

HIV AND COVID-19: VOICES FROM WOMEN IN INDONESIA (South Sumatera Context)

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HIV AND COVID-19: VOICES FROM WOMEN IN INDONESIA

(South Sumatera Context)

**Najmah
Sharyn Graham Davies**



HIV AND COVID-19: VOICES FROM WOMEN IN INDONESIA

HIV dan COVID-19: Suara Dari Perempuan Di Indonesia



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A Child Mourns at her Mother's Funeral

by Najmah Usman Original In Malay



A little child wails at her mother's funeral, the ground is still red sprinkled with fresh flowers
It's been a long time since a simple funeral ceremony took place
An Islamic preacher who lazily recited a very short prayer has left
The group of mourners who had been whispering about her mother have also dispersed
I looked at the child from a distance, and suddenly her crying got louder when nature was quiet and reverent

Mother, finally, you left me alone
Father passed away a few years ago
Later you may meet him
I witnessed that you are a steadfast wife and mother
You were willing to take care of your husband till his last breath with severe lung disease
I heard from neighbors that my father had extramarital partners when he was not with us
People said his sickness was a curse for my father
From a young age, people said, my father behaved badly
But you were so patient; you were a tough woman
You said to me, "do you want your mother to be a divorcee?"
this question silenced my protest.
The word "Divorcee" became a scary thing for you.

Mother, no more warm hugs for me, no more humming to comfort my pain
Even when I also got infected with that disease
The doctor said that my immune system had weakened, so I may suffer from a terrible disease choking on my breathe.
I got infected with tuberculosis.
When people hear this disease, people will step aside from you

Mother, I saw your resilience to compromise abusive actions from others
I remembered in the hospital when you begged for my help, your daughter
You dealt with disrespectful services; I also listened to unfriendly faces and sarcastic words
I wanted to protest, but you calmed me, mom
You were so busy with a red-tape referral system
Finally, you protested.....!
Now, we were busy, yet all in-patient rooms were packed with COVID-19 patients,
I ask you, "What is COVID-19, mom?"
You smiled at me and said it was just like your disease, just a cough.
But I know that the disrespectful health services traumatized you
Until you finally got sick.
Your husband did not leave anything behind, apart from this disease to you (and me)

A Child Mourns at her Mother's Funeral

by Najmah Usman Original In Malay



I cannot help much with my little hand
There are uncles and aunts from non-governmental
organisations to help you
Persuade you to go to the hospital
But you shook your head and said, "I am afraid of..."
Fears of COVID-19 and COVID-19 test
Finally, you passed away
Left me alone

I stepped closer to this little daughter
Holding her shoulders and saying, your mother has a peaceful
life there; she has now met your father.
The daughter nodded...
Your mother and father must be happy in heaven
The daughter tilted her head
Her eyes stare at me in disbelief at my words
Her mouth said softly
And said, "But my father and mother passed away due to HIV."
I am silent
Then the sky is suddenly cloudy

This poem is based on the true story of an HIV-positive widow who was part of the author's research project on stigma and discrimination of HIV and COVID-19. She passed away in July 2021 after postponing seeking healthcare during the COVID-19 pandemic. She left behind an HIV-positive daughter.



Ratap seorang anak di pemakaman ibunya

by Najmah Usman Original In Malay



Seorang anak kecil meratap di pemakaman ibunya yang masih merah,
bertaburkan bungabunga yang masih segar dan harum
Telah lama upacara pemakaman sederhana itu usai, seorang pendakwah
yang tadi dengan malas melafalkan doa yang juga
sangat pendek telah pergi
Rombongan pelayat yang dari tadi asik berbisik-bisik sambil
melirik jijik pun telah bubar
Aku menatapnya dari kejauhan, namun ratapnya terdengar karena
alam tiba-tiba hening dan takzim

Ibu, akhirnya kau tinggalkan aku sendiri, Bapak telah lama mendahului
kita, mungkin engkau akan segera menemuinya..
Aku saksikan engkau ibu istri yang tabah
Engkau rela merawat bapak sampai sisa hidupnya,
dengan penyakit yang di deritanya
Padahal, aku dengar dari bisik-bisik yang di sampaikan
orang-orang di sekeliling kita
Bapak selalu asyik menemui wanita-wanita di luar sana,
saat tidak bersama kita
Kata mereka, sakit itu hukuman buat bapak
Dari muda, kata mereka, bapak berperilaku durjana
Tapi engkau tabah, engkau sabar..
Nak, apa kau mau Ibu menjanda??, jawab ibu membungkam protesmu
Seolah kata "Janda" menjadi hal yang menakutkan bagimu

Ibu, Tak ada lagi pelukan hangatmu untukku, tak ada lagi
senandung menghibur laraku
Bahkan saat penyakit jahanam itu juga menghantuiku
Kata dokter, imunku melemah, sehingga penyakit mengerikan
yang merongrong pernafasankupun mencekam
Aku terkena TBC buk
Penyakit yang bahkan mendengar namanya saja membuat
orang menyingkir jauh

Ibu, bahkan aku lihat kau mampu berkompromi dengan dunia
yang melecehkanmu
Aku ingat di rumah sakit ketika engkau datang memohon sedikit
belaskasih untukku, anakmu
Wajah sinis engkau dapati, bisik-bisik jijik antar mereka mendengking
di telingaku
Aku ingin protes buk, tapi engkau menyabarkanku

Kesana-kemari engkau di permainkan birokrasi
Engkau akhirnya protes...!
Kami sibuk, kamar sudah penuh dengan penderita COVID-19,
itu yang aku dengar
Covid-19 itu apa buk..Lirih ku bertanya
Engkau tersenyum, itu sama seperti penyakitmu nak,
Cuma batuk saja.



Ratap seorang anak di pemakaman ibunya

by Najmah Usman Original In Malay



Tapi aku tahu, perlakuan itu membuat trauma dalam hidupmu
Sampai akhirnya engkau sakit..
Ya bapak ternyata tidak mewariskan apa-apa, selain sakit padamu..

Aku tak bisa menolong mu banyak dengan tanganku yang kecil..
Ada om dan tante dari LSM yang membantu mu
Membujukmu ke rumah sakit
Tapi engkau menggeleng...Aku takut, jawabmu
Takut akan COVID-19 dan tes COVID-19...
Yang akhirnya kau bawa mati
Meninggalkan aku sendiri...

Aku melangkah mendekati anak kecil itu
Memegang pundaknya dan berkata
Nak, ibumu sudah tenang di sana,
dia sekarang telah berjumpa dengan Bapakmu
Anak itu mengangguk..
Ibu Bapakmu pasti Bahagia di Surga
Anak itu menengadahkan kepalanya
Matanya menatapku tak percaya
Mulutnya berkata lirih
Tapi Ibu dan Bapak mati karena HIV...
Aku terdiam...
Langit tiba-tiba mendung..

