iJRASET
International Journal For Research in Applied Science and Engineering Technology



INTERNATIONAL JOURNAL FOR RESEARCH

IN APPLIED SCIENCE & ENGINEERING TECHNOLOGY

Volume: 14 **Issue:** X **Month of publication:** October 2026

DOI: https://doi.org/10.22214/ijraset.2026.85336

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International Journal for Research in Applied Science & Engineering Technology (IJRASET)
ISSN: 2321-9653; IC Value: 45.98; SJ Impact Factor: 7.538
Volume 14 Issue X Oct 2026- Available at www.ijraset.com

DMD Sathi: A Personalised Digital Care Guidance System for DMD Patients & Parents

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Abstract: ***Duchenne muscular dystrophy (DMD) is a progressive X-linked neuromuscular disorder that requires continuous, multidisciplinary care involving neuromuscular specialists, rehabilitation, nutrition, respiratory and cardiac monitoring, medication management, and emergency planning. Families may face difficulty locating understandable and locally relevant information, particularly when information is available in only one language or when healthcare resources are distributed across different providers. This paper presents DMD Sathi, a multilingual web-based guidance portal designed to organize DMD-related educational and care-navigation information for parents and caregivers. The implemented prototype provides English, Hindi, and Marathi language support; child-profile setup; broad age-group organization for 2–5, 6–12, and 13–21 years; symptom and age guidance; nutrition planning with vegetarian/non-vegetarian options; exercise and physiotherapy educational resources; medicine information with generic/conventional and Ayurvedic/complementary-care categorization; emergency guidance; and a healthcare-facility map focused on Nagpur. The system is implemented as a client-side React and TypeScript web application using Vite and React Router. The design intentionally avoids presenting the portal as a diagnostic or prescribing system; it provides educational guidance and encourages consultation with qualified healthcare professionals. For context, a 2026 peer-reviewed Indian study estimated an Indian DMD burden of approximately 51,402 patients using a prevalence estimate of 7.1 cases per 100,000 males and India's male population; this is an epidemiological estimate rather than a national patient registry count. The proposed portal aims to reduce information fragmentation and improve access to understandable, localized, and age-organized DMD care information for families.***

Keywords: ***Duchenne muscular dystrophy, DMD, healthcare portal, multilingual healthcare, parent guidance, physiotherapy, nutrition, emergency care, healthcare navigation.***

I. INTRODUCTION

Duchenne muscular dystrophy is a genetic neuromuscular disorder associated with progressive muscle weakness and multisystem complications. The disease is caused by pathogenic variants in the DMD gene, which affects production or function of dystrophin. DMD predominantly affects males and commonly becomes clinically apparent in early childhood. International care considerations emphasize coordinated management across neuromuscular, rehabilitation, nutritional, respiratory, cardiac, orthopaedic, endocrine, psychosocial, and emergency domains [1]-[3]. Although clinical management is specialist-led, parents and caregivers make many day-to-day decisions about appointments, nutrition, safe activity, medication records, emergency communication, and locating appropriate services. In India, the challenge can be increased by geographic variation in healthcare access, differences in health literacy, language barriers, and the cost and availability of multidisciplinary services.

DMD Sathi was developed as a web-based information and care-navigation portal rather than as a diagnostic or prescribing application. The system organizes educational information into a parent-oriented workflow. A family can select a preferred language, create a child profile, view age-organized guidance, explore nutrition and physiotherapy resources, review medicine information, prepare emergency details, and locate relevant healthcare facilities.

The current prototype deliberately does not claim to replace a doctor, physiotherapist, dietitian, pharmacist, or emergency service. Its purpose is to make existing information easier to understand and navigate. This distinction is important because DMD care recommendations are multidisciplinary and individualized, and many interventions require professional assessment before they are applied to a particular child [1]-[3].

II. PROBLEM STATEMENT

Families affected by DMD require repeated access to information across multiple care domains. Conventional web searches may return information that is difficult to interpret, dispersed across different organizations, written in English, or not localized to the family's healthcare environment. A parent may need separate sources for disease education, age-related concerns, nutrition, physiotherapy, medicines, emergency preparation, and nearby healthcare facilities.

