

NATIONAL ORTHOPAEDIC REGISTRY OF MALAYSIA (NORM)

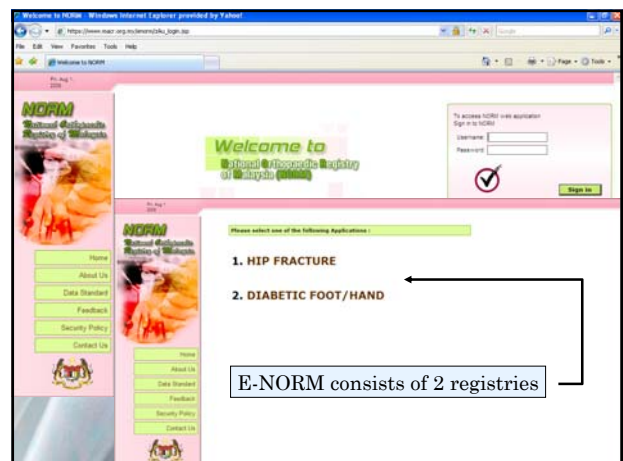
Dr. Ahmad Tajuddin b. Abdullah
Hospital Sultanah Nur Zahirah
Kuala Terengganu

WHY DO WE NEED NORM?

- Polish away the 'guess estimate' attitude - morbidity of hip fracture and diabetic foot/hand in country
- Focus on the **real risk** of hip fracture and diabetic foot/hand
- Determine the **burden** of hip fracture and diabetic foot/hand among Malaysian
- Promote** effective treatment & prevention programs
- Facilitate **research**

NORM OBJECTIVES

- Determine the number and the trend of hip fracture and diabetic foot/hand in Malaysia.
- Determine the socio demographic and identify the high-risk group in our Malaysian population.
- Determine the efficiency and adherence to current treatment guidelines
- Determine the cost burden to the nation and the cost-effectiveness of treatment and prevention programs
- Determine the burden- Cost/OT/Resources



REGISTRIES

Hip Fracture Registry

Chaired by Dr Ahmad Tajuddin Abdullah

Site data provider : 18 sites



Diabetic Foot/Hand Registry

Chaired by Dr Mohammad Anuar Hau Abdullah

Site data provider : 18 sites



PROJECT MANAGEMENT

Dr Jaya Purany Stanley Ponniah
CRC HKL
(Registry Manager)



En Mohd Asrul bin Sani
CRC HKL
(Assistant Registry Manager)



GOVERNANCE BOARD (KIV)

#	Name	Specialty
1	Dr Lim Teck Onn FRCP, M Stat	Director of CRC Network
2	Datuk Dr Teoh Siang Chin <i>PJN</i> MBBS, MSc HHSM	Ex-President MMA
3	Dr Jamaliyah Haniff M Clin Epid	Pakar Kesihatan Umum
4	Datuk Dr Burhan Tan Abdullah	Pakar Bedah Ortopedik, HKL
5	Presiden Majlis Paralimpik (cadangan)	
6	Ketua Rehabilitasi (cadangan)	
7	Presiden Persatuan Ortopedik Malaysia (cadangan)	

STEERING COMMITTEE BOARD

1	Dr. Mohammad Anwar Hau Abdullah (Chairman)	Hospital Raja Perempuan Zainab II, Kota Bharu, Kelantan
2	Dr. Zulkiflee Osman (Co-Chairman)	Hospital Kuala Lumpur
3	Dr. Ahmad Tajuddin	Hospital Sultanah Nur Zahirah, Kuala Terengganu, Terengganu
4	Dr. Se To Boon Chong	Hospital Pulau Pinang
5	Dr. Pan Chee Huan	Hospital Tuanku Fauziah, Perlis
6	Dr. Mohamad Yazid b Din	Hospital Sultanah Bahiyah, Alor Setar, Kedah
7	Dr. Jochaimy Johari	Hospital Raja Perempuan Zainab II, Kota Bharu, Kelantan
8	Dr. Saadon Ibrahim	Hospital Sultan Ismail, Johor
9	Dr. Mohd Zamzuri b. Mohd Zain	Hospital Tengku Ampuan Afzan, Kuantan, Pahang
10	Dr. Tan Boon Chong	Hospital Pulau Pinang
11	Dr. Abdul Rauf Ahmad	Hospital Tuanku Jaafar, Seremban, Negeri Sembilan

