

# Hearing Care Program and Registry in the UK and US: A Review Study

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## Abstract

**Introduction:** Hearing loss is a significant yet preventable health issue. Accordingly, the national health hearing program was introduced by WHO for prevention, detection, and early management of the hearing disorders. Therefore, the purpose of this study was to review the hearing care program and its registry in the US and UK to identify the approaches of these countries to hearing loss.

**Method:** This study reviewed the US and UK hearing care programs in 2019. The search for finding the relevant studies was conducted using appropriate combinations of the following keywords: surveillance system, national survey, hearing loss/disorder/impairment, population-based disease registry, United Kingdom (UK) and United States (US). For data collection, the search was performed in databases and websites, such as the World Health Organization and active organizations relevant to the subject of research in selected countries. Due to the importance of the issue and the necessity of reviewing all documents, the search was conducted without specifying the time period and type of paper. The collected data were summarized and reported through analysis of the content of retrieved studies and in line with the objectives of the study. Sixteen out of 78 retrieved studies related to the study objectives were reviewed.

**Findings:** Efforts to establish a hearing care program in the US and UK showed that hearing care is a national priority. The hearing care program in the studied countries has similarities and differences. The existence of a centralized policy-making system and the development of national hearing care programs were the most important similar aspects of hearing care systems in the two countries. There was, however, a difference between the two countries in relation to the extent of using the information system for hearing loss. It was found that the system collected national data on hearing care program in the US at the state level, and in the UK at the national level. The data are monitored by the Center for Disease Control and Prevention in the US and by the National Center for Health Statistics in the UK based on the determined indicators. In addition, based on the needs of both countries, there was a National Temporal Bone, Hearing, and Balance Pathology Resource Registry in the US and National Bone Conducting Hearing Implant (BCHI) Registry in the UK.

**Conclusion:** Having a robust structure of the hearing system, identifying executive mechanisms (including policy-making authorities), and the existence of national operational programs can increase the success of hearing care programs. In addition, the existence of information systems and registries is an essential requirement for the formation of hearing care systems that helps to draw the hearing health status of the community and enables the monitoring of the goals by providing accurate, timely, and high-quality information.

**Keywords:** Hearing Care Program; Registry; hearing loss/ disorder;

## Introduction

Hearing loss is a very important public health concern because it can affect the lives of individuals, families, and societies (1-4). The most important effects of hearing loss and

deafness are negative health consequences (increase in mortality rate and reduction in the quality of life) (5-7) as well as negative socioeconomic implications (loss of employment, economic power, and productivity) (8-11)). According to the 2018 hearing status report of the World Health Organization (WHO),

6.1% of the global population (466 million) live with disabling hearing loss (12), while 60% of these disorders are avoidable or curable (13, 14). In this regard, the WHO approved the WHA48.9 resolution aiming to prevent hearing loss and deafness through evidence-based interventions to identify, prevent, treat, rehabilitate, and support persons with hearing loss. In order to achieve these goals, the WHO has called on countries to adopt and implement a national plan for the prevention and control of the main causes of preventable hearing loss and early identification and management as part of the primary healthcare system (13-15). Accordingly, various countries implemented a hearing care program to meet the WHO goals of preventing and managing hearing loss. The purpose of this study was to investigate the hearing care program and its registry in the United States (US) and the United Kingdom (UK).

## Method

The present research was a review study conducted in 2019 on the hearing care programs of the US and UK. To collect data, search was performed in the databases of Science Direct, PubMed, Google Scholar, Scopus, and reputable websites such as the WHO and those of active organizations relevant to the research topic in the selected countries. Due to the importance of the issue and the necessity of reviewing all documents, search was conducted without specifying the time period and type of paper and using appropriate combinations of the following keywords: national action plan, hearing loss/disorder/impairment, population-based registry, disease registry, and surveillance system. The collected data were summarized and reported using content analysis techniques and based on the objectives of the study. Sixteen out of 78 retrieved studies related to the study objectives were reviewed.

## Background

The development of a hearing care program helps prevent and control hearing loss and deafness in different countries and can contribute to the WHO goals at the national level. The status of the hearing care program in the US and UK is reviewed in detail below.