Puisi ini didasarkan pada kisah nyata seorang janda HIV-positif yang merupakan bagian dari proyek penelitian penulis tentang stigma dan diskriminasi HIV dan COVID-19. Dia meninggal pada Juli 2021 setelah menunda mencari perawatan kesehatan selama pandemi COVID-19. Dia meninggalkan seorang putri HIV-positif.





Preface

Kata Pengantar



Being an epidemiologist, I mainly focus on quantitative research. Sharyn Graham Davies introduced me another approach to understand the world through qualitative approach. I got excited to understand diseases and its social issues, stigma and discrimination related to HIV and COVID-19.

In Indonesia, we cannot avoid the positive or negative judgments, perception, and assumptions of others. Therefore, HIV-related stigma and discrimination is still significant in most areas of the world, and so did COVID-19. Social stigma against persons infected with COVID-19 and their family members resulting from public fear about this newly emerged infectious disease is not uncommon. Social stigma could negatively impact the emotional, mental, and physical well-being of the patients.

This booklet appeared as a result of a research about stigma around COVID-19 and HIV in Indonesia with funding from Alumni Grant Scheme (AGS) round 2, Australian Awards for Indonesian, a collaboration between Sriwijaya University, Indonesia and Monash University, Australia.

Disclaimer:

The views expressed within this booklet are those of the authors and not necessarily those of the Australian Department of Foreign Affairs and Trade, Australian Embassy, Australia Awards and Australia Global Alumni in Indonesia.

Menjadi seorang ahli epidemiologi, saya lebih fokus pada penelitian kuantitatif. Sharyn Graham Davies memperkenalkan saya pendekatan lain untuk memahami dunia melalui pendekatan kualitatif. Saya bersemangat untuk memahami penyakit dan masalah sosialnya, stigma dan diskriminasi terkait HIV dan COVID-19.

Di Indonesia, kita tidak bisa menghindari penilaian, persepsi, dan asumsi positif atau negatif dari orang lain. Oleh karena itu, stigma dan diskriminasi terkait HIV masih signifikan di sebagian besar wilayah di dunia, begitu juga dengan COVID-19. Stigma sosial terhadap orang yang terinfeksi COVID-19 dan anggota keluarganya akibat ketakutan masyarakat terhadap penyakit menular yang baru muncul ini bukanlah hal yang aneh. Stigma sosial dapat berdampak negatif pada kesejahteraan emosional, mental, dan fisik pasien.

Booklet ini muncul sebagai hasil penelitian tentang stigma seputar COVID-19 dan HIV di Indonesia dengan pendanaan dari Alumni Grant Scheme (AGS) round 2, Australian Awards for Indonesian, kerjasama antara Universitas Sriwijaya, Indonesia dan Monash University, Australia.

Pengakuan:

Pandangan atau pendapat pada buklet ini murni merupakan pendapat pribadi penulis, dan tidak serta merta menggambarkan pandangan Kementerian Luar Negeri dan Perdagangan (DFAT), Kedutaan Besar Australia, Australia Awards, Australia Global Alumni di Indonesia.



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Project Rationale

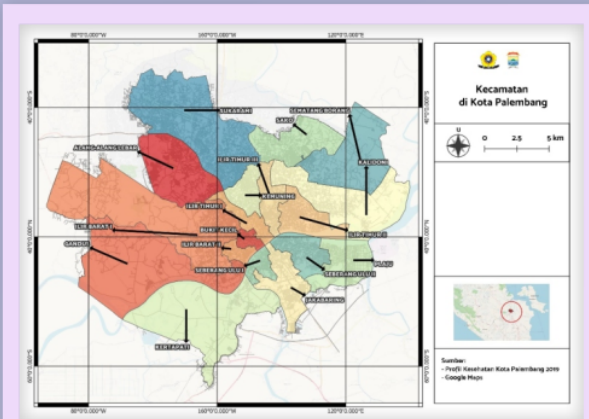
(Latar Belakang Proyek)

This project addresses the issue of stigma associated with ⁶stopping people getting tested; and second by developing strategies that can be implemented to ensure that stigma does not prevent people getting tested for COVID-19, HIV or other diseases as well as accessing COVID-19 vaccines.

Proyek ini membahas masalah stigma yang terkait dengan membuat orang menghindari untuk dites; dan kedua dengan mengembangkan strategi yang dapat diterapkan untuk memastikan bahwa stigma tidak menghalangi orang untuk melakukan tes COVID-19, HIV atau penyakit lainnya serta mengakses vaksin COVID-19.

Setting:

Palembang, South Sumatera



Gambar 1. Mapping of Palembang, South Sumatra
(Credit to Marisa Nurhaliza)

Location: Palembang, South Sumatra-Indonesia

Palembang is bordered by the Banyuasin Regency on the North, East, and West sides, and Muara Enim and Ogan Ilir Regency to the south. The area is about 40,061 km² with a total population of 1.5 million people in 2015. Palembang is divided into two main areas by the Musi River: Seberang Ilir and Seberang Ulu. There are 18 districts (*kecamatan*) in Palembang with 107 sub-districts (*kelurahan*) in all *kecamatan*.

Lokasi: Palembang, Sumatera Selatan-Indonesia

Palembang berbatasan dengan Kabupaten Banyuasin di sebelah Utara, Timur, dan Barat, serta Kabupaten Muara Enim dan Ogan Ilir di sebelah selatan. Luas wilayahnya sekitar 40.061 km² dengan jumlah penduduk 1,5 juta jiwa pada tahun 2015. Palembang dibagi menjadi dua wilayah utama oleh Sungai Musi: Seberang Ilir dan Seberang Ulu. Ada 18 kecamatan di Palembang dengan 107 kelurahan di seluruh kecamatan.





Socio-economic Status

The average monthly income of a Palembang worker is approximately Rp 1.2 million (\$85 US), with about 200,000 or 11 percent of the population living on less than half of that, at RP 480,000, or about \$35 US per month (Statistics of Palembang, 2018). While men and women over 15 years old have similar access to education, unpaid domestic work in the home is still largely undertaken by women; about 92 percent compared to about eight percent of men.

Status Sosial Ekonomi

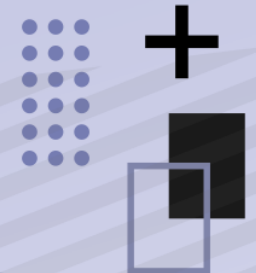
Pendapatan bulanan rata-rata seorang pekerja di Palembang adalah sekitar Rp 1,2 juta (\$85 AS), dengan sekitar 200.000 Penduduk atau 11 persen dari populasi hidup, dengan pendapatan RP 480.000, atau sekitar \$35 AS per bulan (Statistik Palembang, 2018). Sementara laki-laki dan perempuan berusia di atas 15 tahun memiliki akses yang sama ke pendidikan, pekerjaan rumah tangga yang tidak dibayar di rumah sebagian besar masih dilakukan oleh perempuan; sekitar 92 persen dibandingkan dengan sekitar delapan persen laki-laki.