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India-specific burden data also demonstrate why accessible support tools are relevant. A 2026 peer-reviewed study based on India-specific prevalence estimated approximately 51,402 people with DMD in India. The authors calculated this estimate from a prevalence of 7.1 DMD cases per 100,000 males and a living male population of 723,973,437. The same study explicitly cautions that the national burden may be underestimated because of underdiagnosis and variable survival in low- and middle-income settings [4]. Therefore, 51,402 should be reported as an estimated burden, not as a confirmed nationwide registry count.

Indian studies also show that DMD is represented in tertiary genetic and neuromuscular services. A 22-year tertiary-centre study identified 291 DMD patients within its rare-genetic-disease cohort, while a Southern India study enrolled 400 clinically confirmed DMD patients in its broader registered population and analyzed 250 participants [5], [6]. These are institutional or regional cohorts and should not be interpreted as national prevalence.

The problem addressed by this project is therefore the lack of a single, parent-oriented, multilingual interface that organizes general DMD educational information, age-group guidance, nutrition, physiotherapy resources, medicine education, emergency preparation, and local healthcare navigation while clearly communicating the limits of non-clinical guidance.

Table I. Selected India-Related Dmd Data Reported In Published Sources

Source / setting	Reported figure	What it represents	Interpretation
India, 2026 economic-burden study	≈51,402	Estimated national DMD burden	Estimate based on 7.1/100,000 males; not a registry count
Indian tertiary rare-genetic-disease centre, 2000–2022	291	DMD cases in the study cohort	Single-centre diagnostic cohort; not national prevalence
Southern India study, registered population	400	Clinically confirmed DMD patients in the study population	Regional/clinical cohort
Southern India study, analyzed participants	250	Participants included in detailed analysis	Subsample of the above study population

Important data note: The national figure of approximately 51,402 is an estimate derived in the cited 2026 study; no claim is made here that India has a verified national DMD registry containing exactly 51,402 living patients.

III. BACKGROUND AND RELATED WORK

Published DMD care considerations describe DMD management as multidisciplinary. The 2018 recommendations cover diagnosis, neuromuscular management, rehabilitation, endocrine management, gastrointestinal and nutritional care, respiratory management, cardiac management, orthopaedic and surgical management, psychosocial care, emergency management, and transitions across the lifespan [1]–[3]. This broad clinical scope informed the functional grouping used in DMD Sathi.

Indian research highlights the clinical and diagnostic burden of DMD. A Rajasthan population study describes DMD as an X-linked recessive disorder and reports an incidence commonly cited around 1 in 3,500 live births [7]. A Southern India genetic study analyzed 250 genetically confirmed patients and reported substantial variation in mutation patterns [8]. These studies reinforce the importance of accurate diagnosis and specialist involvement while also showing that clinical information needs to be communicated in an understandable form to families. Existing clinical guidance is generally written for healthcare professionals or informed readers. DMD Sathi differs in its intended presentation: it converts broad domains of DMD care into a simple parent-facing navigation structure, adds multilingual interface support, organizes educational information by age group, and connects the user to local healthcare-facility information.

IV. OBJECTIVES

1) To design a professional web-based portal that organizes general DMD information for parents and caregivers.
2) To provide English, Hindi, and Marathi language support across navigation and guidance content.
3) To organize educational guidance around three broad age groups: 2–5 years, 6–12 years, and 13–21 years.
4) To provide general nutrition planning with vegetarian/non-vegetarian filtering and age-related food-texture considerations.
5) To provide exercise and physiotherapy educational resources while emphasizing individualized professional guidance.

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6) To organize medicine information into generic/conventional and Ayurvedic/complementary categories without prescribing medicines or doses.
7) To provide emergency-preparedness information and a local healthcare-facility navigation module for Nagpur.
8) To build the prototype using maintainable web technologies suitable for further academic development.

