a standard method, <sup>S</sup>Subjective by history. Dark columns must be done by neonatologist in tertiary level centers and white columns can be done by trained pediatrician. CLD=Chronic lung disease, GERD=Gastroesophageal reflux disease, IVH=Intraventricular hemorrhage, CHD=Coronary heart disease, ASQ=Ages and stages questionnaire, <sup>b</sup>=Chronic heart disease, <sup>c</sup>=Gastro esophageal reflux disease, <sup>d</sup>=Chronic lung disease, <sup>e</sup>=Developmental dislocation of hip, <sup>f</sup>=Attention deficit-hyperactivity disorder, <sup>g</sup>=Retinopathy of prematurity, <sup>h</sup>=Automated auditory brainstem response

Applied Access database software for data collection and report would be updated and replaced by simple software such as Excel or InfoPath (Micro Soft office), so all staff would be able to work with it, and link to national registry system of NICU. Finally, this system institutionalized in Alzahra Hospital.

## DISCUSSION

We designed and piloted HRIs follow-up surveillance system, so this system innovated for the first time in Iran's health system.

The Children's Medical Services Branch/California Children's Services (CCS) program is restructured the NICU/HRIF program effectively, July 1, 2006. A HRIF program letter 01-0606 was disseminated to provide guidance on the program restructure, including information on patient eligibility, diagnostic services, and provider's responsibilities, reporting requirements, and procedures for billing authorized HRIF services provided to CCS HRIF eligible infants and children. CCS Standards for NICUs require that each CCS-approved NICU shall ensure the follow-up of HRIs discharged from the NICU. Each NICU shall either have an organized HRIF Program or written agreement for the provision of these services by another CCS-approved NICU.<sup>[5]</sup> To achieve the CCS Program's goal of identifying infants and children who may develop a CCS eligible medical condition, the CCS HRIF program provides for a number of diagnostic services for children up to 3 years old, while in present study, HRIF program provides for a number of both screening and diagnostic services for children up to 5-years-old.

Similar to CCS program, we organized a multidisciplinary team of professionals and developed Access database HRIF Reporting System. Our findings indicate on need to analyze the collected data for looking out, and designing proper interventions and evaluation of the program. Early diagnosis and intervention in this program are the important elements in reducing the intensity of the possible various disorders and disabilities in HRIs. We concluded updating and replacing the Access database HRIF reporting system by a simple software such as Excel or InfoPath, user-friendly, all staff be able to work it, and link to national registry system of NICU, help us to identify quality improvement opportunities for NICUs in the reduction of long-term morbidity; allow programs to compare their activities with all sites throughout the country.

In their program, at the time of the referral for HRIF authorization, an authorization for two home assessments by a Home Health Agency nurse, preferably experienced in evaluating the maternal/infant environment, can be separately authorized. We hope to provide follow-up

home visits, after implementation of family physician program throughout the country.

We used preterm babies' growth charts in HRIF program instead of the Disease Control and Prevention<sup>[9]</sup> individual growth charts.<sup>[12]</sup> Our neurodevelopment evaluation tests and its time table conform to HRIF program of the Women and Newborn Health Service of King Edward Memorial Hospital, Australia; Perth.<sup>[13]</sup> Comparing to California program, we considered ASQ screening test and Griffith's extended test instead of Denver II screening test and Bayley extended test for the neurodevelopment assessment, in designed system. According to literature review and decision of expert panel, ASQ has been chosen as a screening test for detection of neurodevelopment disorders with 71–85% (overall 78%) sensitivity and 90–98% specificity.<sup>[14]</sup> However, based on the pilot study, an expert panel suggested using of Bayley screening test as an objective test for HRIs, beside the ASQ as a subjective test that also cause parents participation in care of their babies. The Persian version of Bayley Scales of infant and toddlers development screening test was developed by Soleimani *et al.*, in 2014 and its validity and reliability were determined.<sup>[15]</sup>

In our designed system, when ASQ test failed in a special field or the parents worry or the physician finds any doubtful point in his/her investigation, Griffith's test as an extended neurodevelopment test was been used to investigate more closely. This method is used in King Edward Memorial Hospital in Perth city in Australia.<sup>[16,17]</sup> However, after the pilot study and consensus with national committee of child development, expert panel suggested using of Bayley test instead of Griffith's test as a more specific and extended neurodevelopment test be used to investigate more closely, throughout country.<sup>[18]</sup>

Regarding to importance of ECD and programming for its stages including survival, health and physical growth and development, especially in HRIs, we tried to support all of the three broad domains of early child development contributing to health, and play a key role in health equity, across the lifelong: Physical, social/emotional, and language/cognitive in designed program.

The absence of DN in current care taking system is an importance limitation that must be considered in the standard staff context of NICU ward.

As we mentioned HRIF certificate notebook, need to revision, so that the physicians be able to see the results of all visits in one view. Regarding to the importance of the self-care and empowering the parents for care giving, after the pilot study, an expert panel confirmed abstracting of the certificate notebook and adding to supplemental guidance of care for parents.

This program establishes the linkage between inpatient and outpatient HRI health services that are called



continuity of care as a principle of primary health care services. We believe this program is a dynamic process, and it requires to be evaluated annually or each 2 years. Analysis and interpretation of collected data help us to notify our possible mismanagements in NICU and follow-up clinic and improvement of them.

Now, we have started to analyze the quantitative data and determine the outcomes of the implemented program. We hope developing of the HRIFs program in East Azarbijan providence, help us to suggest a nationwide surveillance system for implementation in the whole country.

## CONCLUSIONS

We designed and piloted HRIFs follow-up surveillance system, so this system institutionalized in Alzahra Hospital, finally. It can be prepared to implement in the whole country, after detecting the quantitative outcomes and developing of the program in East Azarbijan.

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