Health facilities and health workers needs

Palembang has 147 clinics, hospitals and public or community health centres. However, the ratio of health workers to population is low, at about 0.5 per 1000 population or about 2000 health workers for 1.5 million people. In terms of ante-natal visits, the majority of women (about 90%) in 2017 to 2020, made at least four visits. Contraceptive methods among married spouses are mainly progesterone injections, the pill, and implants.

Fasilitas kesehatan dan kebutuhan tenaga kesehatan

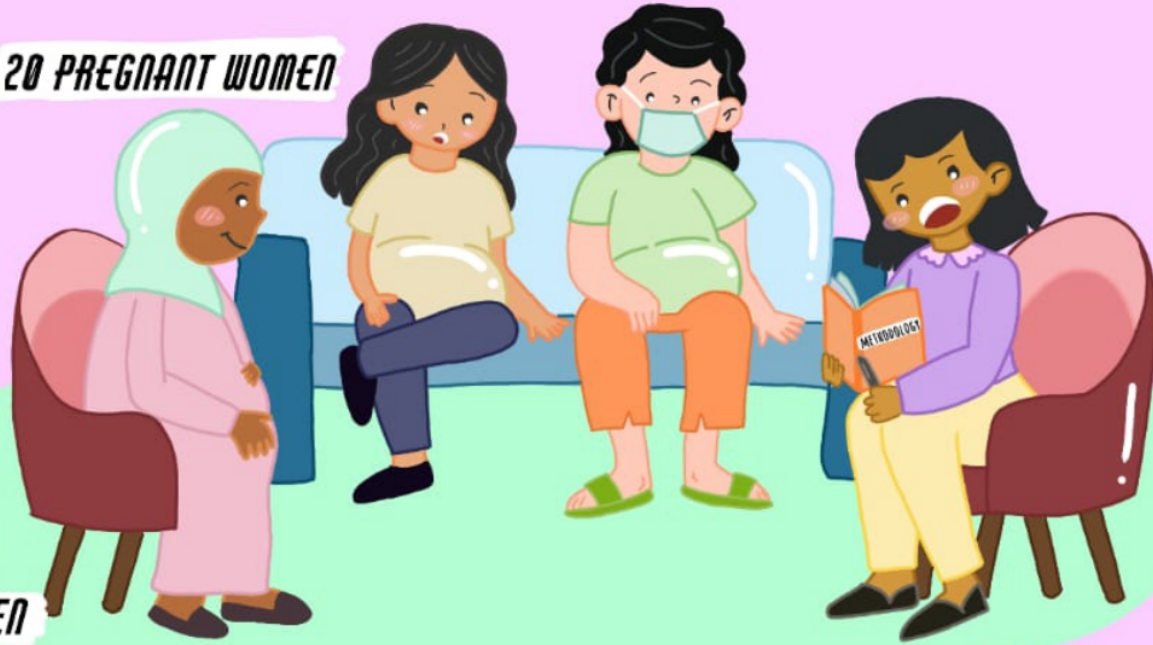
Palembang memiliki 147 klinik, rumah sakit dan Puskesmas. Namun rasio tenaga kesehatan terhadap penduduk masih rendah, yaitu sekitar 0,5 per 1000 penduduk atau sekitar 2000 tenaga kesehatan untuk 1,5 juta orang. Dari sisi kunjungan antenatal, mayoritas ibu (sekitar 90%) pada tahun 2017 hingga 2020, melakukan setidaknya empat kali kunjungan. Metode kontrasepsi pada pasangan suami istri terutama adalah suntik progesteron, pil, dan implan.





20 PREGNANT WOMEN

20 HIV POSITIVE WOMEN



Methodology

Data Collection Cycle



Description:

1. FGD with two groups of HIV-positive mothers
2. FGD with two groups of not working women (Ibu Rumah Tangga) who were pregnant during pandemic
3. Virtual FGD with one group of working women who were pregnant during pandemic
4. Virtual interview with 5 HIV-positive women and mothers
5. Virtual interview with 5 pregnant women
6. Informal interview with 10 health district officers in Palembang



1

3

5

2

4

6

January - February
2021

March 2021

March - July
2021

16

Metodologi

Alur Pengumpulan Data



Keterangan:

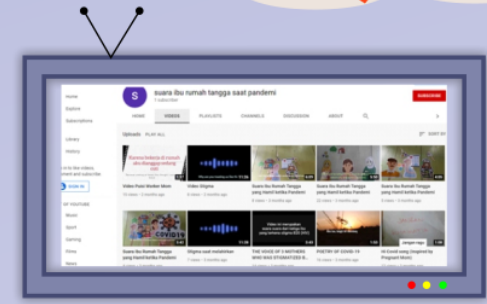
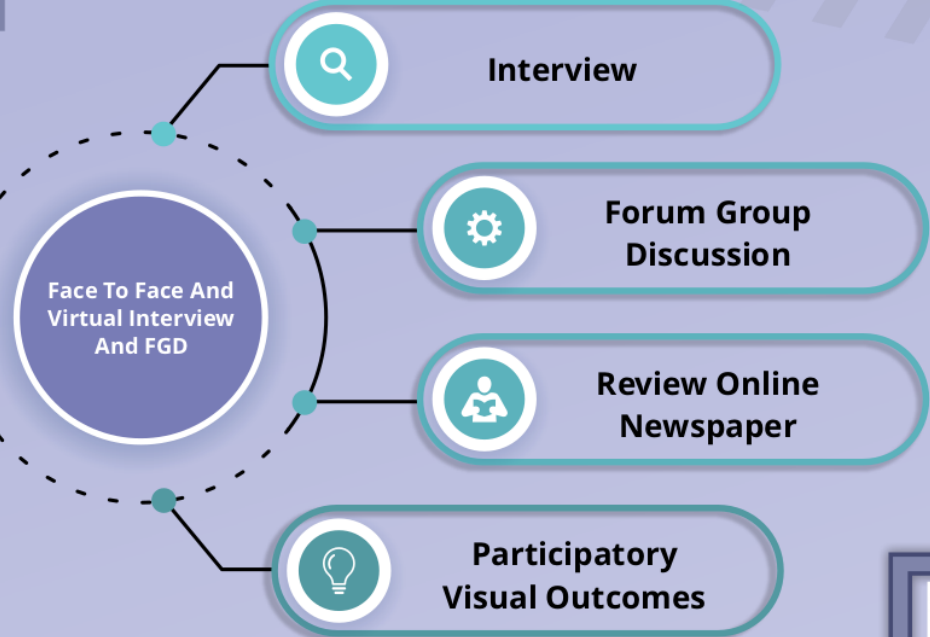
1. FGD dengan dua kelompok ibu positif HIV
2. FGD dengan dua kelompok ibu rumah tangga yang hamil di masa pandemi
3. FGD secara virtual dengan satu kelompok wanita pekerja yang sedang hamil di masa pandemi
4. Wawancara secara virtual dengan 5 ibu positif HIV
5. Wawancara secara virtual dengan 5 ibu hamil
6. Wawancara Informal dengan 10 pengambil kebijakan di Dinas Kesehatan Kota Palembang



