Achieving Maximum Patient Engagement through Connected Care

SPINAL MUSCULAR ATROPHY

Siriraj Hospital Patient Follow-up Program

Initiatives to improve patient care and quality of life for spinal muscular atrophy patients

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ประธานศูนย์ความเป็นเลิศโรคกล้ามเนื้ออ่อนแรง

รองผู้จัดการหน่วยบริหารจัดการงานวิจัยเพื่อความเป็นเลิศ

คณะแพทยศาสตร์ศิริราชพยาบาล

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Disclosure

- Research Funding: Sanofi, Norvatis, F. Hoffmann-La Roche, Thermo Fisher Scientific, lifomics

- Speaker's Bureau: Sanofi, Norvatis, F. Hoffmann-La Roche

- Board member/ advisory panel: Thai SMA and Pompe advisory panel, Foundation to Eradicate Neuromuscular Diseases (FEND) board member

Impact of Patient Engagement on Healthcare Quality

- Patients: crucial stakeholders of health care and decision-making, involve in the treatment process

- Inform and motivate patient to be involved in their own medical care

- Patient engagement: benefit to patients and service providers

- Strengthen and support patients' abilities and self-care responsibilities and then collaborate with their healthcare providers to **improve their health and achieve the maximum values of healthcare services**

Sima Marzban, 2022

Spinal muscular atrophy (SMA)

Rare disease : incidence 1:10,000
SMN1 gene → progressive weakness
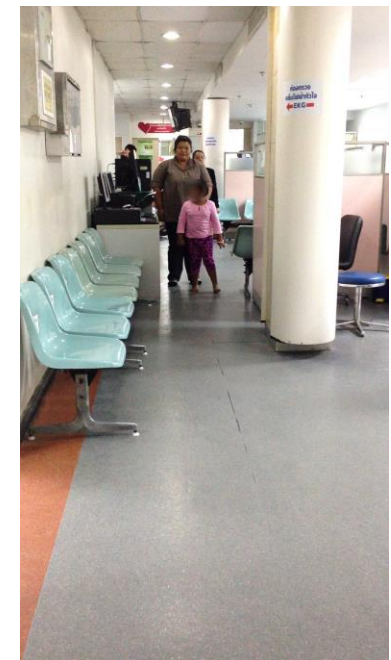
Advance therapy: gene and genetic modifying therapy

Type 1	Type 2	Type 3

Multidisciplinary treatment

Rehabilitation

PT/ OT

Neurology

Orthotics

Psychosocial support

Thai traditional medicine

Nutrition

→ Consultation
Orthopedics
Cardiology
Pulmonology
Gastroenterology
Palliative care
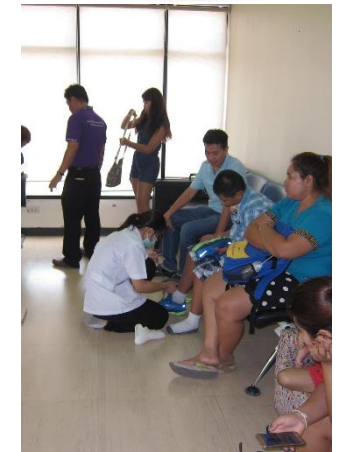
Genetic Counseling

Special education

Music therapy

Outcome measure in SMA treatment

Clinical/ functional outcome measure

Survival

Ventilator dependent

Quality of life and independence

EQ5D, PedQOL,
SMA independent scale (SMAIS)

Pulmonary function

Swallowing function

Biomarkers - CMAP

Description

- Genetic base treatment for SMA: companionate use at Siriraj Hospital since 2021

    - Clinical and patient outcome in real world data

    - Submit care for SMA package for UCBP: Dx, Rx, FU

- The program aimed to **improve patient care and quality of life** by utilizing standardized **questionnaires and digital tools** to enhance data collection, analysis, and accessibility

- Collaboration with Promptly

A LIFE LESS FULFILLED

The severity of the condition and resulting disabilities, as well as the amount of time spent providing care and resulting isolation, affects patients and caregivers on multiple levels. Holistic support is needed to help them cope.

