



مركز الملك سلمان لأبحاث الإعاقة

King Salman Center For Disability Research

Science Benefiting People

علم ينفع الناس

2018 Scientific Report

Science Benefiting People



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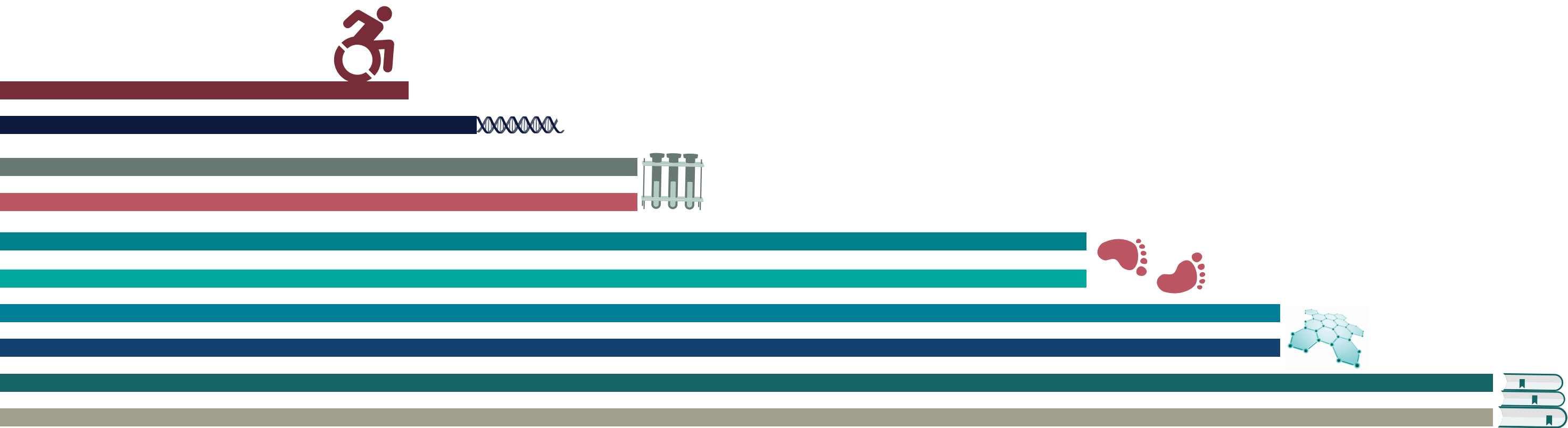


And say, Do [as you will], for Allah
will see your deeds, and [so, will]
His Messenger and the believers.

Surah At-Tawbah [9:105]

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Psychological Health

In 2018, the project team worked with Harvard University and University of Michigan, Ann Arbor on finalizing the survey sample weighting details. Weighting adjustment is a correction technique used in statistical analysis to assign adjustment weights to survey respondents. Using this technique, respondents who were under-represented or over-represented in the sample were 'weighted' to represent the actual Saudi population. This technique makes the findings of our study stronger and more precise as it better represents every Saudi in the country. Following this, statistical analyses were conducted and began reviewing the results. Using these findings, the investigators are working on the core publications that will inform the health community, the policy makers, and the public, about the status of mental health in KSA.

At the same time, the investigators are working on publications related to the survey methodology accomplishments of the SNMHS, which are one of the first of their kind in the Gulf region. Survey methodology and techniques are still scarcely researched in the Gulf. This project is one of the pioneers in the Gulf to share its high-quality survey methodology experience with the scientific community. To-date, the investigators have published three articles on this topic in high ranking peer-reviewed scientific journals.

Achievements During 2018 :

1. External Reviewers (KACST):

The project reports received high praise from reviewers at King AbdulAziz for City for Science and Technology (KACST) for two of interim progress reports. For the 2017 review, a score of 26/30 with an excellent rating was awarded with reviewer's comment: 'project progress and report documentation exceed expectations. For the 2018 review, two reviewers gave a score of 29/30 and 26/30 respectively, both excellent ratings where one of the reviewer's noted that 'this project will have a significant impact on the knowledge and implications for services related to mental health in Saudi Arabia'.

2. Data Analysis:

Data analysis is currently being carried out by the World Mental Health Data Analysis Center at Harvard School of Medicine. Their team of specialized advanced survey analysts, epidemiologists and statisticians are working with the PI to ensure all

aims of the project are addressed and accomplished, by implementing a detailed data analysis plan and roadmap, based on the needs and objectives. For some results, additional verification was decided upon, which is accomplished by conducting additional interviews with Saudi respondents using a gold standard interview known as SCID (Structured Clinical Interview for DSM-5).

3. 3) Research Collaboration with the University of Michigan Ann Arbor:

Project team has made great progress in 2018 while working closely with University of Michigan, Ann Arbor on the following aspects:

- a. Data management, carrying out data cleaning and weighting on the collected survey data so as to perform statistical analyses.
- b. Survey methodology papers for scientific journal publication.

- c. Coding CIDI instrument open-ended questions. The coding will be used to analyze results for a potential paper using the SNMHS data on the topic of satisfying, a new area of survey research which explores respondent thought processes during an interview.

4. Genetics and Scientific Advancement:

The SNMHS is one of the distinctively scientific studies participating in the World Mental Health Survey Consortium, which has collected over 2000 saliva samples from its respondents after obtaining an additional consent from them.