V. PROPOSED SYSTEM

A. *User Flow*

The proposed workflow begins with an informational landing page. The user then enters the family-care space, selects English, Hindi, or Marathi, and completes a child profile. The portal uses the child's age to organize educational content into a broad age group. The dashboard provides access to profile, age guide, exercise and physiotherapy, nutrition, medicines, care centre, emergency, and healthcare-facility navigation modules.

B. *Design Principles*

1) Parent-centered language: technical information is organized into short, readable sections.
2) Safety-first boundaries: educational information is separated from diagnosis, prescribing, and individualized clinical decisions.
3) Multilingual access: core navigation and module content are available in English, Hindi, and Marathi.
4) Age organization: educational resources are grouped into 2–5, 6–12, and 13–21 years.
5) Local navigation: healthcare facilities are organized for practical discovery in the Nagpur context.
6) Modular implementation: individual modules can be updated without redesigning the entire application.

VI. SYSTEM ARCHITECTURE AND METHODOLOGY

A. *Technology Stack*

Table II. List Of Technologies Used

Layer	Technology / implementation	Purpose
Frontend	React 19	Component-based user interface
Language / logic	TypeScript	Typed application logic and maintainability
Build tooling	Vite	Development and production build workflow
Routing	React Router	Navigation among public, setup, and application pages
UI icons	Lucide React	Consistent interface icons
Styling	CSS / Tailwind-related project configuration	Responsive visual presentation
Data	Local structured JSON / application state	Physiotherapy resources and healthcare-facility information

B. *System Architecture*

The implementation follows a client-side modular architecture. The application state stores language selection, child profile data, nutrition preferences, medicine records, and emergency-profile fields. Route-level modules render the dashboard and individual care functions. Structured data files are used for physiotherapy resources and healthcare facilities. The approach keeps the prototype lightweight and allows future integration with authenticated databases or verified healthcare APIs.

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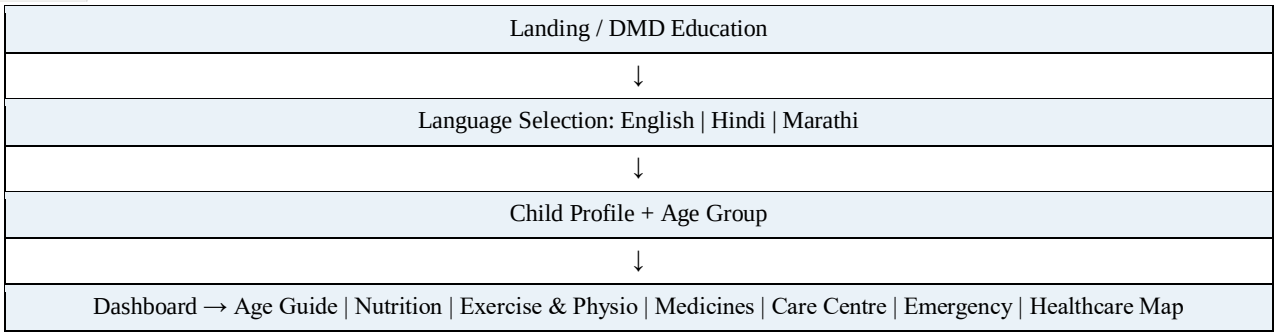


Fig. 1. HIGH-LEVEL DMD SATHI SYSTEM FLOW

VII. FUNCTIONAL MODULE

A. Public DMD Information

The landing and learning pages introduce DMD, its genetic basis, broad care needs, and the importance of professional care. The content is intended for education and awareness, not diagnosis.

B. Language and Child Profile

Users can select English, Hindi, or Marathi. The child profile captures basic information used to personalize the presentation. The system uses broad age groups of 2–5, 6–12, and 13–21 years for educational organization.

C. Age Guide and Symptoms

The age-guide workflow presents age-related educational information and allows the parent to understand possible concerns. The interface explicitly avoids using age alone to diagnose or prescribe.