### Hearing care program in USA

Hearing-related health promotion policies in the US have been included by the Office of Disease Prevention and Health Promotion (ODPHP) in the form of healthy people strategies. The US Department of Health and Human Services (DHHS) is responsible for defining the goals of "Hearing and Other Sensory or Communication Disorders" in Healthy People strategies. This forms the overall goal of Healthy People 2020 in the field of hearing, i.e. reducing the prevalence and severity of hearing and balance, smell and taste, voice, speech, and language disorders and focusing on other issues such as newborn hearing screening, ear infections, and tinnitus (16, 17). In this regard, the hearing care program was developed by the Center for Disease Control and Prevention (CDC) in the 1980s to track children with hearing loss. The main purpose of this program was to identify potential risk factors for hearing loss and assist service providers to

determine the burden of disease and disorders, estimate the cost of services, and support the required resources. The Early Hearing Detection and Intervention (18) of the CDC interacts with different states to ensure that screening processes (before one month of age), diagnostic auditory test (before three months of age), and intervention services (before six months of age) are provided for children. In fact, the three main components of the EHDI program include screening, diagnostic evaluation, and interventional services. The CDC's activity in the field of hearing care is focused on raising awareness of the risk factors that can increase the odds of hearing loss in children, which is useful in educating people about methods to prevent hearing impairment (16, 19). With the participation of other states and national agencies, the CDC develops the goals and performance indicators in the area of hearing health. Several sources are employed to develop these goals and indicators, including state guidelines and the statements by the American Academy of Pediatrics and the Joint Committee on Infant Hearing (20, 21). The CDC also conducts two national surveys entitled "National Health and Nutrition Examination Survey" (NHANES) and "National Health Interview Survey" (NHIS) (22). NHANES is a research program designed in the 1960s to assess the health and nutrition status of adults and children, which combines interviews and physical examinations. The findings of this study are used to identify the underlying causes of illness (23). Moreover, NHIS is the primary source of information on the health of the civilian population, whose primary objective is to monitor the health of the US population by collecting and analyzing data in a wide range of health topics (24). The two above-mentioned programs are the most important data collection programs at the National Center for Health Statistics (NCHS) in the US, which is a part of the CDC. Hearing impairment is one of the diseases and health indicators covered by these programs, collecting the information needed to assess the ear and hearing health care (in the form of audiometric tests) at the national and state level for all demographic groups as well as estimates of the incidence of hearing loss in different age groups (25, 26).

In the United States; health services, medical treatment, prevention and rehabilitation of hearing loss are provided by nongovernmental and private organizations, and fewer public organizations participate in the implementation of these programs. The collection of health-related hearing data in the Healthy People 2020 strategy is performed by the National Center for Health Statistics (NCHS) and the monitoring of the targets by the CDC (17). Each of the organizations (governmental and non-governmental) participating in the US hearing care program has an independent database whose data are derived from activities and programs. Each state has an EHDI information system for integrity in collecting auditory care data. The EHDI Information System is designed to provide data systematically and continuously; analyze and interpret data during schedules (screening, evaluation, diagnosis, and intervention) which are used to conduct activities; plan, implement, and evaluate programs; and develop research hypotheses (21, 27, 28).

Treatment centers and hospitals report hearing data to the state EHDI through the state information system, auditory

experts, and ear, nose, and throat (ENT) specialists by standard paper forms or Web-based systems. Therefore, the process of data collection on hearing impairment starts with hearing service provider centers, and the data are then sent to local and state health centers. Data reporting is obligatory from production to the local and state levels but is optional from the state level to the CDC (27). Given that the focus of collecting hearing health data in the US falls under the responsibility of the NCHS, the data collected from the state level are sent to the Center and then processed according to the indicators of auditory objectives of Healthy People 2020 strategy. In addition, the Center collects the demographic auditory care data through various national surveys and ultimately provides an overview of the state of hearing health in the US (19, 27). Based on the information from the National Center for Health Statistics, the CDC follows the goals set out in the Hearing and Other Sensory or Communication Disorders “ section of the Healthy People 2020 strategy (27).

Since the temporal bone is one of the most valuable sources for identifying and learning the pathology and pathophysiology of hearing disorders, the National Institute on Deafness and Other Communication Disorders (NIDCD) created the National Temporal Bone, Hearing, and Balance Pathology Resource Registry (29). This registry is regarded as a source of information for scientists worldwide to analyze data on temporal bone specimens. The database of this registry system contains information on bone samples stored in various laboratories from across the US (30).

### **Hearing care program in UK**

The activities related to hearing impairment programs in the UK were initiated by the Royal National Institute for Deaf People (RNID), aiming to protect, care for, and provide access to hearing care services (31). Following the formation of the NHS in 1948, hearing-related care activities e.g. fees, home-based hearing care, and hearing aids services were assigned to the organization. In 2000, which was the beginning of the new millennium in the UK Hearing Care program, the structure of the NHS Auditory System was revised and modified (32). Thus, given the high prevalence of congenital permanent hearing impairment, the National Newborn Hearing Screening Program (NHSP) was approved by the UK National Screening Committee (UK NSC) and the management of the program was delegated to the Public Health England (PHE) in order to identify hearing impairment in newborns. This program offers screening tests, referral to the NHSP, and provision of urgent care, which is based on the early identification of hearing impairment (33, 34).