All saliva samples collected during the interviews from all areas of KSA were sent to KFSH&RC for extraction and freezing until further analyses. The DNA specimens extracted from these samples will be used to study genetic risk factors for mental health conditions prevalent in the Saudi population.

5. Principal Investigator of SNMHS became Visiting Faculty at Harvard University School of Medicine:

As a result of several years working closely with Professor Ron Kessler and his team at Harvard School of Medicine, in July 2018, Dr. Yasmin Altwaijri became a Visiting Faculty at Harvard University – School of Medicine, Boston USA. During 2018 she was working closely with the data analysis team (data analysts, epidemiologists, and biostatisticians) at Harvard School of Medicine, developing each facet of the analysis plan, reviewing them with the team, and discussing the output and results. She is also in the process of forming potential

collaborations with experts in the field for publications using the results of the SNMHS.

6. Conferences and Workshops:

- The WHO World Mental Health Initiative Annual Meeting held at Harvard University, July, 2018, Boston, USA.
- The 5th International Conference on Disability and Rehabilitation, organized by King Salman Center for Disability Research, April 1-2, 2018, Riyadh, KSA.
- The 2018 MENA Summit, February 7-8, 2018, Abu Dhabi, UAE.
- The 2nd Middle East Psychological Association Conference and Expo held on April 12th-14th, 2018 in Dubai, UAE.
- The Ethereal Summit NY which was held from 11 - 12 May 2018 at the Knockdown Center, Maspeth, New York, USA.

7. The Training Workshops:

- September 2, 2018: 1st SCID Training Workshop
- September 2018: Clinical Psychology interns at Prince Nora University were introduced to the SCID interview; trainees begin conducting the phone interviews with the survey participants (sub-sample of the original sample).
- October 2018: 2nd SCID Training Workshop (refresher) training. The interviewers then conducted phone OCD-SCID interviews for

and additional batch of survey participants.

- November 2018: with the involvement of the Harvard University team, a workshop was conducted to discuss the notes and diagnoses of SCID interview results. These results are compared to the Yale-Brown Obsessive-Compulsive Scale, which is part of the Saudi survey CIDI instrument. Comparison results will be used to fine tune the OCD prevalence results, and its margin of errors in the population.
- December 2018: Training Workshop: SCID- Separation Anxiety Disorder (SAD). Following the training the interviewers started the SAD-SCID interviews for a sample of 75 cases.

8. Publications:

In an effort to highlight the efforts exerted by the Kingdom of Saudi Arabia to care for the mental health and the efforts exerted by KSCDR on this important national project, the investigators are in discussion with a high ranking journal in psychiatry, to publish a “special issue about the Saudi National Mental Health Survey”. It will include several scientific manuscripts, which have resulted from the project. A peer-reviewed manuscript was published in 2018:

Mneimneh, Z. N., Hibben, K. C., Bilal, L., Hyder, S., Shahab, M., Binmuammar, A., & Altwaijri, Y. (2018). Probing for sensitivity in translated survey questions: Differences in respondent feedback across cognitive probe types. *Translation & Interpreting*, 10(2), 73-88. <https://doi.org/10.12807/ti.110202.2018.a06>

Future Directions:

- Continue collaboration with Harvard University School of Medicine, World Mental Health Data Analysis Center, on the data analyses for the survey.
- Continue working on writing publications using the psychology results from the data analyses.
- Continue working on publications related to the survey methodology accomplishments and experience of the SNMHS.
- Begin working on exploratory in-depth analyses of data.
- Additional grant funding will be sought to support the continuation of data analysis.
- Additional funding will be sought, for the genetic analysis aspect of the survey.
- Discussing the possibility to incorporate additional analytical tools and instruments using advanced analytics (Artificial Intelligence and Machine Learning), which will allow to leverage the information for the project data, providing actionable insight to enable intelligent automation for mental health disease prevention, early detection and decision making.

Integrated Day Care Assessment and Development System Program

The daycare centers' assessment system is a comprehensive, integrated system, which assesses and improves the operations, programs, and services provided to children with disabilities and their families by providing the training and guidance needed to improve these processes, a critical factor in bringing about changes in the centers serving these groups of children. And to enhance the performance of centers This document created a kind of motivation for these centers, where all centers desired to receive training according to the criteria and terms of this program so that they would always be within the typical range.

The system was developed for the Ministry of Labor and Social Development in Saudi Arabia by a team composed of officials affiliated to the King Salman Center for Disability Research in Riyadh and others affiliated with the Academy of Scientific Development, as well as various contributions from many stakeholders. The system involves both the Ministry of Labor and Social Development and the daycare center (s) in the evaluation and improvement process to support the operations, programs, and services provided to disabled children and their families through these centers. This document describes how this system was developed.

Current status:

- The Ministry of Labor and Social Development seeks to establish clear rules and standards that follow the new regulations of the Ministry and a practical framework to ensure an objective and comprehensive evaluation of care centers throughout the Kingdom to achieve the vision of the Kingdom 2030.
- Complete the scientific research plan and work on developing the measurement criteria for the program.
- Accordingly, it was agreed to rely on the evaluation criteria included in the guidelines for the evaluation system of daycare centers approved by the King Salman Center for Disability Research and to review and develop the standards in order to start evaluating daycare centers.
- And through these workshops and meetings with researchers and consultants from the King Salman Center for Disability Research and project consultants by the Ministry to take the views and discussions regarding evaluation criteria.
- Agreeing upon any amendments on standards made by the leading team

Academic Training Program:

A number of workshops and training courses were organized to:

- Discuss some of the criteria for the assessment tool for the current and future status (the Centers Evaluation Program after changing regulations).