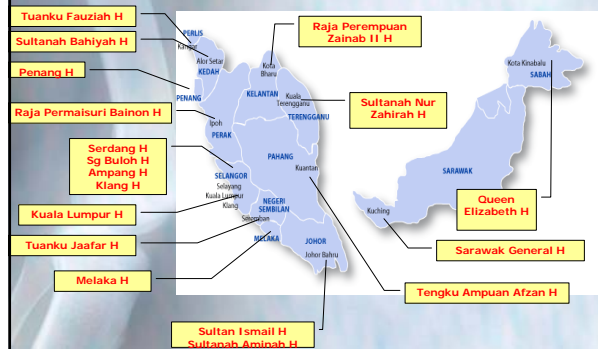
SOURCE DATA PROVIDERS (SDP)

🦴 Currently 18 MOH Hospitals

🦴 Later others

- Private
- Universities
- armed forces

18 participating Sites.....



SITE PI.

Investigator(s)	Clinical Site
1. Dr. Zulkiflee Osman	Hospital Kuala Lumpur
2. Dr. Faris Kamaruddin	Hospital Umum Sarawak
3. Dr. Nahulan A/L V.Theva Rajah	Hospital Queen Elizabeth, Kota Kinabalu, Sabah
4. Dr. Saadon Ibrahim	Hospital Sultan Ismail, Johor
5. Dr. Pan Chee Huan	Hospital Tuanku Fauziah, Kangar
6. Dr. Se To Boon Chong	Hospital Pulau Pinang
7. Dato' Dr Suresh Chopra	Hospital Bahiyah, Alor Star, Kedah
8. Dato' Dr. Ramanathan A/L Ramaiah	Hospital Ipoh, Perak
9. Dr. Mohd Zamzuri b. Mohd Zain	Hospital Tengku Ampuan Rahimah, Klang

SITE PI (CONT.)...

10. Dr. Basir Towil	Hospital Serdang, Selangor
11. Dr. Ng Yue Onn	Hospital Ampang, Selangor
12. Dr. Abdul Rauf Ahmad	Hospital Tuanku Jaafar, N.Sembilan
13. Dr. N.Sivapathasundram	Hospital Melaka, Melaka
14. Dr. Thevarajaan Karuppiah	Hospital Sultanah Aminah, Johor Bharu, Johor
15. Dato' Dr. Premchandran A/L P.S. Menon	Hospital Tengku Ampuan Afzan, Kuantan, Pahang
16. Dr. Ahmad Tajuddin	Hospital Sultanah Nur Zahirah, Kuala Terengganu, Terengganu
17. Dr. Mohammad Anwar Hau Abdullah	Hospital Raja Perempuan Zainab II, Kota Bharu, Kelantan
18. Dr. Zamyn Zuki Mohd Zuki	Hospital Sungai Buloh, Selangor

E-NORM SECURITY FEATURES

Please key in the authentication code that has just been sent to you via SMS.

Username: asrul

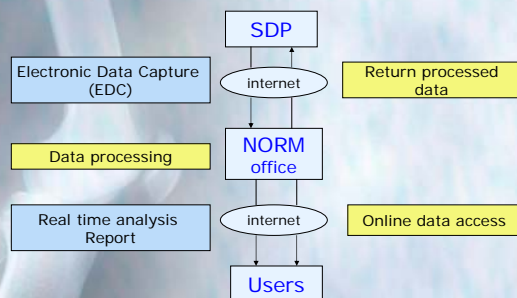
Auth Code:

Submit

[Auth Code help](#)

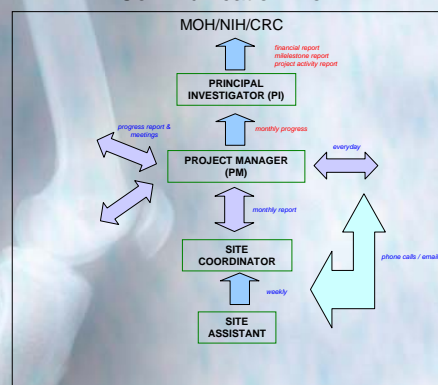
Web application owner authentication using SSL (Secure Sockets Layer) certificate is applied to conduct an authenticated, **strongly encrypted online transaction**. This certificate ensures that the web site does not belong to an impostor and message privacy.