The PHE has created the National IT system known as Smart for Hearing (S4H) which collects data related to hearing impairment in order to support the new born auditory screening program and manage the data from hearing care programs. In this system, immediately after the screening process is completed, hearing care data are collected by care providers. A portion of the data is also transmitted online by the screening equipment to the system (34, 35). The system supports both hospital and community-based screening programs and also provides data for

the audit and development of services. The following activities assist the system in achieving these goals: interacting with different registries such as the registry of birth, empowering care providers to manage infants during treatment, identification of talented people for screening and improving screening coverage, continual storage of screening results, ensuring the integrity of the NHSP screening data in the UK, facilitating the sharing of information with other services (such as audiology), and reporting and performing national and local audits (34).

The Elderly Hearing Care Program is also based on a project entitled “Assessment of Hearing in the Elderly: Aging and Degeneration-Integration through Immediate Intervention” (AHEAD III). This project was carried out between 2008 and 2011 in Europe, including the UK, to achieve the following objectives: Provide evidence the effects of hearing impairment in the elderly people; establishment of minimum requirements for screening methods and diagnostic techniques; development of guidelines for the successful implementation of screening programs using various methods; analysis of protocols and models for localization in accordance with local, social, and economic conditions of a country or region; and assessment of the cause, epidemiology, and effects of age-related hearing impairment, screening techniques, and diagnostic methods. Within the framework of this project, the hearing screening program for adults and older adults was run in the UK as a pilot, and a conceptual model of auditory screening was developed (36). However, the UK National Screening Committee currently does not support hearing screening for the elderly (37).

Upon the introduction of hearing impairment as a crucial public health issue, the UK government sought to limit this disorder through the development of a national strategy for hearing impairment (38). As a result, the Department of Health (DoH), NHS and Public Health England (PHE) assumed responsibility for policymaking and developing the Hearing Loss Action Plan in the National Hearing Impairment Strategy. The main goal of this program was improving activities and bringing about changes in all state and private sectors in order to provide better auditory services and outcomes and further support those with hearing impairment. This operational program focused on the prevention, early detection, treatment, and support for people with hearing impairment in all age groups. Then, a framework for clinical commissioning groups was developed by the NHS with the main aim of supporting clinical care providers in order to make appropriate decisions with regard to the target population and provide integrated, high-quality, and continuous care for meeting the needs of people with hearing impairment (33, 39). It presented a list of key performance indicators for meeting local needs in the following service domains: auditory services for infants and children (0-17 years) and adults (>18 years) with hearing impairment. Strategic auditory programs in the UK are directed by regional teams. In each district as per the division made by the UK health organization, these teams interact with local authorities and clinical commissioning groups (CCGs) (39, 40).

In addition to the National Information Technology (IT) system, the Bone Conducting Hearing Implant National Registry (BCHI registry) was developed by Ear Foundation aiming at collecting information about the users of the UK Bone Conducting Hearing Implant system. The mission of the bone conducting hearing implant national system in the UK is to increase awareness of the use of bone conducting hearing implant; improve evidence supporting the implant for individuals, families,

and professionals; and notify authorities for policy-making and planning. The data required for the registry system are collected from 21 hearing care centers all over the UK and entered in the system (41).

### Findings

The findings of the present study on hearing care programs in the US and UK are given in Table-1.