Januari - Februari
2021

Maret 2021

Maret - Juli
2021




¹ *Participatory visual methods are considered modes of inquiry, production, and representation in the co-creation of knowledge*



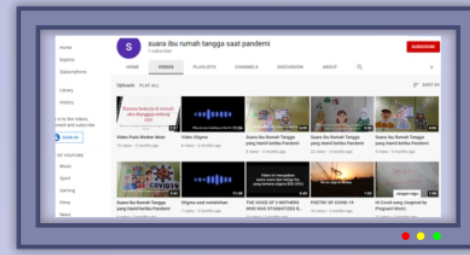
 **Wawancara**

 **Forum Grup Diskusi**

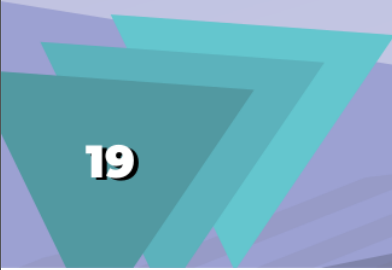
 **Mentelaah berita online**

 **Partisipatif Hasil Visual**

tatap muka dan wawancara virtual dan FGD



Metode visual partisipatif dianggap sebagai cara bertanya, menghasilkan iuran dan representasi dalam mengkontruksi pengetahuan bersama-sama.





Study Context:

Defining Gender Roles in Indonesia



Najmah's Journey

Motherhood¹ is a prestigious and high-status role in Islam as the *Hadith* states: "paradise lies at the feet of the mother" (Pappano & Olwan, 2016, p. 1)

¹ As a Muslim woman in Sumatra of my generation (born after 1980), I was responsible for choosing a good man as a husband. I was raised with the value of having no sexual pleasure or sexual engagement before marriage. After getting married, I hoped my married life would be good, as well as my career, education, family, and religion. I was taught that marriage and motherhood was a part of worship of God (*ibadah*) and I learned to be sincere (*ikhlas*) in performing my motherhood roles for the sake of God, and to apply kindness (*kebaikan*) within my family. I also work as a lecturer to support my family's income. I also maintained my dignity as a faithful wife, and my husband's role to provide virtuous guidance and be the main breadwinner of my family while sharing the roles of nurturing our three children (Najmah's Research Journal, 2018).



Konteks Studi:

Mendefinisikan Peran Gender di Indonesia



Perjalanan Najmah

Ibu adalah peran bergengsi dan berstatus tinggi dalam Islam sebagaimana hadits menyatakan: "surga terletak di telapak kaki ibu" (Pappano & Olwan, 2016, p. 1).

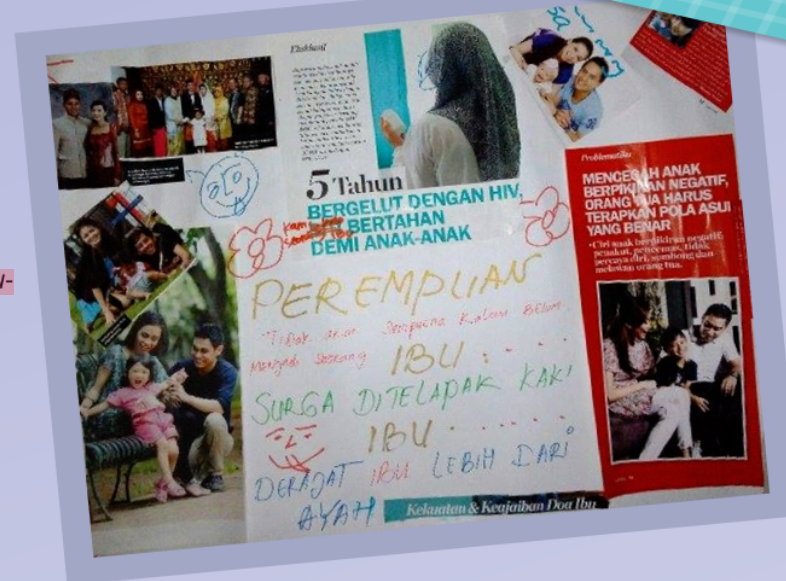
Sebagai seorang wanita Muslim di Sumatera dari generasi saya (lahir setelah 1980), saya bertanggung jawab untuk memilih pria yang baik sebagai suami. Saya dibesarkan dengan nilai menjauhi kesenangan seksual atau melakukan hubungan seksual sebelum menikah. Setelah menikah, saya berharap kehidupan pernikahan saya akan baik-baik saja, begitu juga dengan karir, pendidikan, keluarga, dan agama saya. Saya diajari bahwa menikah dan menjadi ibu adalah bagian dari ibadah kepada Tuhan (ibadah) dan saya belajar untuk ikhlas dalam menjalankan peran saya sebagai ibu demi Tuhan, dan menerapkan kebaikan dalam keluarga saya. Saya juga bekerja sebagai dosen untuk menghidupi keluarga saya. Saya juga menjaga martabat saya sebagai istri yang setia, dan peran suami saya untuk memberikan bimbingan yang bijak dan menjadi pencari nafkah utama keluarga saya sambil berbagi peran dalam mengasuh ketiga anak kami. (Jurnal Riset Najmah, 2018)



HIV-Positive Mother's Journey

Figure 1. Paradise lies at the feet of the mother-Surga ditelapak kaki Ibu (Collage by Sehati A, 6 HIV-positive women)

Note: *Derajat ibu lebih dari ayah*- mother's dignity is over father;
Perempuan-tidak akan sempurna kalau belum menjadi seorang Ibu-
a woman is not perfect if she does not have a child;
5 tahun bergelut dengan HIV dan bertahan demi anak-anak-
5 years living with HIV and surviving for the kids.



A Working Mothers' Journey



Poem:

I, a mother, a pregnant woman and a worker
Oleh Ibu Winda, A Working Mom.