Support Needed

78.9%
Programs on living with NMD (self-care, etc.)

72.2%
Assistance with the cost of medication/treatment

63.3%
Financial aid for daily living expenses

56.7%
Counselling service or hotline

53.3%
Assistance with transport

51.1%
Homeschooling

48.9%
Connecting with other NMD patients

44.4%
Assistance in finding job opportunities

Support Received

50%
help with daily living, transport etc.

33.3%
emotional support

32.2%
financial assistance

31.1%
receive support from FEND

15.6%
receive support from SNMRI

Impact on Caregiver

45.6% had to give up their careers

- Strained relationship among family members, including extended family
- Financial burden

Impact on Patient

87.8% lost ability to carry out daily activities

56.7% had to give up career or studies

- Unfulfilled potential and dreams because of physical limitations
- Worry that condition will worsen
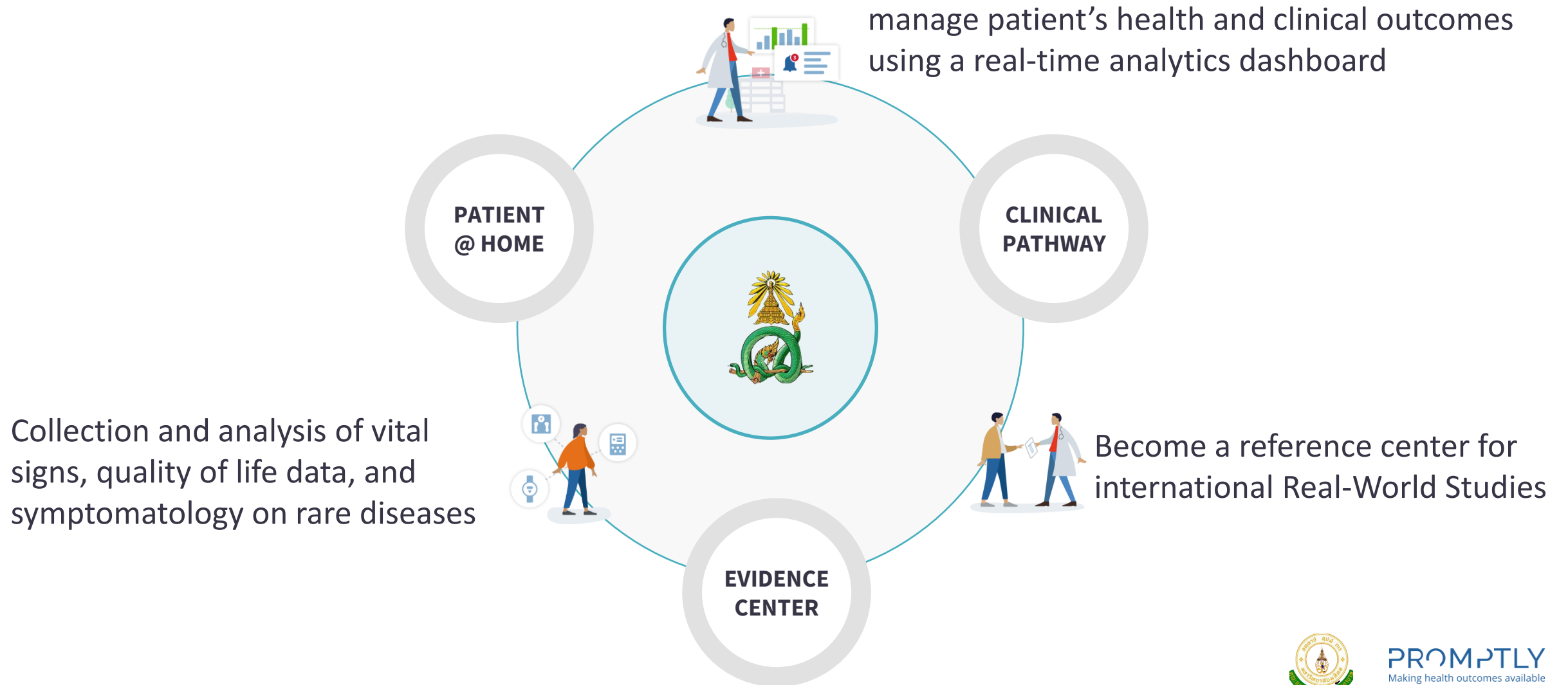- Low self-esteem because of perceived