**Table 1:** Comparison of hearing care programs in the US and UK

US and UK Comparative Criteria	US	UK
<b>Hearing care program</b>	-EHDI in line with the Healthy People 2020 strategy	-National Operational Hearing Impairment Program - NHSP
<b>Objectives</b>	-Identification of potential risk factors for hearing impairments and assisting service providers and interventions to determine the burden of disease and disorders, estimate service costs, and support the resources needed - Auditory screening of infants before the age of one month; performing a hearing diagnosis evaluation before three months; timely and appropriate interventions before six months of age; early identification of children with late, progressive, or acquired hearing impairment; home health services for all infants with hearing impairment	- Improvement of hearing health for all individuals - Reduction of injustice by preventing hearing impairment - Special attention to the early identification of hearing impairment in groups with a higher risk and prevalence - Patient-centered and coherent management - Support for people with hearing impairments and deafness (personal, social, and welfare support)
<b>Indicators</b>	-National indicators for screening, diagnostic, and auditory intervention	National hearing screening indicators
<b>Organization responsible for policy planning and national hearing care objectives</b>	Office for the Prevention of Diseases and the Health Promotion	<ul style="list-style-type: none"> <li>• UK Health Organization</li> <li>• NHS</li> <li>• PHE</li> </ul>
<b>Organization responsible for Monitoring the hearing care objectives</b>	CDC	<ul style="list-style-type: none"> <li>• National Health Statistics Center</li> <li>• PHE</li> </ul>
<b>Implementation of hearing care programs</b>	Decentralized and state-run	Centralized and national
<b>Hearing care/registry information system</b>	<ul style="list-style-type: none"> <li>• EHDI Information System focused on the State EHDI Information System</li> <li>• National Temporal Bone, Hearing, and Balance Pathology Resource Registry</li> </ul>	<ul style="list-style-type: none"> <li>•National Information Technology System</li> <li>National BCHI Registry</li> </ul>

### Discussion

The realization of the goals of the WHO for preventing and controlling hearing loss requires the provision of health-related hearing care programs. For this purpose, each country has adopted a different approach to the implementation of these programs based on their health care system. In the United States, although hearing care was not considered as a national health priority, the high prevalence of hearing impairment and deafness in the country motivated the policy-makers to pay special attention to hearing care topics. Thus, given that national health policies are centrally adopted by the DHHS, national health care policies have been designated by the DHHS as part of the Healthy People 2020 hearing section in contrast, in the UK, hearing care

is considered as a national health priority, and hearing-related health policies have been centrally and jointly developed by DoH, NHS and PHE. Depending on the focus of the US private and non-governmental system on healthcare delivery, decentralized hearing care services are provided by the healthcare sector in different states. In the UK, focusing on the provision of health services by the public sector and the DoH, NHS and PHE provide focused hearing care. In both countries the data resulting from the implementation of hearing care activities and programs are collected by the information system and sent to the NCHS for monitoring and analysis. In order to provide a comprehensive view of hearing care, attention to the wide range of data produced for hearing care from different sources is necessary. Much of this data is generated during the provision of hearing-care services by

healthcare provider organizations. Therefore, the most important aspect of the similarity of the auditory information system from data collection in the studied countries is the collection of all data related to hearing care. Other similarities included having a comprehensive view of hearing care data collection through research, monitoring systems, health information, and registry systems. In the studied countries, registries and information systems are based on the needs and priorities for collecting hearing care data. Nevertheless, the difference between the two countries is that, in the US, each state has an independent EHDI program, affiliate programs are independently controlled by each state, each state makes its own protocols, standards, and quality assurance procedures, and CDCs merely suggests measures in the form of a proposal. Each state also has an Early Hearing Detection and Intervention information system (EHDI-IS) for managing data related to the EHDI program and collects hearing care data (screening, diagnosis, interventions, and actions) by the system, and then the data from the state level are reported to the CDC. This center has a data reporting system and requests each state to provide its information on the number of children screened, diagnosed, and received by the intervention. As the system is voluntary, there are weaknesses in the data, and the lack of follow-up at all stages of the EHDI program is one of the major dilemmas in the country. In the UK, however, the IT system has national-level hearing screening, all centers in the system directly report hearing care data, and monitoring is performed centrally. Hearing care data are automatically reported to the system through screening equipment or directly by care providers.

## Conclusion

Hearing loss is a significant public health issue, leading to negative health consequences for society, e.g. reducing the economic and social power, productivity, and the life quality of individuals. Consequently, it is essential to develop programs or take actions to control and prevent hearing loss. In this regard, the findings of this study indicated the importance of developing a hearing care program to achieve goals such as preventing and controlling hearing impairment in different societies and the first step in providing hearing care services is the development of a comprehensive and integrated hearing management program. Access to high-quality information is the main component of hearing care programs, which requires the availability of information systems and the registry of hearing impairment. Creating a hearing information system and designing a high-quality hearing impairment registry requires attention to the experience of other countries, especially developed countries. Accordingly, one of the most noticeable points in the development of the hearing care program and registry is attention to the governing structure of the health care system. In a country like the US, the establishment of a decentralized and state-run hearing care system and registry can meet the information needs of the country, while this program can be nationally enforced in a country such as the UK. The necessity for data transmission (UK) against voluntary reporting of data from the state level to the national level (US) also depends on the structure of the country's care system. As a result, one must pay attention to

the structure of the governing health care system in designing a hearing care program and creating an information system and a registry. Furthermore, considering the successful experience of other countries, the integration and utilization of various types of hearing care-related information are recommended for the success of the care program.

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