D. Nutrition Planner

The nutrition module provides affordable, familiar food ideas organized by age and dietary preference. It includes vegetarian/non-vegetarian filtering, meal categories, nutrition information, dairy guidance, and age-wise texture ideas. It also warns that individual nutritional needs should be reviewed with the child's clinical team.

E. Exercise and Physiotherapy

The physiotherapy module provides categorized educational resources, age filters, resource-language handling, and safety notices. It discourages forced stretching and directs families toward individualized physiotherapy plans.

F. Medicine Information

The medicine module separates generic/conventional medicine information from Ayurvedic/complementary-care information. It emphasizes that medicines should not be started, stopped, or changed without qualified professional advice. Ayurvedic interventions are presented as complementary rather than as an established cure for DMD.

G. Care Centre

The care-centre module provides generic/conventional and Ayurveda facility categories, service categories, and DMD-relevance tiers. The interface communicates that listing a facility does not mean DMD can be cured there.

H. Emergency Module

The emergency module is designed to help parents prepare key information and recognize when online guidance is not sufficient. It includes emergency contact details and prompts relevant to DMD care.

I. Healthcare Map

The Nagpur healthcare module supports discovery of DMD-relevant services such as hospitals, neurology, rehabilitation, physiotherapy, emergency services, pharmacies, and Ayurveda facilities. Facility listings are accompanied by verification and timing disclaimers where appropriate.

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VIII. RESULT AND DISCUSSION

The implemented prototype demonstrates a complete parent-oriented navigation flow from DMD education to profile setup and care modules. The following qualitative outcomes were achieved during prototype implementation:

IX. LIMITATIONS AND SAFETY CONSIDERATION

1) The portal is an educational and navigation tool and cannot diagnose DMD, determine prognosis, or prescribe medicines, supplements, diet, exercise, or physiotherapy.
2) Age-group guidance is intentionally broad. Individual DMD needs differ by mobility status, cardiac and respiratory condition, steroid use, nutrition, bone health, and other clinical factors.
3) Healthcare-facility information may change over time. Facility listing, opening hours, service availability, and DMD expertise should be confirmed before relying on the information.
4) The Indian patient figure used in the problem statement is an epidemiological estimate, not a complete national registry count. Underdiagnosis and differences in survival may cause the true burden to differ [4].
5) The current prototype is not a replacement for emergency services and does not establish a clinical decision-support relationship with a hospital or physician.
6) The current implementation is primarily client-side. Secure authentication, backend storage, audit logging, role-based access, and privacy controls would be required before handling real patient records at production scale.

X. FUTURE SCOPE

1) Clinical review and validation of all educational content by neurologists, physiotherapists, dietitians, pediatricians, pharmacists, and other DMD-care professionals.
2) Usability studies with parents/caregivers from different literacy and language backgrounds.
3) Secure backend and authentication for storing family profiles with appropriate privacy and consent controls.
4) Verified healthcare-facility APIs or institutional data feeds with clear update timestamps.
5) Accessibility improvements including screen-reader optimization, larger text options, keyboard navigation, and low-bandwidth support.
6) Expansion beyond Nagpur using verified state- and district-level healthcare resources.
7) Outcome evaluation using usability, task-completion, comprehension, and caregiver-satisfaction measures rather than unvalidated clinical claims.

XI. CONCLUSION

DMD Sathi presents a structured approach to organizing DMD-related educational and care-navigation information for parents and caregivers. The project combines multilingual access, child-profile and age organization, nutrition planning, physiotherapy resources, medicine education, emergency preparation, and local healthcare navigation in one web interface. Its design is aligned with the multidisciplinary nature of DMD care while maintaining a clear boundary between education and clinical decision-making.

The Indian burden estimate cited in this paper indicates a substantial population-level need for accessible DMD support, while existing Indian studies demonstrate the presence of DMD within clinical and genetic-service cohorts. The current prototype provides a foundation for future clinical content validation, usability evaluation, secure patient-data handling, and expansion to additional regions.

