



Kementerian Kesihatan Malaysia

## ***Setting up a National Diabetes Register to Improve the Quality of Care for Patients***

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## RATIONALE

- Prevalence of diabetes in Malaysia has increased from 8.3% (NHMS II,1996) to 14.9% (NHMS III,2006)
- Poor diabetes controlled leads to higher rate of morbidity and mortality
- Precise estimate on the incidence and prevalence of diabetes in Malaysia is lacking

## Objectives of Diabetes Register, Malaysia (DRM\_ADCM)

1. Determine the **demographic** of the diabetic patients attending the Ministry of Health (MOH) health clinics/hospital
2. Determine the **diabetic management** and **preventive program** among patients attending their regular follow-up in MOH health clinics/hospitals
3. Determine the **diabetic complications** workload in health clinics/hospitals KKM

## Objectives.. cont

4. Determine the demographic of the diabetic patients attending the MOH health clinics/hospital because of diabetes complications
5. Determine the **diabetic treatment outcome** in patients attending the MOH health clinics/hospital
6. To **facilitate service improvements** by providing robust nationally comparable data for diabetic care.
7. **Stimulate and facilitate diabetic research** activities using this database.

## Vision

### ***An Accessible Diabetes Health Information System***

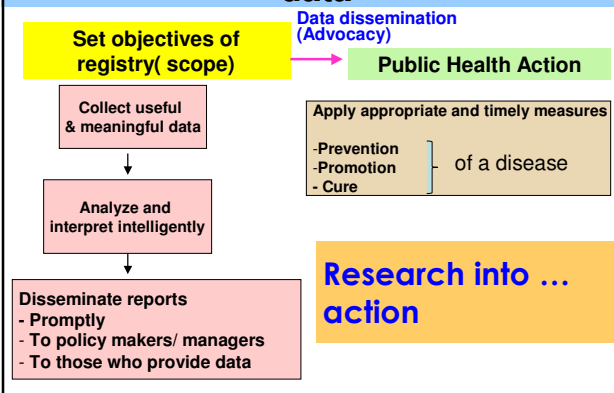
## Background

- First established in May 2008.
- Initially, called Audit Diabetes Control and Management audit (ADCM) but subsequently changed to Diabetes Register Malaysia (DRM\_ADCM)
- Started as pilot project involving health clinics and hospitals within the MOH Malaysia in Negeri Sembilan.

## MOH policies & guidelines

1. Protocol development
2. National Malaysian Research Registry (NMRR) registration
3. Ethical conduct of registry & MREC ethics approval
4. Individual informed consent vs Public notice vs Outright waiver
5. Publication policy & Director General of Health approval
6. Patient privacy & data confidentiality
7. Human resource: hiring & contracts
8. Financial admin
9. *Health Informatics Technology Division* approval for IT system used for research & registry projects

## Setting Registry and Use of Registry data



## Uses of Registry data

### Conventional

- **Epidemiology**
  - Public health service planning
- **Outcome assessment**
  - Standard of care
- **Quality Assurance**
- **Research**

Presentation at meetings

Data

Information

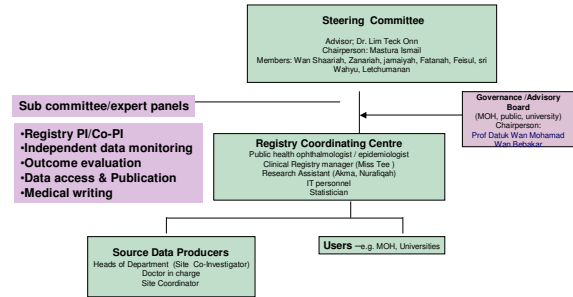
Wisdom

### Expansion

- **Trending and tracking**
  - Benchmarking
- **Quality assurance**
  - eKPI
- **Performance monitoring**
  - eCUSUM