*just realised the joy of life
When covid was around
It turned out that
Everyone was afraid of sickness and death
I just realised the pleasure of working
When keeping distance is a key
So that everyone can avoid harm
I just realised the pleasure with family
When the policy of stay at home have to be enforced
Because everyone is busy taking care of themselves
I just realised the joy of being a mother
When I spent my 24 hours looking after my child
Because I don't want him to know how worried am I
I just realised the joy of being a wife
Because working at home, they thought I was on leave
Then, finally I asked myself "is it fair?"
I just realised the pleasure of eating a bowl of hot noodles
Because I am a mother and a lecturer at the same time
Make me to the point of insanity
But in the end
I have to keep in my mind His great blessings
I am a mother and a worker who gave birth during the pandemic.*



Puisi:

Aku, Ibu, Hamil dan Pekerja selama Pandemi

Oleh Ibu Winda

Aku baru menyadari nikmatnya hidup
Ketika cobaan COVID ada di dunia ini
Ternyata semua orang takut akan sakit dan kematian

Aku baru menyadari nikmatnya bekerja
Ketika menjaga jarak menjadi kuncinya
Agar semua orang terhindari dari bahaya

Aku baru menyadari nikmatnya bersama keluarga
Ketika kebijakan dirumah saja harus dijalani
Karena semua orang menjaga diri

Aku baru menyadari nikmatnya menjadi ibu
Ketika 24 jam menjaga anakku
Karena tak ingin ia tau bagaimana khawatirnya aku

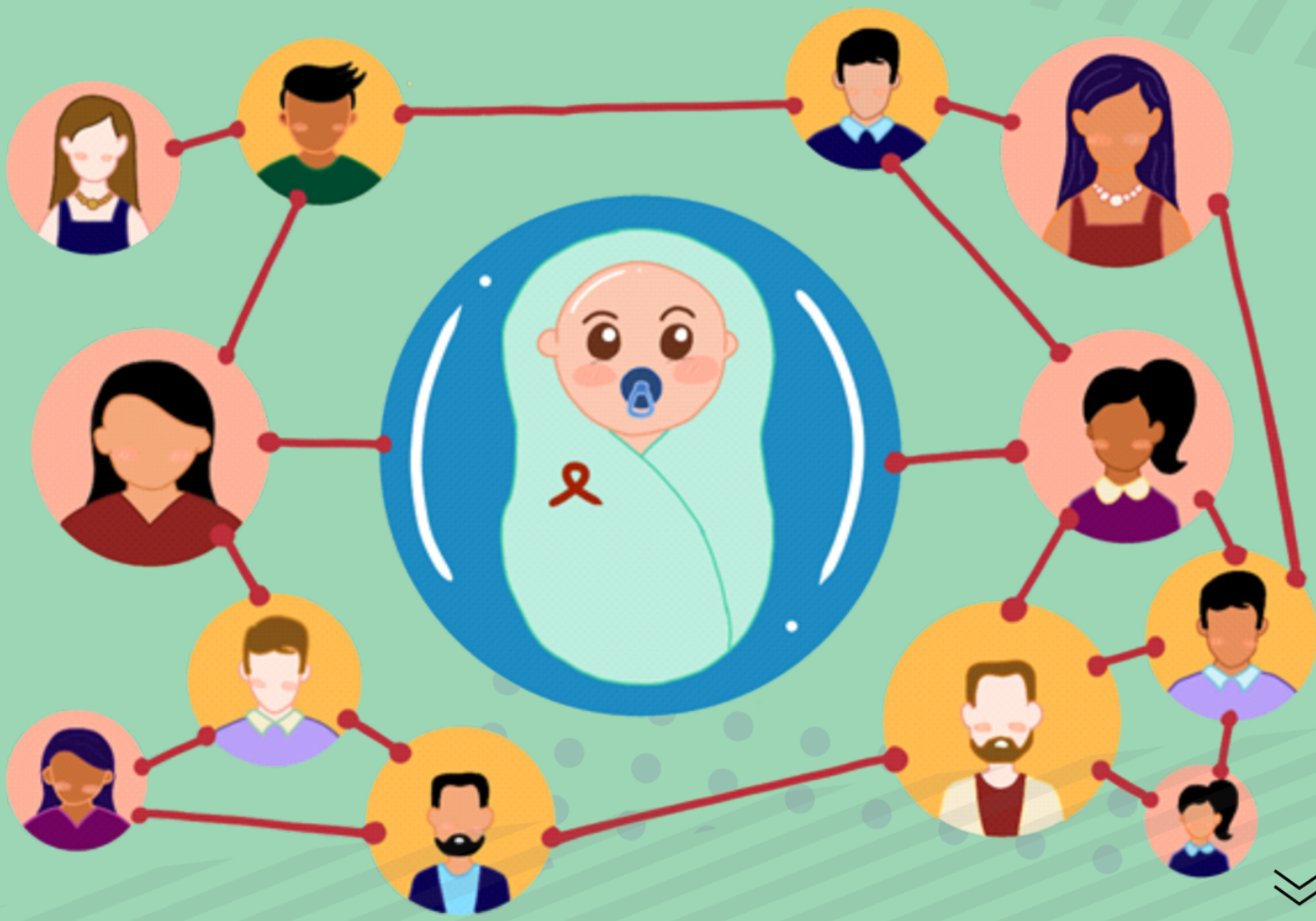
Aku baru menyadari nikmatnya menjadi istri
Karena bekerja di rumah aku dianggap sedang cuti
Hingga membuat aku bertanya adilkah ini

Aku baru menyadari nikmatnya semangkok mie rebus panas
Ketika menjadi ibu asuh dan ibu dosen dijalani bersamaan
Hingga membuat ku pada titik kegilaan

Namun pada akhirnya
Aku tetap harus menyadari nikmat-Nya yang begitu besar

Aku, seorang...ibu pekerja dan ibu yang melahirkan anak ketika pandemi





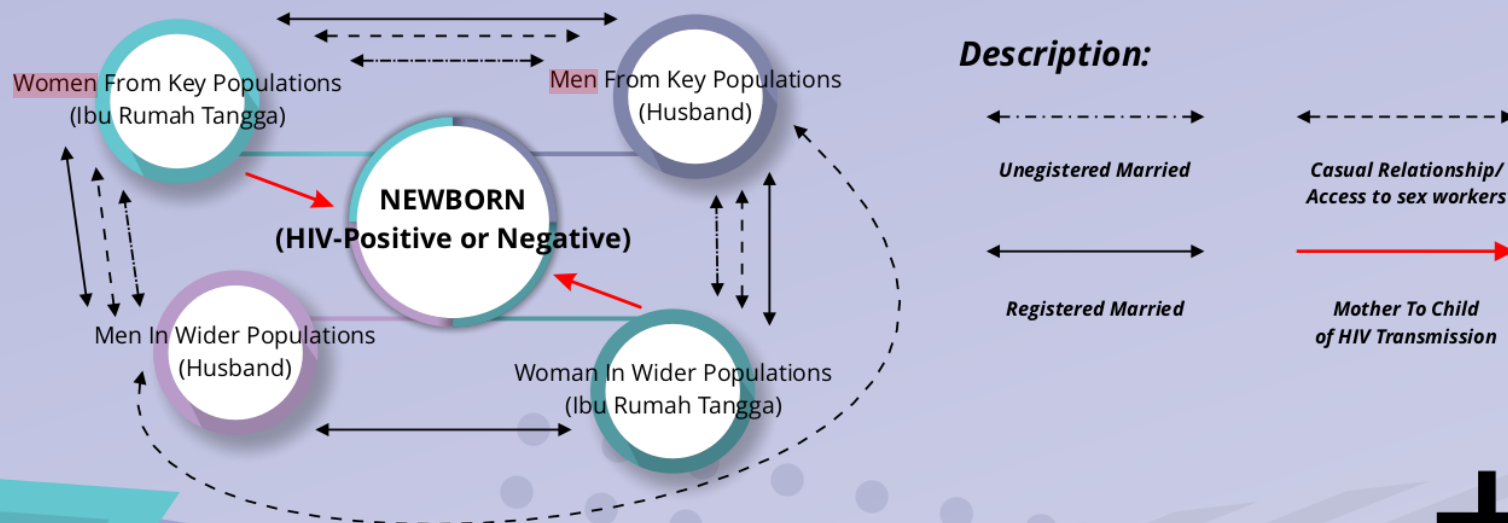
HIV Epidemiology:

Mothers And Wives At Risk Of HIV



This study highlights the need for every Indonesian ¹ to be aware that s/he is at risk of HIV, even if s/he does not engage in any high-risk behaviours. The metaphor of a spider's web is used to demonstrate the transmissible links between high, and low risk groups.

