GOVERNMENT OF INDIA
MINISTRY OF HEALTH AND FAMILY WELFARE
DEPARTMENT OF HEALTH RESEARCH

LOK SABHA
STARRED QUESTION NO.70
TO BE ANSWERED ON THE 23RD JULY, 2021

RESEARCH ON RARE GENETIC DISEASES

*70. DR. ARVIND KUMAR SHARMA:
DR. BHARATIBEN DHIRUBHAI SHIYAL:

Will the Minister of **HEALTH AND FAMILY WELFARE** be pleased to state:

(a)   whether the Government proposes to ramp up dedicated research & development on rare genetic diseases like spinal muscular atrophy and others along with the deployment of available resources for treatments to get maximum health gains for patients suffering from such diseases;

(b)   if so, the details thereof;

(c)   if so the details of the steps taken by the Government to improve Telehealth services and other Digital health services for citizens across the national in order to achieve "Health for all";

(d)   whether the Government is taking measures to ensure immunization of those who have been left out during the COVID pandemic under Indradhanush 3.0; and

(e)   If so, the details thereof?

ANSWER
THE MINISTER OF HEALTH AND FAMILY WELFARE
(SHRI MANSUKH MANDAVIYA)

(a) to (e):   A Statement is laid on the Table of the House.

(a) and (b) To ramp up dedicated research and development on rare genetic diseases, Indian Council of Medical Research (ICMR), an autonomous body under the administrative control of the Department of Health Research, has created a Task Force on Rare Diseases. Under this Task Force currently, project proposals are being funded on diagnostic research, interventions and on understanding of rare disease mechanisms. These projects are focusing on diseases like Primary Immunodeficiency disorders, Trigeminal Neuralgia, Amyloidosis, Neuromyelitis Optica, Alport Syndrome, etc.

Recently ICMR has also set up a Registry on Rare Diseases. This Registry is focusing on storage disorders, Small Molecule Inborn Errors of Metabolism (IEMs), Skeletal dysplasias, Primary Immune deficiencies, Neuromuscular Disorders and Hematological Disorders.

Council of Scientific and Industrial Research (CSIR) through its constituent laboratory, CSIR-Institute of Genomics and Integrative Biology (CSIR-IGIB) is working in the area of molecular genetics of neurodegenerative disorders, biology of neuromuscular diseases, and is involved in developing genetic screening methodologies for Duchhene Muscular Dystrophy and Spinal Muscular Dystrophy.

(c) Government recognizes the immense potential of digital technologies in improving health care delivery. In this regard, various initiatives have been taken for implementing digital health services in an integrated manner at both the central and state level.

Telehealth Services: eSanjeevani Application- National Telemedicine Service – eSanjeevani has been rolled out on 13th April, 2020 in the country.

- eSanjeevani comprises of two variants of eSanjeevani namely - doctor to doctor (eSanjeevani AB-HWC) telemedicine platform and patient to doctor telemedicine platform (eSanjeevaniOPD) which provides outpatient services to the citizens in the confines of their homes. Currently the eSanjeevani application is operational in 35 States and has rendered around 78 lakh consultations.

- To ensure safe and secure implementation of telemedicine services across the country, the National Medical Commission has issued Telemedicine Practice Guidelines in March 2020 to enable registered medical practitioners to provide healthcare using telemedicine. ICMR is also working in the domain of Tele health to achieve "Health for all".
- eSanjeevani application has also been integrated with country's 3.74 lakh Common Service Centres (CSCs) to enable telemedicine services to the remotest area of the country
- Financial support has been provided to States/UTs under National Health Mission for implementation of Telemedicine.

National Health Policy, 2017 advocates extensive deployment of digital tools for improving the efficiency and outcome of healthcare system. The policy aims at an integrated health information system which shall serve the needs of all stake-holders and shall facilitate improvement in efficiency, transparency, and citizen experience.

For establishing a comprehensive, nationwide integration of Digital Health Ecosystem, MoHFW has released **National Health Digital Blueprint (NDHB)-** an architectural framework for digital interventions in October 2019.

Implementation of **National Digital Health Mission (NDHM)** was announced on 15th August 2020 with vision to create national digital health ecosystem that supports universal health coverage in an efficient, accessible, inclusive, affordable, timely and safe manner.

Currently, NDHM is being implemented in 6 Union Territories (Andaman & Nicobar Islands, Chandigarh, Dadra & Nagar Haveli and Daman & Diu, Lakshadweep, Ladakh and Puducherry) in Phase- I.

A large number of applications such as Maternal & Child Health Tracking application, NCD application, IHIP, Nikshay, Covid-19 portal etc. provides required data driven insights in implementation of various health programs.

To augment the Digital Health infrastructure with a view to aid data driven insights and ensuring availability of healthcare delivery in rural and remote areas, additional support is being provided under Emergency Covid Response

Package II to augment telehealth services and implementation of Hospital Management Information System (HMIS).

(d) and (e)   Two rounds of Intensified Mission Indradhanush (IMI) 3.0 were conducted from February 2021 to March 2021, to ensure immunization of those who have been left out during the COVID pandemic. A total of 250 districts were identified across 29 states/UTs, based on factors like immunization coverage and burden of vaccine preventable diseases, where more than 9.5 lakh children and 2.24 lakh pregnant women were vaccinated under IMI 3.0.

*****