7

" **Mandatory measurement and reporting of outcomes** is perhaps the single most important step in reforming the health care system.

Michael E. Porter

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SMA

Patient follow-up program based on 3 strategic axis

manage patient's health and clinical outcomes using a real-time analytics dashboard

PATIENT @ HOME

CLINICAL PATHWAY

Collection and analysis of vital signs, quality of life data, and symptomatology on rare diseases

Become a reference center for international Real-World Studies

EVIDENCE CENTER

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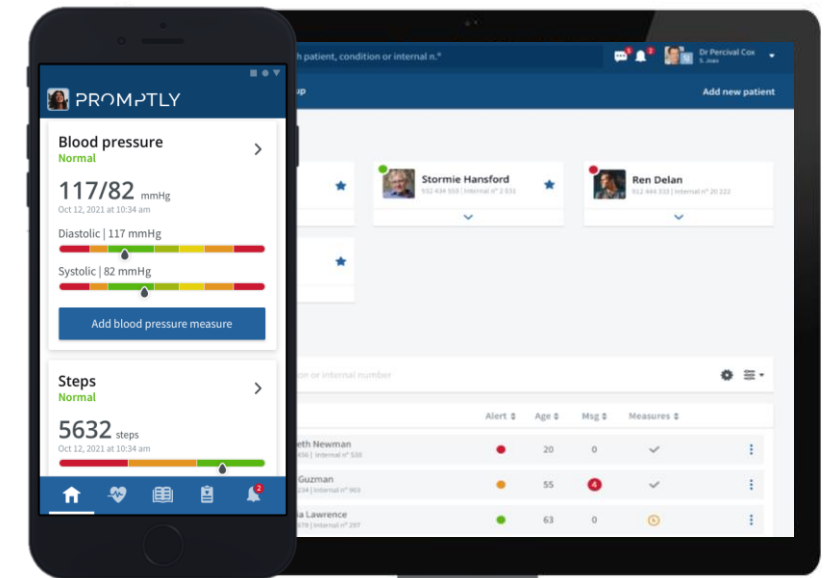Making health outcomes available

Digital solutions

Leveraging two solutions:
1. an e-patient report outcome-PRO (COLLECT)
2. a web-based population management portal (MONITOR)

PATIENT – DIGITAL JOURNEY

CLINICIAN – MANAGEMENT PORTAL

Program overview

The SMA patient follow-up program uses standardized measures and digital tools to improve patient care and quality of life

Launched in 2022

The SMA patient follow-up program was launched in August 2022

37 SMA patients

The program monitors 37 SMA patients across 3 types (SMA type 1, 2, 3), during one year since diagnosis

Digital Data Collection

The program leverages an omnichannel **ePRO solution to increase participation and optimize the patient experience (74 PROs digitally collected so far)**

Data quality improved

Transition to digital platform improved **data accuracy and consistency by up to 40%**

Note: ePRO - Electronic patient-reported outcomes

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Clinician portal

Clinical outcomes score are available at the patient and population level

The clinical team can access:

- All **scores from PROs and clinical assessments submitted** by the Patients on a global level: SMAIS, HFMSE, etc

- **Individual patient scores** and their evolution over the care journey

- **Individual question answers** to use in the appointments

SMAIS - Month 3

1 แบบสอบถามต่อไปนี้มีวัตถุประสงค์เพื่อประเมินระดับความเป็นอิสระของผู้ป่วย จะใช้เวลาประมาณ 15 นาทีจึงจะเสร็จสมบูรณ์
ดำเนินการต่อ