Figure 2: ¹ The Spider's Web of HIV Transmission Among Married Couples in Indonesia.



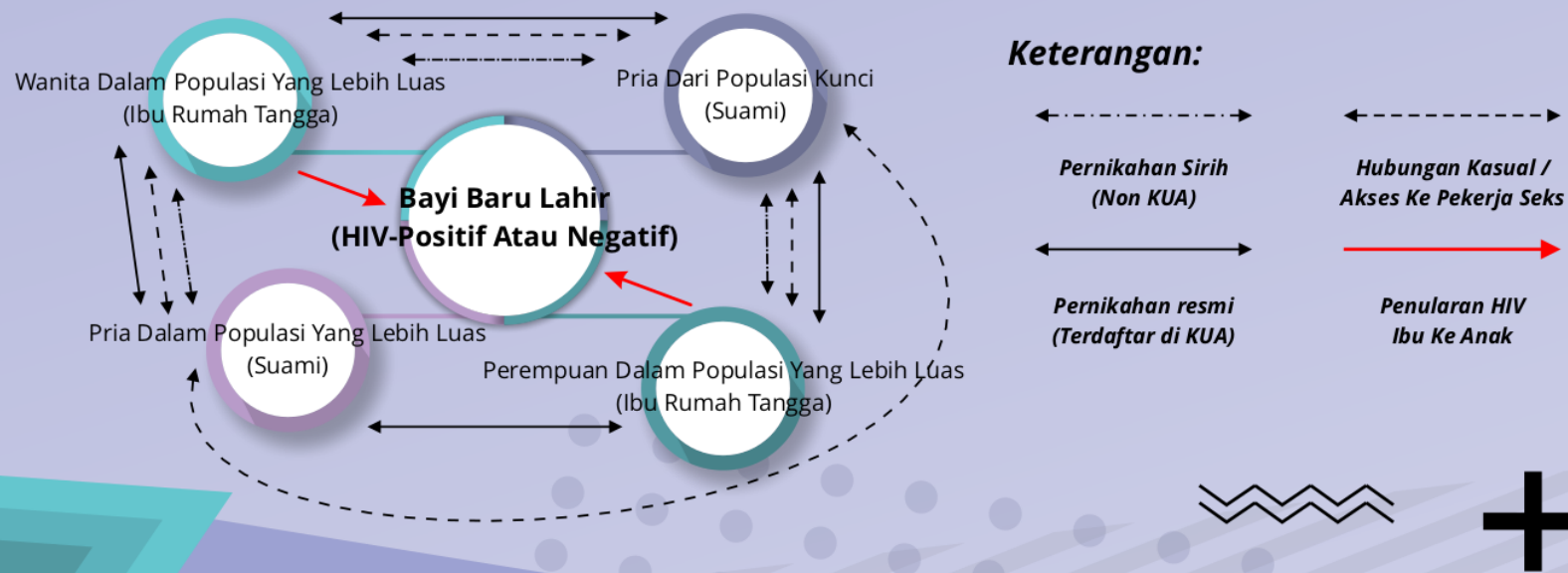
Epidemiologi HIV:

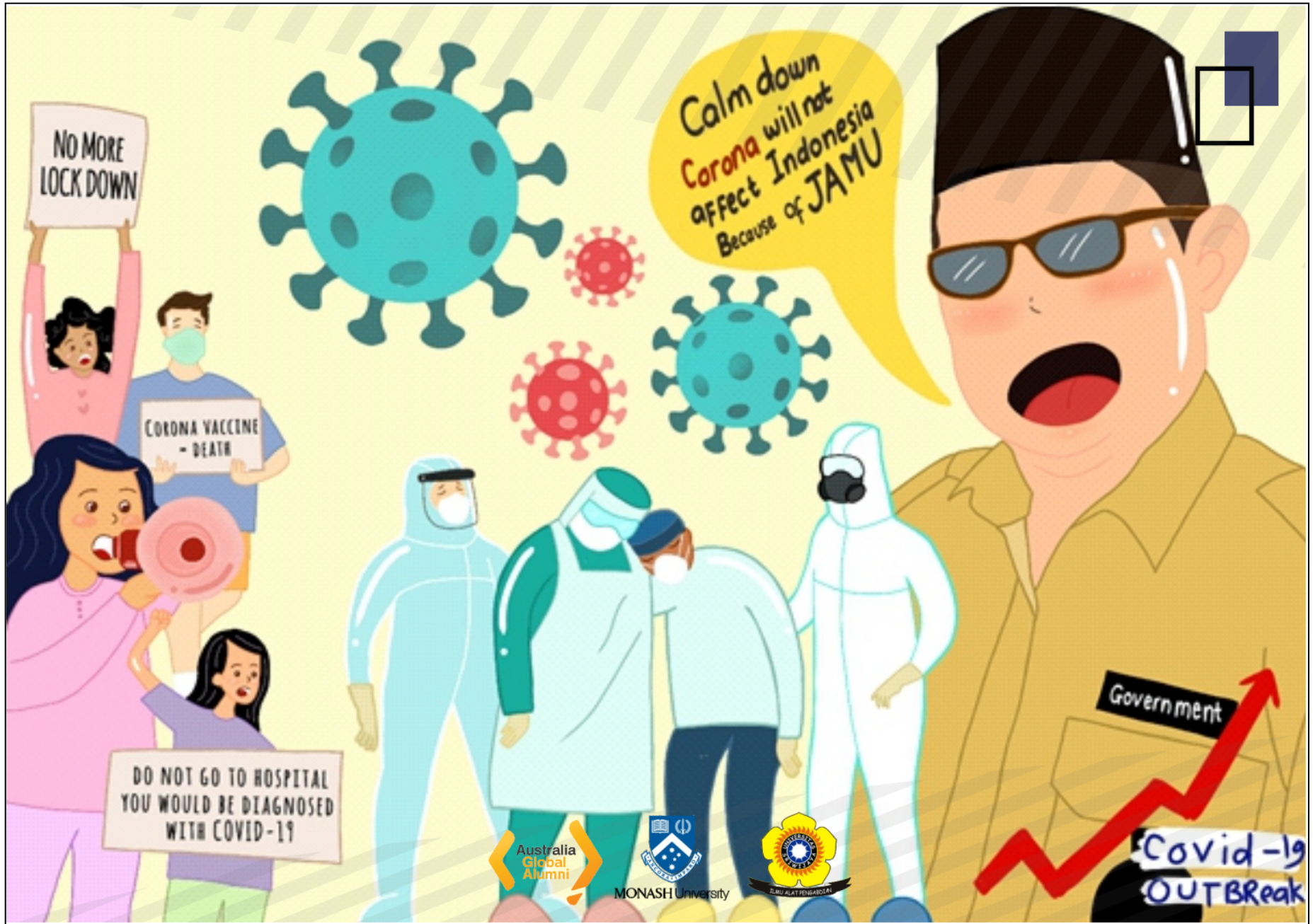
Ibu Dan Istri Berisiko HIV



Studi ini menyoroti perlunya setiap orang Indonesia untuk menyadari bahwa setiap perempuan (termasuk ibu dan istri) berisiko HIV, bahkan jika dia tidak terlibat dalam perilaku berisiko tinggi. Metafora jaring laba-laba digunakan untuk menunjukkan kompleksitas penularan HIV dari kelompok berisiko tinggi ke kelompok berisiko rendah.