Apply in clinical practice or effect change in Healthcare Policy

## Organization chart



## STEERING COMMITTEE

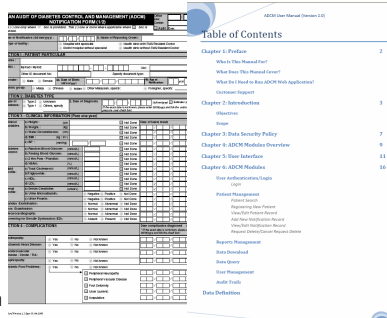


## DATA COLLECTION & TRANSFER

- Data collected via manual forms & web-based application
- Source Data Producers:
  - STATE level via the State Epidemiologist
  - Site coordinator: Senior paramedical staff
  - Monthly returns entered via front-end application and transmitted to the Data Management Centre
- State Epidemiologist will track data returns and prompt Source data providers (SDPs) if they fall behind schedule in reporting data

# INSTRUMENT

- Case Report Form:
  - Identification
  - Demographics
- Instruction Manual
  - Project Background
  - Data Definition



## Method: On-line web based registry

app.acrm.org.my/adcm

1. Data collection & entry  
- at participating site

2. Data analysis  
- real time  
- automated

3. Online report to users and data providers

Centres

internet

Registry  
-virtual

internet

Users  
/Public

**Confidentiality**  
-data encryption  
-password protection  
-no patient identifier  
- review only own centre data

## Materials and Methods

- Age 18 and above years old
- Type 1 and Type 2 Diabetes seen in any of the participating sites.
- Old and newly diagnosed cases
- Open for health clinics and hospital
- Center need to register with DRM\_ADCM
- Centre Participation Self Reply Form
- Authorization Form
- Information Security Policy/User Agreement
- Upon receiving these documents, the centre shall be registered and each of the users of the DRM\_ADCM shall be notified via their e-mail address.

## Progress : Preliminary report

Cases Reported by SDP (As of 9th March 2009)

SDP	Number patients notified
ALL	22449

### Total Diabetes Patients Reported to DRM\_ADCM by Ethnic Group

Ethnic Group	Male		Female		Total	
	N	%	N	%	N	%
Melayu	4991	52.33%	7137	57.02%	12128	54.99%
Cina	2156	22.60%	2382	19.03%	4538	20.58%
India	2330	24.43%	2920	23.33%	5250	23.80%
Lain-lain	61	0.64%	78	0.62%	139	0.63%
<b>Total</b>	<b>9538</b>	<b>100.00</b>	<b>12517</b>	<b>100.00</b>	<b>22055</b>	<b>100.00%</b>

### Distribution of clinical variables in the target (n=22449)

Variable	Targets	Total Test	Percentage	Meeting targets	
				No.	%
HbA1c	<7.0%	13114	58.42%	3995	30.46%
BP	<130/80 mmHg	19697	87.74%	6131	31.13%
T. Chol	<4.5 mmol/l	15746	70.14%	4244	26.95%
TG	<1.7 mmol/l	15775	70.27%	8195	51.95%
HDL	≥1.1 mmol/l	14781	65.84%	10309	69.74%
LDL	<2.6 mmol/l	14600	65.04%	3934	26.95%
BMI	<23 kg/m2	16320	72.70%	2461	15.08%
WC	<90 cm (Male)	5224	23.27%	1719	32.91%
WC	<80 cm (Female)	7439	33.14%	1048	14.09%

### Distribution of clinical information (qualitative) in the target (n=22449)

Variable	Test Total	%	Abnormal	%
Urine Protein	11485	51.16%	3633	31.63%
Urine Microalbumin	8404	37.44%	2684	31.94%
Foot Examination	12094	53.87%	319	2.64%
Fundus Examination	4761	21.21%	884	18.57%
Electrocardiography	10669	47.53%	864	8.10%
Screening for Erectile Dysfunction (ED)	833	3.71%	265	31.81%