- Aims at organizing daycare centers, encouraging the private sector to participate in the care and rehabilitation of persons with disabilities, and developing programs and services provided to them and follows the regulations and standards of evaluation programs.
- Presentation of workshops and lectures aimed at introducing the program
- Accurate and precise definition according to international standards, commensurate with the local community and services provided at this center.
- Continuous follow-up and supervision on the maintenance of information related to whole officials and stakeholders.



Courses and training workshops for the year 2018:

- Three general training courses for specialists and officials of the Ministry of Labor and Social Development
- eight workshops to Business and procedures Development Management Team of Ministry of Labor and Social Development
- Three training courses for center managers on the self-assessment process and improvement plan for administrators and teachers from daycare centers for people with special needs.
- 15 training courses for surveyors from the Ministry of Labor and Social Development supervisors on the evaluation program.

These activities were attended by (789 participants) specialists and officials from the Department of Labor Development from the Ministry of Labor and Social Development and from associations and centers, supervisors from the Ministry and managers of centers from different regions of the Kingdom of Saudi Arabia.

Using Intelligent Enabling as a guide for people with disabilities

Under the guidance of His Royal Highness Prince Sultan bin Salman bin Abdulaziz, Chairman of the Board of Trustees of the King Salman Center for Disability Research, to provide Intelligent applications as a platform to serve people with disabilities.

Project description:

In a new gesture used for the first time in the kingdom, coordinated with a competent company to use Intelligent Enabling Service, which allows persons with disabilities easy to move within any building by using mobile phones after providing a special code, and will provide them self-reliance and full independence Without seeking assistance and support in their movement between the halls, the venues of sessions and workshops, and the provision of services, as well as the provision of information and the identification and accessibility of places.

The techniques of Artificial Intelligence or Intelligent Enabling have created exceptional solutions in enabling people with disabilities and have opened up new horizons to empower them, and we look forward to enhancing the use of all the services that the center provides, and to create and implement enabling and supportive environments for persons with disabilities To the extent possible to enable them to overcome their challenges and their full involvement in society, which we consider to be an integral part of the Centre's objectives and the achievement of its strategy, in an intelligent format that facilitates the access of beneficiaries.

The Intelligent Enabling Service was launched at the Conference to serve persons with disabilities, where persons with disabilities were able to access this service as soon as they reached the service providers and provided them with their own code, and they rely on Bluetooth technology and form additional features to access information and find ways For all facilities, the deaf will be able to track alerts through vibration, and the features of wheelchair users enable them to access different sections and facilities by choosing wheelchair-accessible routes, The blind accessibility features enable them to navigate more freely by warning The way of sound from the obstructions around him.

Related Project:

Guidelines for comprehensive access standards for evacuation (fires and natural disasters)

A guide for the training of civil defense centers, related bodies, hospitals, disabled persons, their guardians, and workers in the centers for the care and rehabilitation of disabled persons to deal with incidents of fire and natural disasters and to carry out evictions with the latest special equipment and devices for the disabled and the elderly.

Newborn Screening Program 2018



المختبر الوطني للكشف المبكر على حديثي الولادة
National Laboratory for Newborn Screening

The Newborn Screening (NBS) is one of KSCDR supported Programs and considered to be one of the most effective public health programs that has an ultimate goal for prevention of mortality, morbidity, and disabilities through early detection of disorders that are potentially treatable and before the development of symptoms, thereby, allowing for early intervention and case management. Currently, the Saudi National Newborn Screening Program screens for 17 metabolic and endocrine disorders. Prevalence of these conditions in Saudi Arabia is estimated to be around one affected newborn per 1000 screened and considered to be one of the highest prevalence worldwide.

Screening is achieved through the analysis of few drops of blood collected from the newborn's heel and spotted on specific filter paper cards containing all required demographics of the infant and parents. The collection is mostly done after 24-48 hours of birth. Screening test includes certain metabolic and endocrinal disorders. If the initial and the retest of the first dried blood sample (DBS) turn to be positive, then a recall/ second DBS sample along with other samples (urine or plasma) if applicable are requested of the same newborn from the referral hospital. When received, if the analysis result is still positive an abnormal report will be generated and sent to hospitals. If further confirmation testing is needed, then a specific diagnostic test for the disorder will be initiated to confirm the diagnosis (figure1).