XII. ACKNOWLEDGEMENT

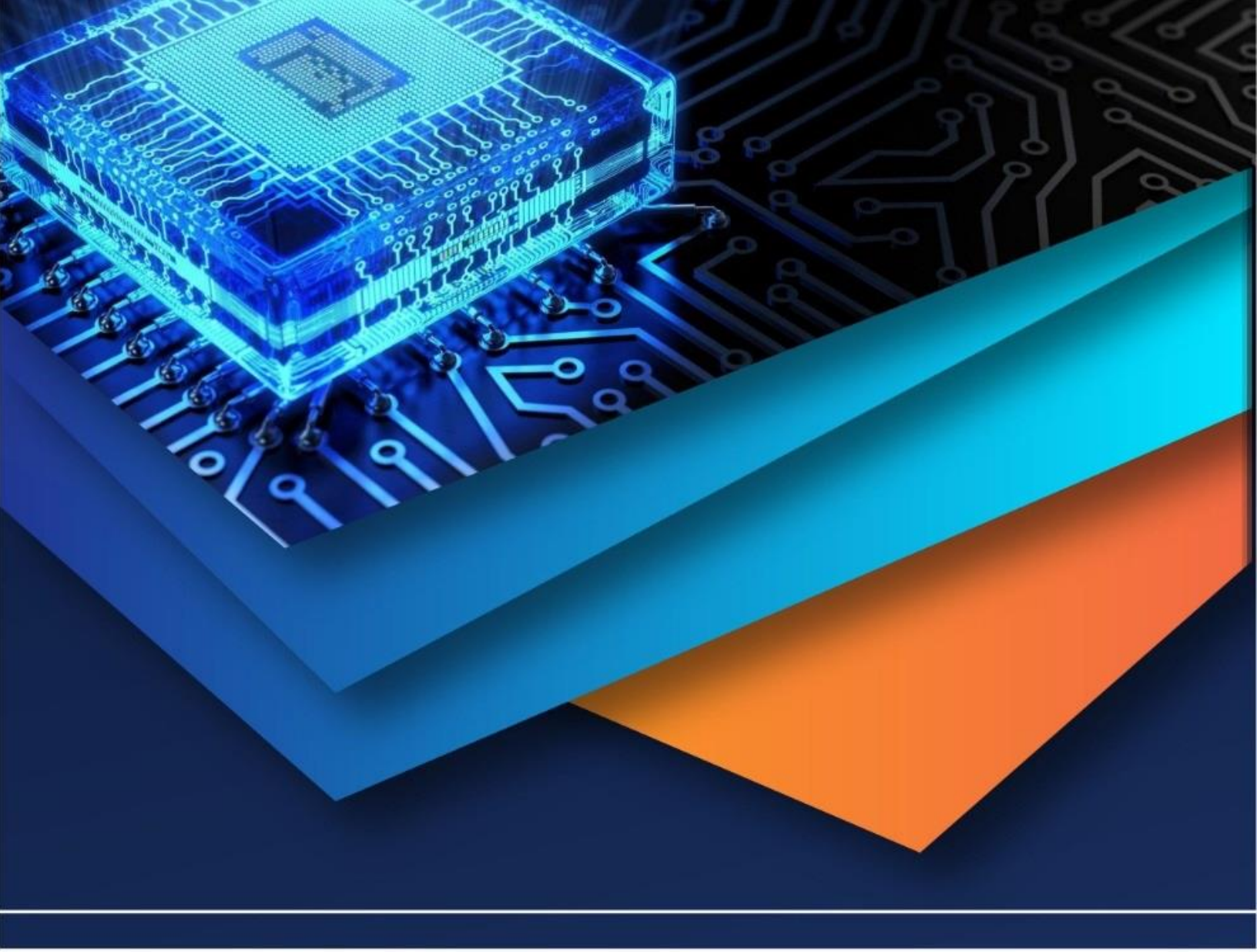
The authors acknowledge their project guide, department, and the healthcare and research community whose published DMD care recommendations and Indian studies provide the evidence base for organizing this educational prototype. The authors also acknowledge the importance of qualified healthcare professionals and patient-family support networks in the management of Duchenne muscular dystrophy.

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