

ADVOCACY FOR AFFORDABLE ACCESS TO DAA THERAPY FROM THE Community Perspective:

LESSONS FROM MALAYSIA

YATIE JONET (PLHCV - WUD)

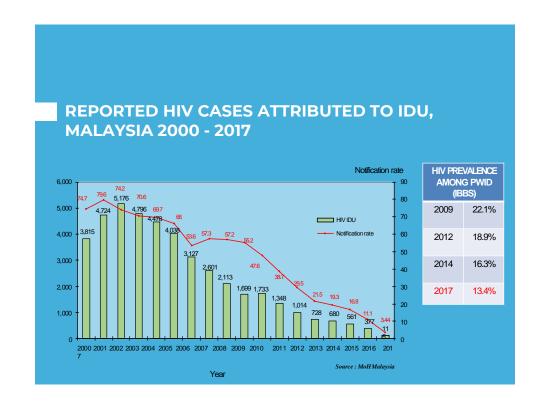
ADVOCACY OFFICER (SHIFT PROJECT)
MALAYSIAN AIDS COUNCIL
INHSU – I ISBON – 19 to 21 SEPTEMBER 2018

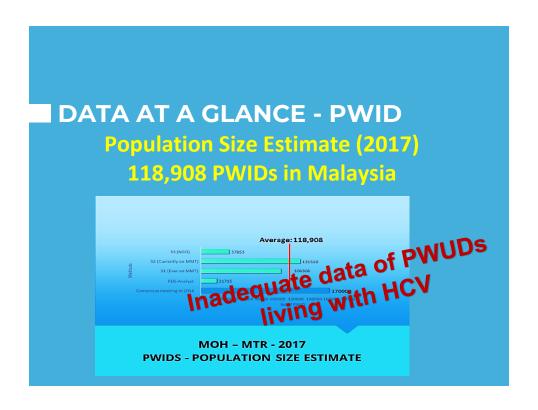


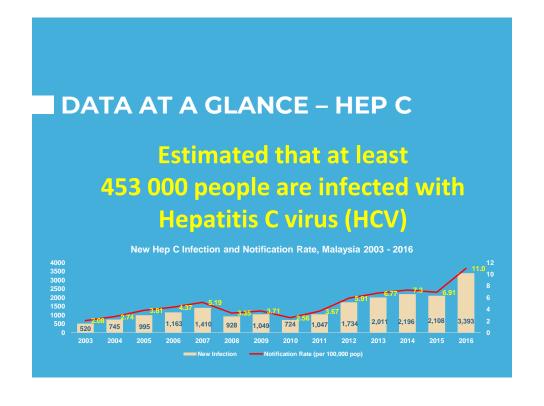
- Multiracial and multicultural country
- o Pop: 32.4 million (2018)
- 13 states and 2 federal territories
- Peninsular Malaysia, Sabah and Sarawak (Island of Borneo)

HIGHLIGHTS

- SNAPSHOT –Hepatitis C in Malaysia MOH, IBBS, PSE, Hep C
- Successes vs Challenges & Recommendations
- Community Mobilisations
 Initiated since 2015
- Future efforts to be anticipated today







My Experience before 2015...

- Harm reduction program from 2011
- o 2013 went to FBC HCV REACTIVE
- MO advised use condom and DON'T GET PREGNANT
- Family members to go HCV screening
- PAID LAB Genotyping
- o 3 MONTH W.A.I.T.I.N.G
- Genotype UNDETECTED (< 2000)
- Come back NEXT YEAR.....

Community Activities 2015-2016

PUBLIC AWARENESS OF HEPATITIS C REMAINS UNACCEPTABLY LOW - Less than 3/10 people knew what hepatitis C was before their diagnosis.

Wider awareness of hepatitis C and its impact is required to improve treatment success and disease prevention.

- ✓ PWID program to actively promote awareness on
- HCV status

 ✓ MTAAG is actively advocating on the ground for HCV
- testing and access to affordable treatment
- HCV Advocacy Training (building PWID awareness on HCV to advocate for access to treatment)
- ✓ Participated in First Meeting of Hepatitis Programme Focal Points from High Burden Countries in Asia (22-24 June 2016)



"I really want to try these DAAs but I can't afford them. These DAAs are good, right? I have only just found out about them and I think the government should offer them to us."

✓ DAA trial treatment is ongoing in Malaysia by DNDi with 200++ PWIDs patient "I can't afford DAAs....If I am meant to die because of HCV, then let it be.It is up to the government if they want to help drug users like me...."

https://myxhepc.com/

https://www.facebook.com/MYxHEPC/



Towards the vision of "...a world where viral hepatitis transmission is halted and everyone living with viral hepatitis has access to safe, affordable and effective prevention, care and treatment services".

- WHO Global Health Sector Strategy on Viral Hepatitis, 2016



Put into consideration: We can't do it alone!

Only a collaborative effort bridging science and policy and uniting multiple public health stakeholders will succeed in ensuring no patients are left behind.

HEPC - CURABLE!

CSO & MOH WORKS & STILL

Political Will

 Commitment, Funding, Priority

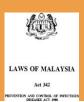


Policy

Workable policy.... impact







Participation

Shared responsibility





https://www.thestar.com.my/news/nation/2018/07/28/wait-over-for-hep-c-screening-50000-rapid-diagnostic-kits-to-be-available-in-selected-clinics/

"Our core business in the Ministry of Health is **to provide affordable, accessible and equitable healthcare for the citizens of Malaysia**," said Dr Hisham Abdullah Director-General of Health Malaysia. "The evidence generated by both the FIND and DNDi projects will be used to update national guidelines that will cover **HCV screening, diagnosis, treatment and monitoring, for an effective HCV public health approach in Malaysia."**

KEY CHALLENGES & SUCCESSES

CHALLENGES

Community awareness on HCV (we need more KP led)

No specific funding

Punitive drug laws (fear to seek treatment) KP usually not prioritised TOP to BOTTOM administrations creates GAPs: HCP - PWIDs

SUCCESSES

- Compulsory Licensing
- Health care system in Malaysia – heavily subsidised
- Join forces MAC-MOH-MTAAG+
- DAA Trial Studies

REFLECTING ON FUTURE EFFORTS

- Data on PWUDs living with HCV vs. treatment vs. follow up
 - Based on Gender (Male, Female, TG)
- Use our HIV experiences in HCV programmes
- Include HCV with HIV screening among PWIDs, at the same time educating them when obtaining informed consent



OBRIGADO!

Any questions?

You can find me at: yatiejonet@gmail.com haryati@mac.org.my