2 โปรดนึกถึงจำนวนความช่วยเหลือที่ต้องการจากบุคคลอื่นในการดำเนินกิจกรรมในช่วง 7 วันที่ผ่านมา
ดำเนินการต่อ

3 การสระผมของ เขา/เธอ
ผู้ป่วยไม่สามารถทำกิจกรรมนี้ได้เลยหากไม่ได้รับความช่วยเหลือ

4 การล้างหน้าของเขา/เธอ
ผู้ป่วยต้องการความช่วยเหลืออยู่บ้าง

5 การล้างมือ ของเขา/เธอ
ผู้ป่วยต้องการความช่วยเหลืออยู่บ้าง

6 การอาบน้ำของเขา/เธอ
ผู้ป่วยไม่สามารถทำกิจกรรมนี้ได้เลยหากไม่ได้รับความช่วยเหลือ

7 การแปรงฟันของเขา/เธอ
ผู้ป่วยต้องการความช่วยเหลืออยู่บ้าง
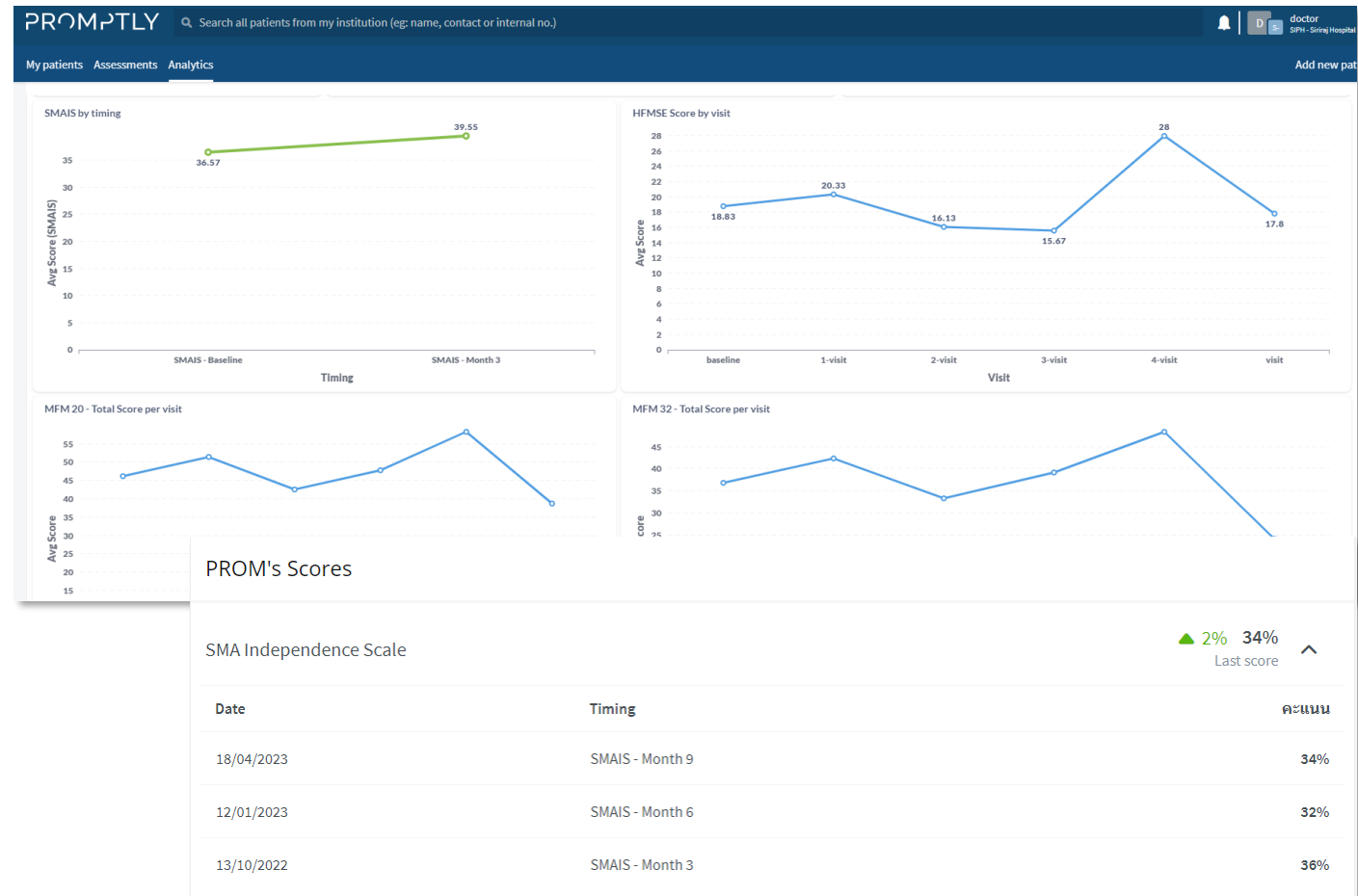
Impact