Achievements of this project includes

- The screening panel of the NBS Program includes 17 disorders (see table 1).
- One additional Hospital joined giving a rise of a total of more than 190 hospitals participated in the program.
- The total number of newborns screened during 2018 was 80069. The distribution of the samples throughout regions is shown in (figure 2).
- The total number of cases detected during 2018 was 47 cases. The distribution of detected cases per region is illustrated in (figure 3A & B).
- CH then CAH followed by MMA were the highest detected cases during 2018. (Figure 4) showed the number of cases detected during 2018.
- The total number of screened Newborns since the beginning of the Program was 1182468.
- The accumulative disorders prevalence per 100000 newborns screened from August 2005 until December 2018 of each disorder is demonstrated in (figure 5).
- Total number of received and tested sick babies during 2018 was 7094.
- Number of samples received from major hospitals participated in the Program till December 2018 is illustrated in (figure 6).
- Total Number of cases discovered since the establishment of the NBS Program from August 2005 till December 2018 was 1046 See (figure 7).
- The following Manuscript was published,
- The Prevalence of Phenylketonuria in Arab Countries, Turkey, and Iran: A Systematic Review. El-Metwally A, Yousef Al-Ahaidib L, Ayman Sunqurah A, Al-Surimi K, Househ M, Alshehri A, Da'ar OB, Abdul Razzak H, AlOdaib AN. Biomed Res Int. 2018 Apr 18; 2018. PMID: 29850564.

Future Directions

One of the country's 2030 visions is to achieve the "Vibrant Society with Strong Foundations" theme that aims to offer a fulfilling & healthy life through improving healthcare service by ease of access to healthcare services and strengthen prevention against health threats. Accordingly, future efforts will be continued to attain this aim through the following:

1. Preparations of a comprehensive newborn screening guideline to unify and enhance the quality of the newborn screening laboratory and improve the provision of its diagnostic services. Expanding screening accessibility and coverage of countries newborns through enrollment of more clients from private & university hospitals.
2. Preparation toward establishment of a unified registry platform for disorders included in the newborn screening program.
3. Conducting more of population data research in addition to metabolomics research that eventually will assess in evaluating and enhancing the effectiveness of the screening process.

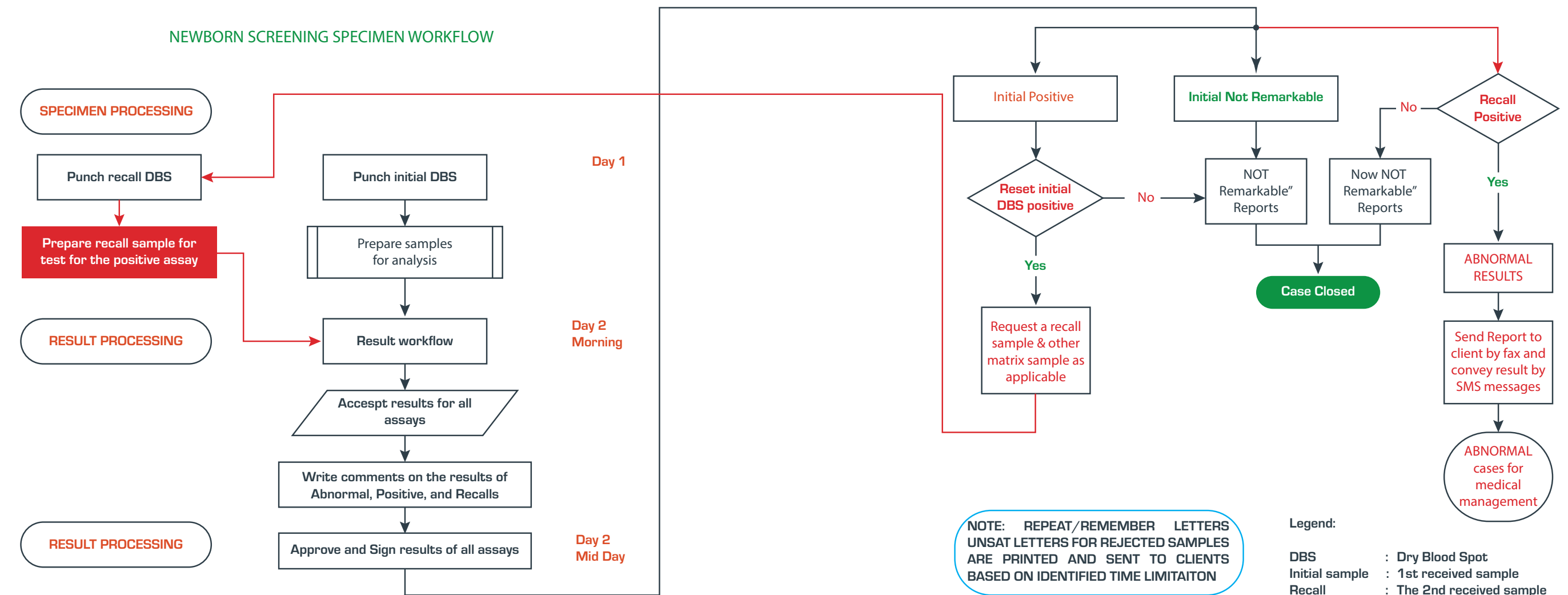


Figure 1: The newborn screening workflow.