NORM DATA FLOW



User Group	Data entry				Report	Data download	Data query
	View	Update	Request Delete	Delete			
1 Medical Assistant/Nurse/RA/Medical Officer	✓ Ovm centre	✓ Ovm centre	✓ Ovm centre	X	X	X	✓ Ovm centre
2 SDP (Doctor In Charge)	✓ Ovm centre	✓ Ovm centre	✓ Ovm centre	X	✓ Ovm centre	X	✓ Ovm centre
3 SDP Specialist-in-charge of registry	✓ Ovm centre	✓ Ovm centre	✓ Ovm centre	X	✓ Ovm centre	✓ Ovm centre	✓ Ovm centre
4 Head of Department	✓ All Centre	✓ Ovm centre	✓ Ovm centre	X	✓ All Centre	X	✓ Ovm centre
5 Assistant Registry Manager	✓ All Centre	✓ All Centre	✓ All Centre	X	✓ All Centre	✓ All Centre	✓ All Centre
6 Registry Manager	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre
7 Administrator	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre	✓ All Centre

Communication Flow



What is the Benefit ?

- For **clinicians**: collect data about disease presentation and outcome in a real world picture
- For **organization**: Determine the degree in which the clinician are managing cases /OT burden-compare with guidelines.
- For **MOH** –Burden-standard care for patient-resources-cost
- For **Drug/device manufacturer**- performance,help develop hypotheses, post marketing.

BENEFITS WITH E-NORM

REAL TIME REPORT

YOUR OWN CENTRE DATA at FINGER TIPS

Compare YOUR CENTRE STATISTICS with NATIONAL STATISTICS

DUMMY TABLES FOR e-NORM (Diabetic Foot/Hand)

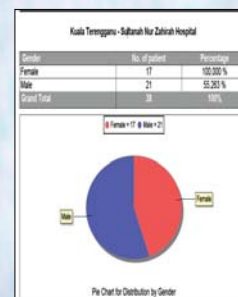
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BENEFITS CONTINUES...

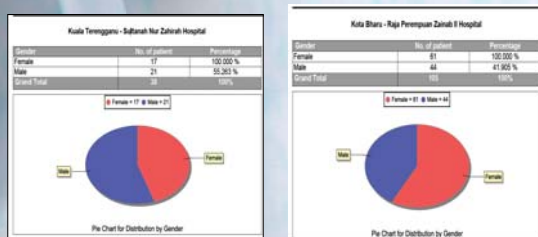
- ✓ CAPABLE of DOWNLOADING YOUR OWN CENTRE DATA
 - For further analysis
 - For your own research use
 - Improvement of treating skills
 - Increase Publication
- ✓ Invitation to all function organized by NORM
- ✓ Acknowledgment in all publication of NORM

RESULT

- Only aggregated statistical result will be reported by the registry.
- No result that can identify patient will be published.



Compare data



Patient Consent

- This is an observational study-no intervention therefore no need informed consent .
- However we will need to request waiver from MREC
- All SDP will have to place **PUBLIC NOTICE** at their site –informing the centre is participating in NORM and we are collecting Pt. data.
- However if patient is not keen they can request their data not to be included.

Sample of Public Notice

This notice is to inform you that this healthcare facility is participating in the

AN AUDIT OF DIABETES CONTROL AND MANAGEMENT (ADCMD)

Relevant data concerning your health and medical condition will be submitted to this Registry.

This data is used strictly for statistical purpose only. Such information is required to plan and manage patient care services and may also be used for clinical research. The registry will publish only aggregate statistics (eg. Average age, % of patients receiving treatment, etc.), no information on individual patient will be published or disclosed to third party.

The Registry also observes strict policy and practices to ensure information security, and does comply with both national and international security standards.

However, if you may choose not to have your data submitted to the Registry, please inform the doctor attending to you in this healthcare facility.

We appreciate your cooperation and understanding.

For further information, please contact us at...

MILESTONES

#	Project Activities	Date
1	Preparation of proposal	September 2007
2	Paper CRF drafted & revised	September 2007
3	Proposal approved (by sponsors) and funding	November 2007
4	Participation of all SDP secured	June 2008
5	Pilot study	July 2008
6	NORM national launch	August 2008
7	First report of data	October 2009