The transition from paper to a digital system reduced administrative burden while guaranteeing higher patient engagement

ADDED-VALUE FOR PATIENTS	PATIENT ENGAGEMENT	CLINICAL INSIGHTS	OPERATIONAL EFFICIENCY	RESEARCH CAPACITY
Improved proximity to the patients by offering a remote follow-up service, supporting them in understanding how their health is evolving over time, and improving overall health literacy	**Patients report quality of life data from their homes** using standardized questionnaires through digital outcomes collection solution, giving them back information on their scores	Clinicians leverage clinical outcomes data and patient-reported data to **optimize treatment pathways and engage in deeper discussions with patients and parents**	Implemented a **standardized system for outcomes collection and analysis streamlining processes**, reducing administrative burden, and ensuring higher data quality (~40% fewer errors)	**Scaled the amount of data and sources at disposal for high-quality research and regulatory discussions**, in a time where PRO / CRO data is highly valued for policy making

Note: ePRO - Electronic patient-reported outcomes; PRO - Patient-reported outcomes; CRO - Clinical-reported outcomes

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Challenges & Opportunities

Collecting PROs from pediatric populations can be challenging

Pediatric patients have limited ability to express experiences/emotions

(vocabulary and cognitive skills)

Clinical teams face time limitations

Doctors and nurses have very limited time with each patient, making it hard to do in-depth assessments.

Accurate data capture is difficult

Without direct patient input, clinicians must rely on observation and proxy reporting from parents, which can be unreliable.

How to address them?

AGE-SPECIFIC PROM TOOLS

Develop patient-reported outcome measures that are **tailored to different age groups of pediatric patients to improve ease of use** and relevance

PARENT/CAREGIVER INVOLVEMENT

Engage parents and caregivers in completing PROMs for pediatric patients to obtain complementary perspectives, and **create a more personalized care journey**

MULTICHANNEL DATA CAPTURE

Leverage digital and on-site channels such as tablets or kiosks to collect PRO data from pediatric patients in waiting rooms or after visits, to improve compliance

CLINICIAN TRAINING ON PROMS

Create awareness on clinicians around the importance of PROMs and their proper administration to pediatric patients to maximize engagement and data quality

Note: PRO - Patient-reported outcomes

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Future Plans

Scaling the program, sharing learnings, and establishing an observatory will help optimize SMA care nationwide