Disorders Included in the Program
(Phenylketonuria (PKU
(Maple Syrup Urine Disease (MSUD
(Argininosuccinate Lyase deficiency (ASL
(Citrullinemia (CIT
(Propionic Acidemia (PPA
(Methylmalonic Acidemia (MMA
(Glutaric Acidemia type-I (GA-I
(Isovaleric Acidemia (IVA
(MCC 3) Methylcrotonyl-CoA Carboxylase Deficiency-3
(Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD
(Very Long-Chain Acyl-CoA Dehydrogease Deficiency (VLCAD*
(Methylglutaryl-CoA Lyase Deficiency (HMG-3-Hydroxy-3
(Beta-Ketothiolase Deficiency (BKT
(Biotinidase Deficiency (BTD
(Galactosemia (GALT
(Congenital Hypothyroidism (CH
(Congenital Adrenal Hyperplasia (CAH

Table 1: Disorders included in the Newborn Screening Panel

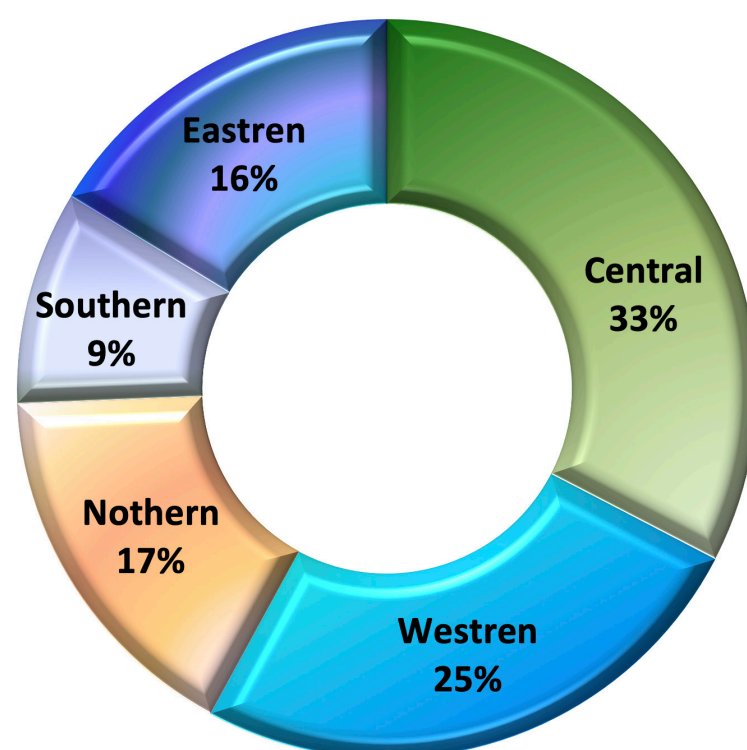


Figure 2: Regional distributions of NBS samples received during 2018

Regional Distribution of Cases Diagnosed During 2018

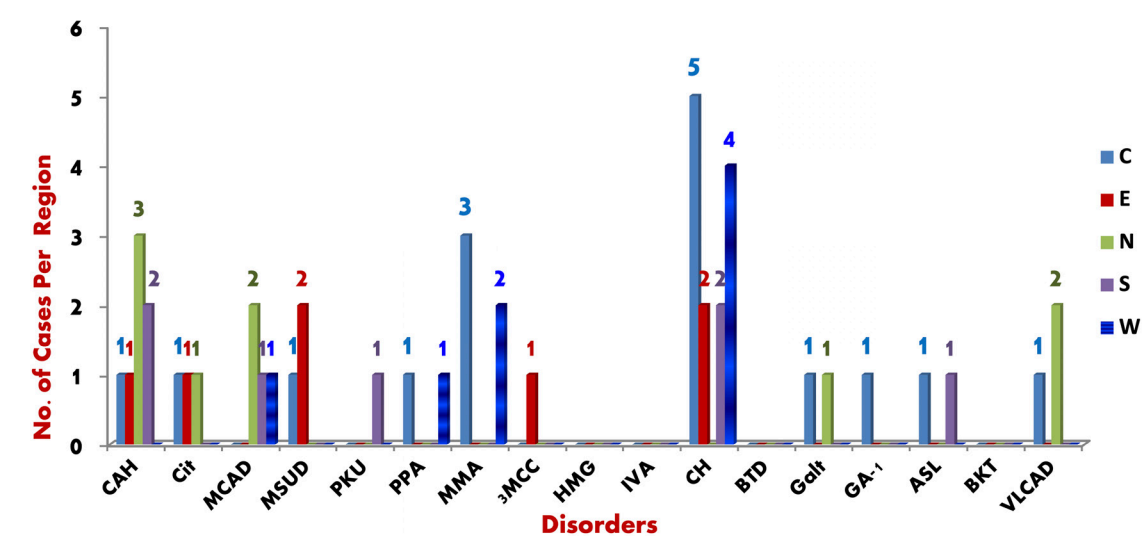


Figure 3A: Demonstrates regional distribution of each disorder during 2018

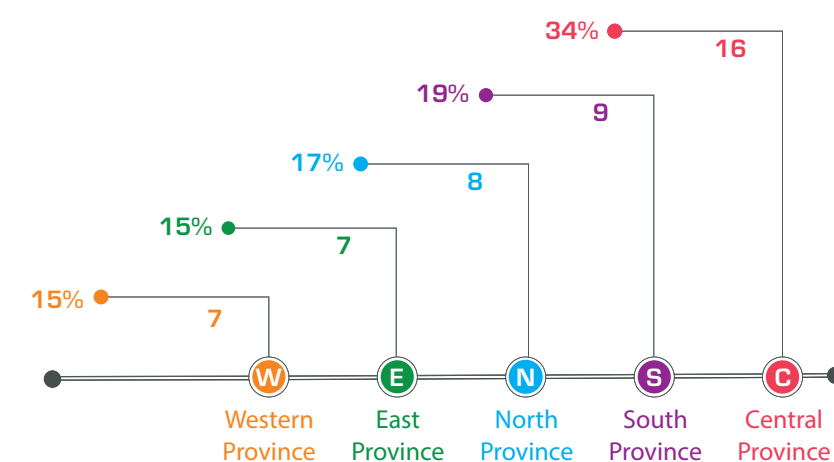


Figure 3B: Shows the total number of detected cases per regions during 2018.