### Activities.....

1. SC meeting: 20th February 2008 and 5th June 2008
2. Protocol development: The final version was released on 30<sup>th</sup> Oct 2008 (Protocol Number: NMRR ID: 08-12-1167)
1. MREC submission: The ADCM obtained its approval from MREC on 15<sup>th</sup> Dec 2008
2. CRF development: Latest version is version 1.2 which was released on 1<sup>st</sup> Apr 2008
3. Web application for ADCM was released in May 2008
4. User training :
  - 3<sup>rd</sup> July 2008 (Hospital Seremban),
  - 25<sup>th</sup> July 2008 (PKD Gombak),
  - 19<sup>th</sup> August 2008 (KK Teluk Datok),
  - 13<sup>th</sup> November 2008 (JKN K.Terengganu)
  - 24<sup>th</sup> February 2009 (JKN Kedah)
  - 20<sup>th</sup> March 2009 (JKN Perak)
  - 23<sup>rd</sup> March 2009 (JKWP KLP)
  - 13<sup>th</sup> April 2009 (JKN Kelantan)
  - 11<sup>th</sup> May 2009 (JKN Pahang)

## Activities

- Registry operations: the day-to-day operations of the DRM\_ADCM will be undertaken by the registry staff
- DRM\_ADCM Technical Committee meets 6-monthly to ensure that the logistics/ technical aspects are effectively run
- Advisory Committee: annually
- Progress monitoring by National Inst. Health and Clinical Research Centre
- Ongoing training
- Website

## Site initiation and training



## Current Challenges / Ways to overcome

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• Participation – MOH only, not national data</li> <li>• Data ascertainment – not 100%</li> <li>• Data Quality             <ul style="list-style-type: none"> <li>– missing values</li> <li>– wrong values</li> <li>– as it is web based with real time report, data cleaning at RCC is difficult</li> </ul> </li> <li>• Use of data on ADCM web – not yet widely used and present or published</li> <li>• Change of staff lead to problem in data collection.</li> <li>• Funding – special registry grant</li> </ul> | <ul style="list-style-type: none"> <li>• Invite private centre as SDP</li> <li>• Data collection -Need to incorporate into routine work flow and need to maintain alertness of staff</li> <li>• Data quality             <ul style="list-style-type: none"> <li>– At system – must fill, accuracy check, range check ,pop up message</li> <li>– At SDP sites :                 <ul style="list-style-type: none"> <li>• Training /awareness-doctor</li> <li>• Eyeball CRF before data entry - site coordinator</li> </ul> </li> </ul> </li> <li>• HOD- encourage use of data at             <ul style="list-style-type: none"> <li>– CME/CNE</li> <li>– Dept audit</li> <li>– Publication/ presentation at scientific meetings</li> </ul> </li> <li>• Seek other means – e-KPI/e-CUSUM</li> </ul> |
|--|---|

## Future Direction

- Recruiting more SDPs: Participation of all diabetes care providers
- Promotional activities, more training and website design
- Establish medical writing committee- publish more papers
- Cohort (systematic random sampling)
- Expansion of ADCM
  - Link Tele Diab. retinopathy screening data
  - Link DICARE (Children Diabetes Register)
  - Link with National Nephropathy Screening data
  - Pulling data from TelePrimary Care (TPC)
  - Link To Hypertension Registry
- On-line registration of SDP
- DRM\_ADCM widen its scope
  - e-KPI
- Sponsorship/Funding

## Discussion

1. **DRM\_ADCM provides sound evidence for Public Health Actions –Service & training**
2. **Users can then put effort to meet the unmet needs**
3. **Use of DRM\_ADCM data for Healthcare Provider**
  - **Plan for diabetes services**
  - **Outcome of treatment**
  - **Economic burden of treatment**
  - **Research databases**
  - **e-KPI**
4. **Use of DRM\_ADCM data by policy makers to ensure good health is**
  - **Accessible**
  - **Affordable**
  - **Provided with equity**

## Conclusion

**R**egistry provides information essential for public health advocacy

**e**-registry- *Make it easy*

**R**esearch into action - *improve public diabetes care*

**F**uture direction –DRM\_ADCM to widen scope  
– evaluating quality, cost effectiveness and accessibility of health care

## Acknowledgement

We wish to thank

- CRC Network Director: Dr TO Lim
- DRM\_ADCM advisor
- DRM\_ADCM Steering committee members
- Principal investigators of registries
- HODs as site co-investigators
- SDP Doctors in charge
- SDP Site-Coordinators
- All the staff of Hospital and health clinics, MOH
- Registry Coordinating Unit :Miss Tee Chin Kim, Noor Akma Hashim, Norzaiti Ab Majid
- Manager CRC Hospitals