Scaling the data collection system

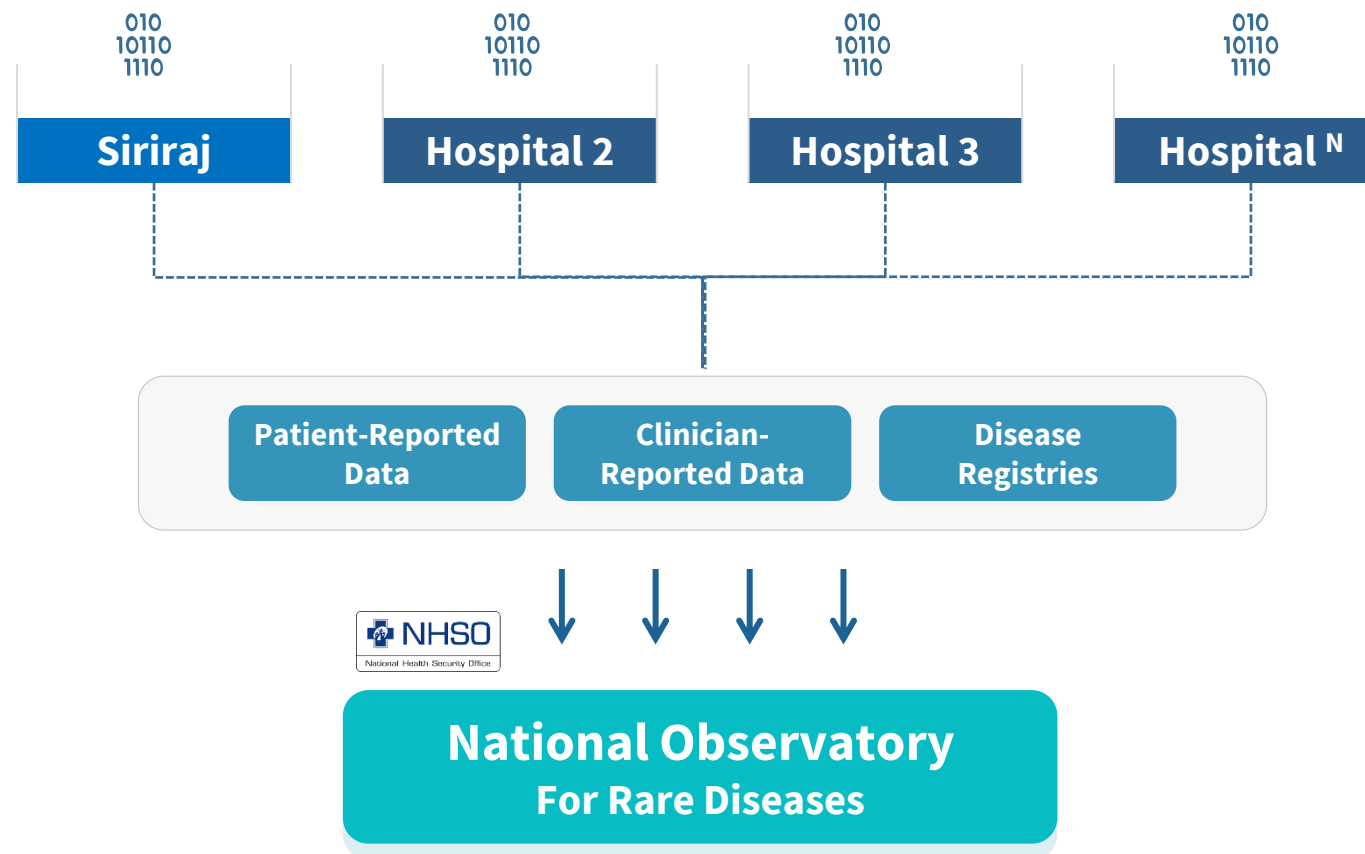Expand data collection through digital platforms and onsite channels

Integrating with EHR systems

Streamline data flow by integrating the platform with hospital EHR systems

Sharing learnings with other centers

Share outcomes strategy with other leading rare disease centers

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Siriraj	**Hospital 2**	**Hospital 3**	**Hospital ^{N}**

Patient-Reported Data	Clinician-Reported Data	Disease Registries

NHSO
National Health Security Office

National Observatory
For Rare Diseases

Note: EHR - Electronic Health Record

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When there is no data, patients miss the opportunity. Data is essential for policymakers to address rare diseases in healthcare policy

Q&A

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Acknowledgement

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ขอบคุณค่ะ

SiNMD
Siriraj neuromuscular disease

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