Number of Screened Confirmed Disorders 2018

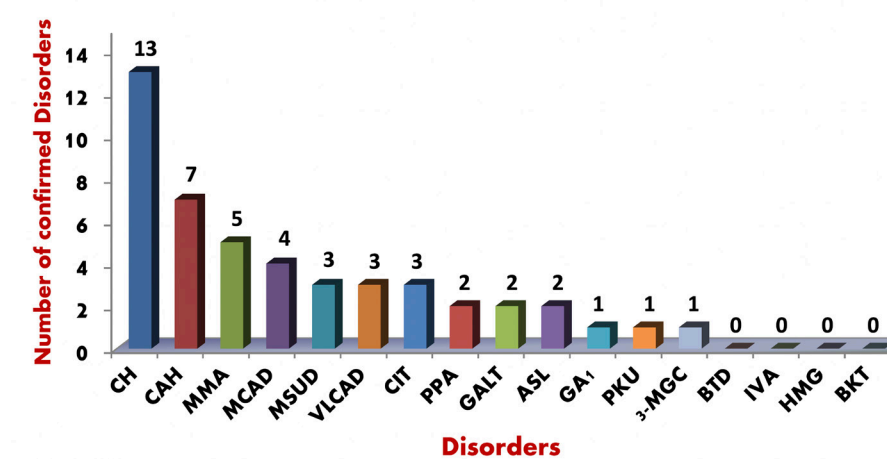


Figure 4: Showing the number of disorders detected during 2018

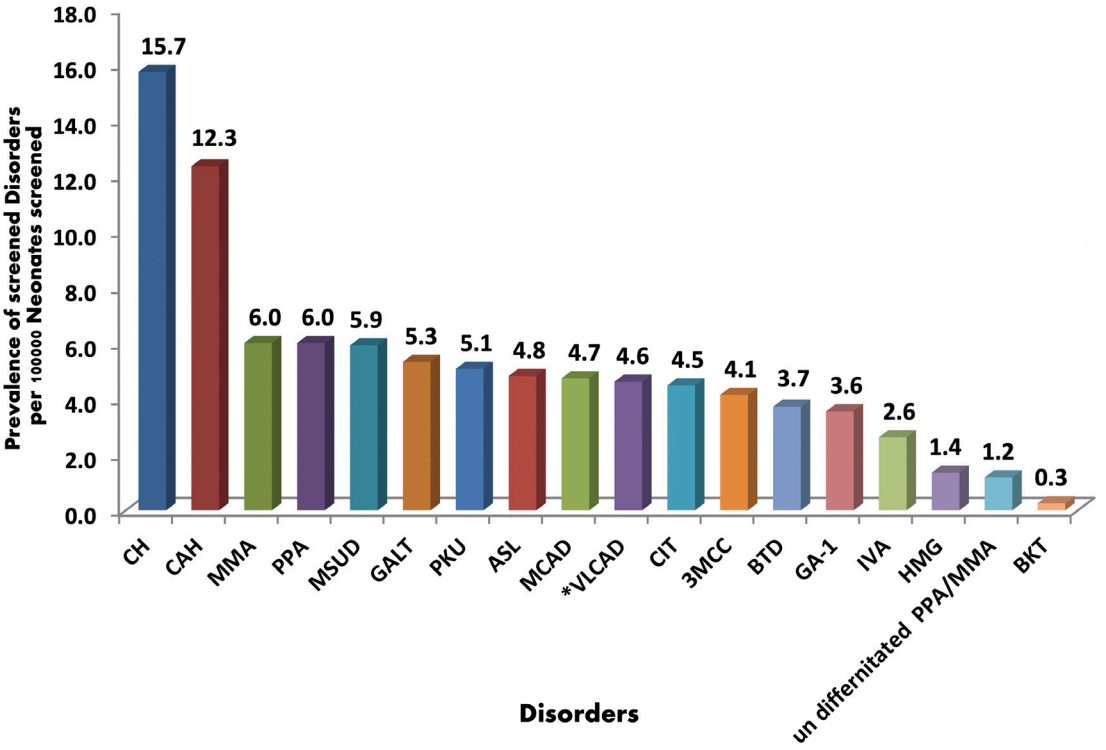


Figure 5: Demonstrating the accumulative prevalence of each disorder per the total number of newborns screened during the period August 2005- December 2018 which is 1182468 newborns.

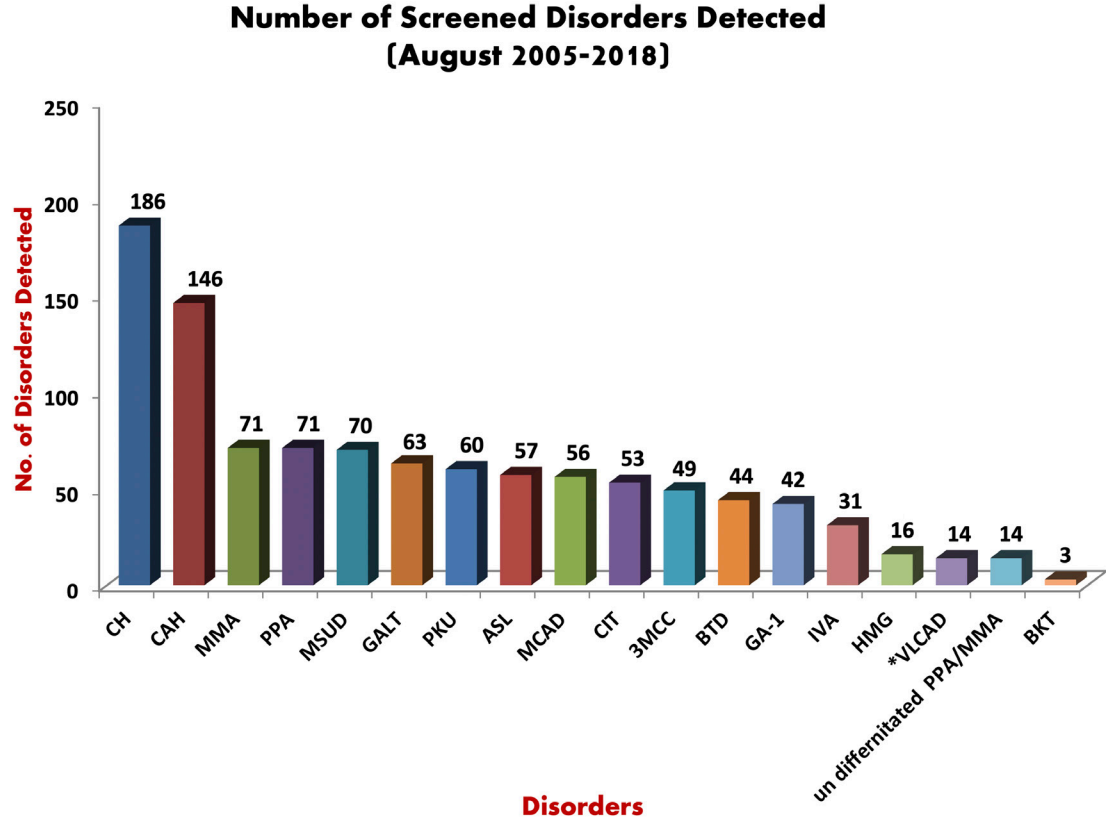


Figure 7: Shows the number of disorders detected since the beginning of the NBS Program (August 2005- December 2018).

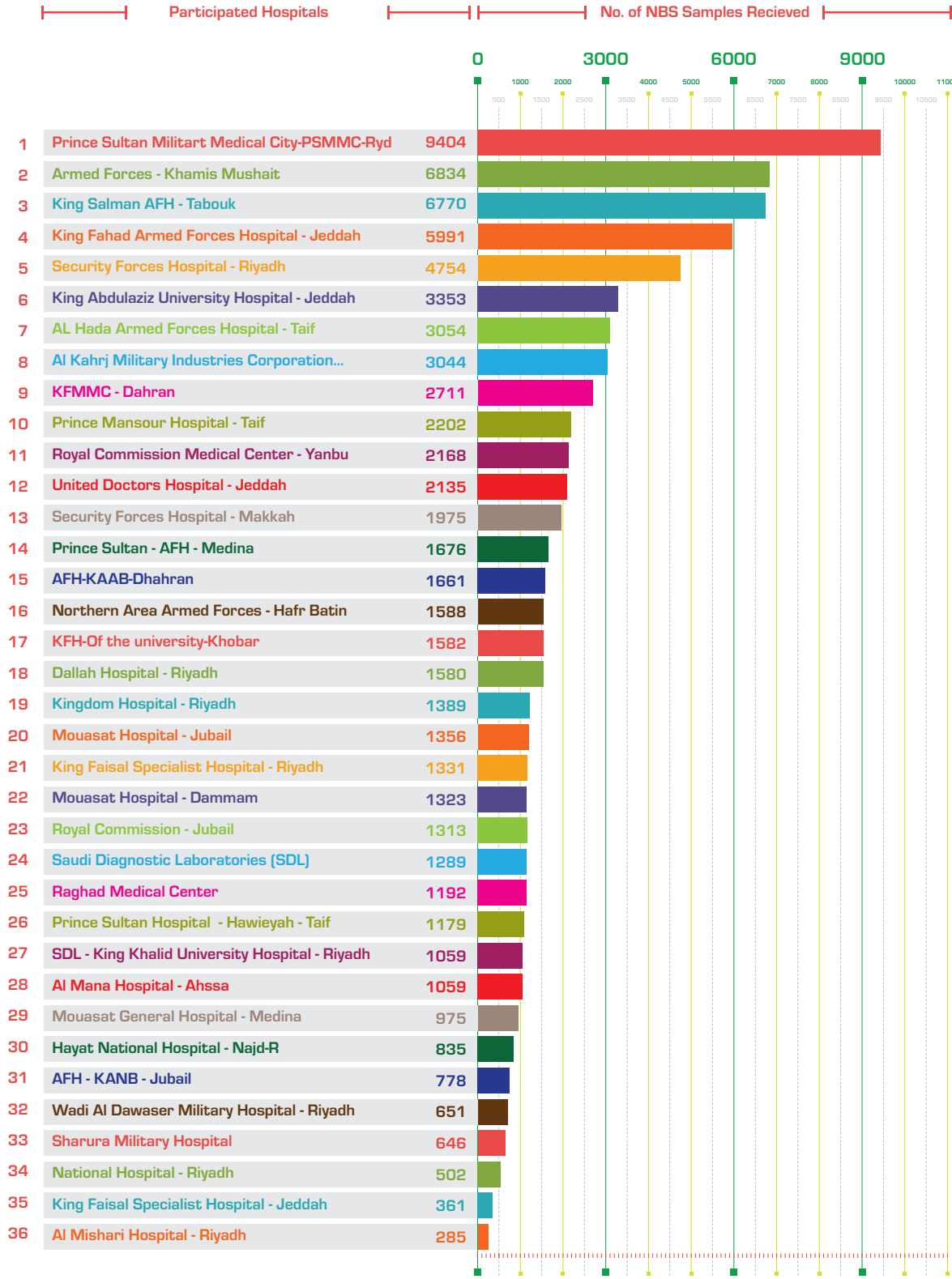


Figure 6: Demonstrating the number of newborn samples received from major participated hospitals during 2018

The Framework of Reference to Access the General Curriculum for Students with Disabilities in GCC

Background and objectives of the project

The aim of this frame is to support the access of students with disabilities to the general curriculum in their educational institutions as an alternative to the special curriculum by clarifying the concept and nature of the general curriculum for teachers of general education and special education, so as to help them to understand the dimensions of this curriculum, its elements and types, and the importance of their access to the curriculum General. It aims to provide these teachers with a deep understanding of the nature of access to the general curriculum of these students and the mechanisms by which such access can be supported. In addition to explaining how these students benefit from the general curriculum in a way that corresponds to the abilities of each student. Help them in how to plan the access of the general curriculum in a way that ensures that students with disabilities learn without underestimating their ability and in a deeper way to integrate them.

Final completion of the second part of the project (Practical and Scientific guide preparation)

- Working in a team to prepare the practical and scientific section of the whole frame in each dialog and design and remove it in its final form.
 - Preparation and design of the "Trainer's Manual" for the frame, which contains instructions and procedures for training and its mechanism.
 - Prepare and Design "Trainee Manual" which includes activities to be offered to trainees to ensure that they are familiar with the content provided to them.
 - Design and output of the application frame, which contains all the activities found in the trainee's guide.
- The training program was offered in:
 - ◊ Kingdom of Bahrain on 26-27/4/2018 in cooperation with the Ministry of Education of the Kingdom of Bahrain.
 - ◊ Kuwait on 26-27/9/2018 in cooperation with the Ministry of Education in Kuwait.
 - ◊ Kingdom of Saudi Arabia on 3-4/10/2018 in cooperation with the National Center for Vocational Education in the Ministry of Education.
 - ◊ United Arab Emirates on 4-5/11/2018 in cooperation with the Ministry of Education at the Teacher Training Institute in Ajman.
 - ◊ Sultanate of Oman on 5-6 / 12/2018 in cooperation with the Ministry of Education in Muscat.



After the completion of the training program, a comprehensive review of all the evaluations issued by the training programs provided and the development of the final additions to the bag was done, where:

- Taking all the visuals from the training programs established in the Kingdom of Bahrain, Kuwait, the Kingdom of Saudi Arabia, the United Arab Emirates and the Sultanate of Oman and adding the contents and axes based on the proposals received.
- A final review of all the contents of the frame has been made to ensure that any design and output errors are free.
- The portfolio is finalized and its contents (Trainer's Guide and Trainee's Guide) delivered to King Salman Center and the Education office.
- His Royal Highness the Chairman of the Board of Trustees inaugurated the terms of reference for students with disabilities to the general curriculum in the presence of the

Minister of Education and members of the Board of Trustees.

- Design of paper copies as well as digital copies to be published after approval for publication by King Fahd National Library.
- It will be uploaded on the center's website in preparation for its publication to all sectors and destinations.
- A plan of action will be developed for all regions of the kingdom to provide the frame through a group of trainers from different regions of the kingdom after being trained in the center.
- The project was completed by the end of December 2018.

The terms of reference for pupils with disabilities have been issued to the general curriculum

This release is the result of the distinctive partnership between the King Salman Center for Disability Research and the Arab Bureau of Education for the Gulf States, which aims to provide

the necessary support for students with disabilities, to reach the general curriculum in the comprehensive school and the less restrictive environments and to give these students skills Academic, social and integration with their regular peers. This frame seeks to support the efforts of the Member States of the Arab Bureau of Education for the Gulf States in achieving equal opportunities for all students.

The frame of reference is divided into four publications (registered in the King Fahd Library):

- Theoretical and theological aspects (Deposit No. 10421/1439 ISBN 5-427-15-9960)
- And the practical and scientific side (deposit No. 10424/1439 ISBN-727-15-9960- x)
- Trainer's Manual (ISBN 10423/1439 1-726-15-9960)
- Trainee's Manual (ISBN 10422/1439 3-725-15-9960)

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