Gambar 2: Jaring Laba-laba Penularan HIV Pada Pasangan Menikah di Indonesia





NO MORE
LOCK DOWN

CORONA VACCINE
- DEATH

DO NOT GO TO HOSPITAL
YOU WOULD BE DIAGNOSED
WITH COVID-19

Calm down
Corona will not
affect Indonesia
Because of JAMU

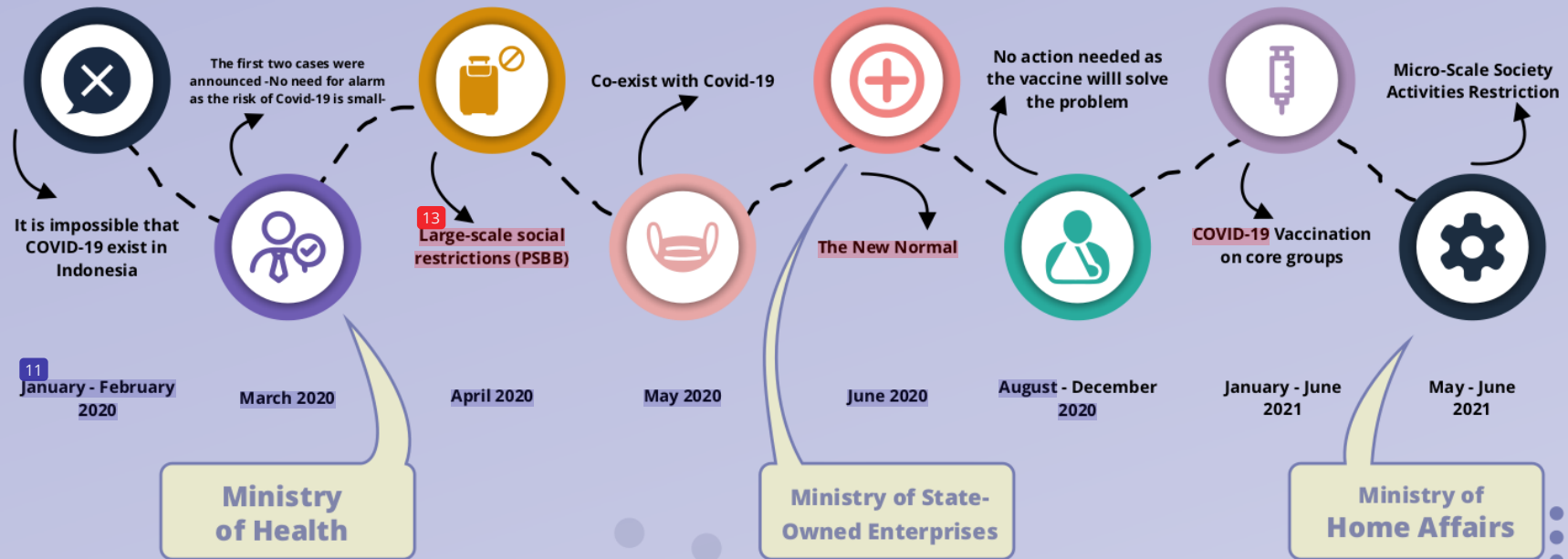
Government

Covid-19
OUTBREAK

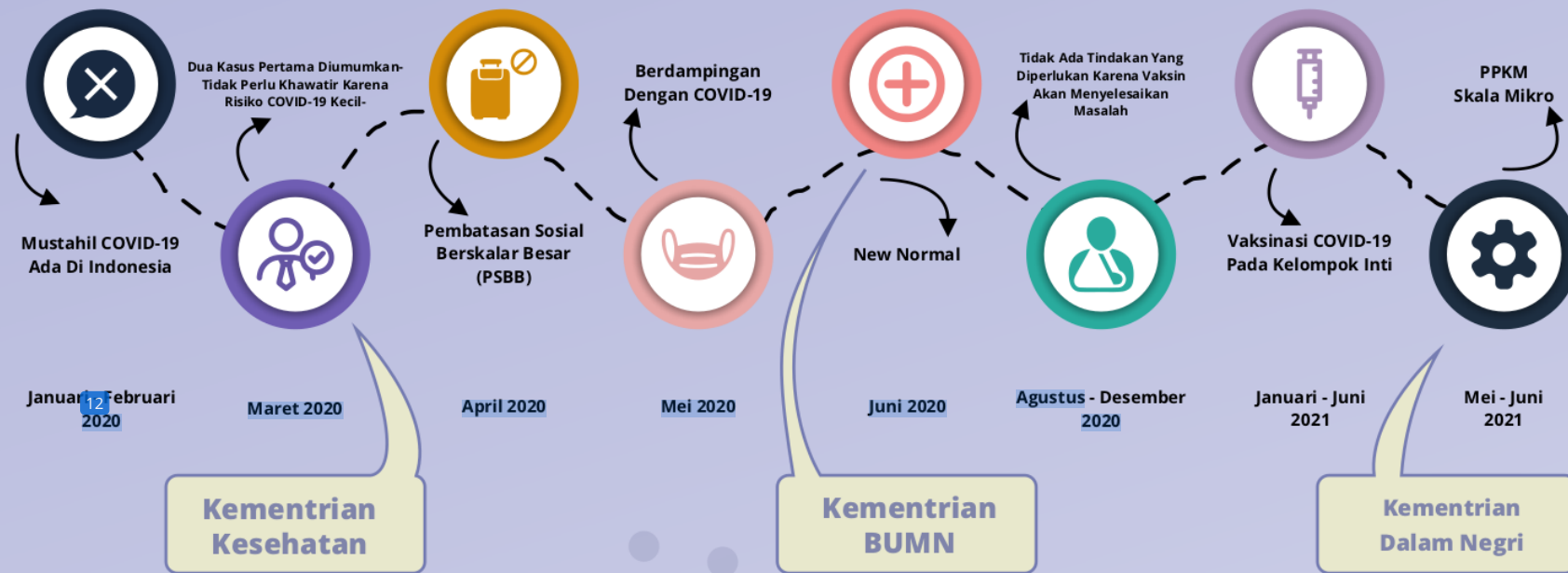


COVID-19 Chronicle

In Indonesia

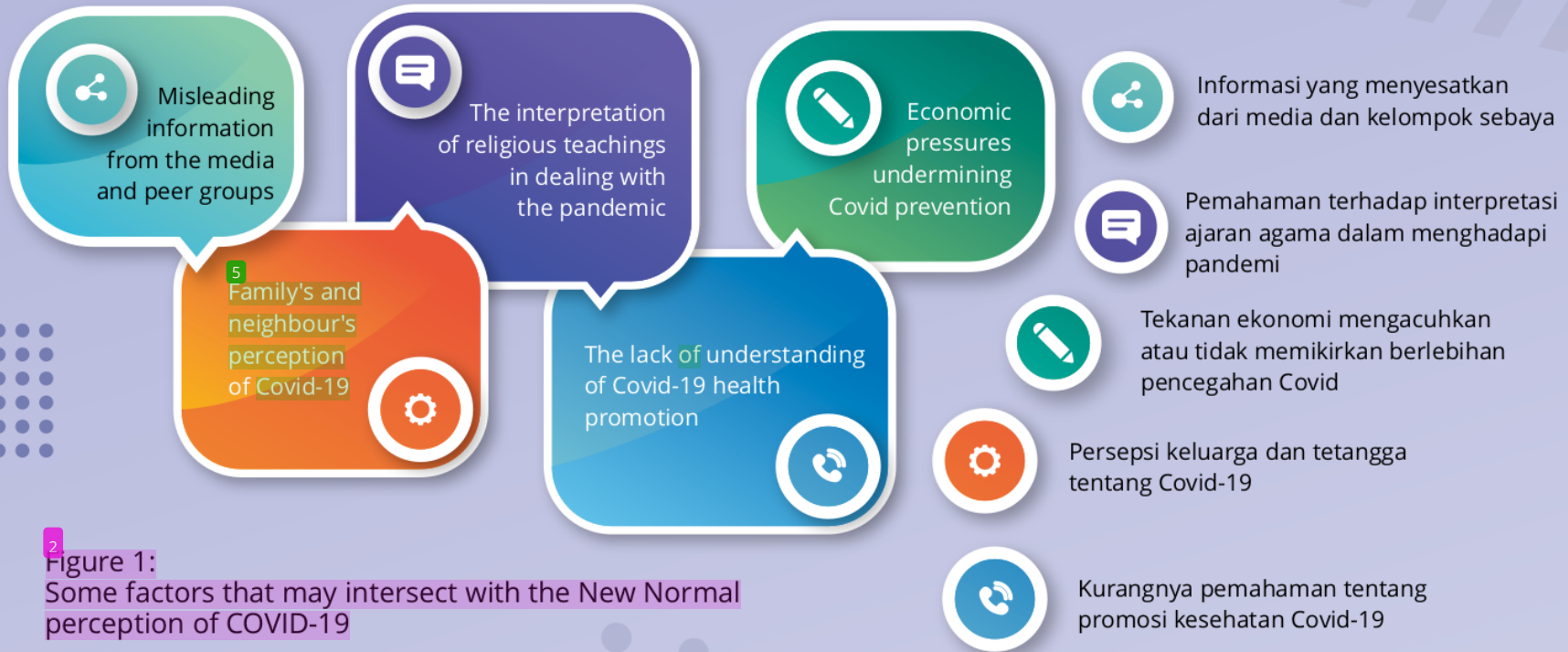


Kronologis COVID-19 di Indonesia



COVID-19 Denial In Indonesia

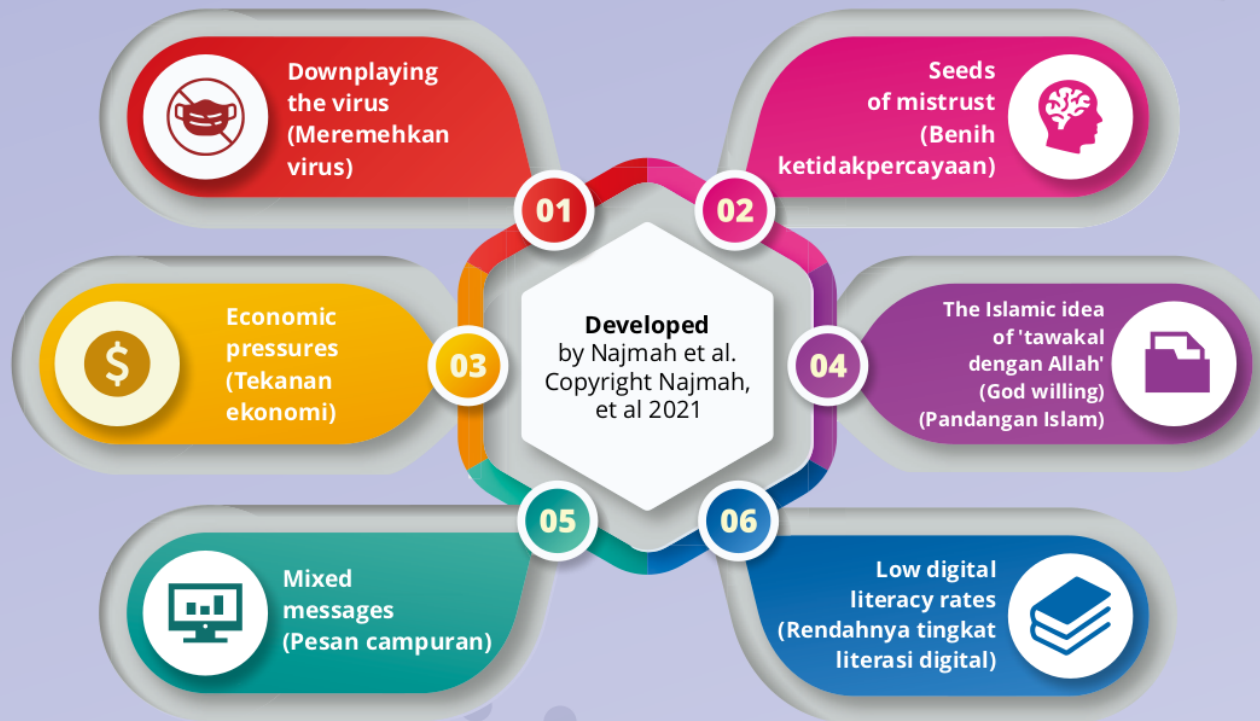
Penyangkalan COVID-19 di Indonesia

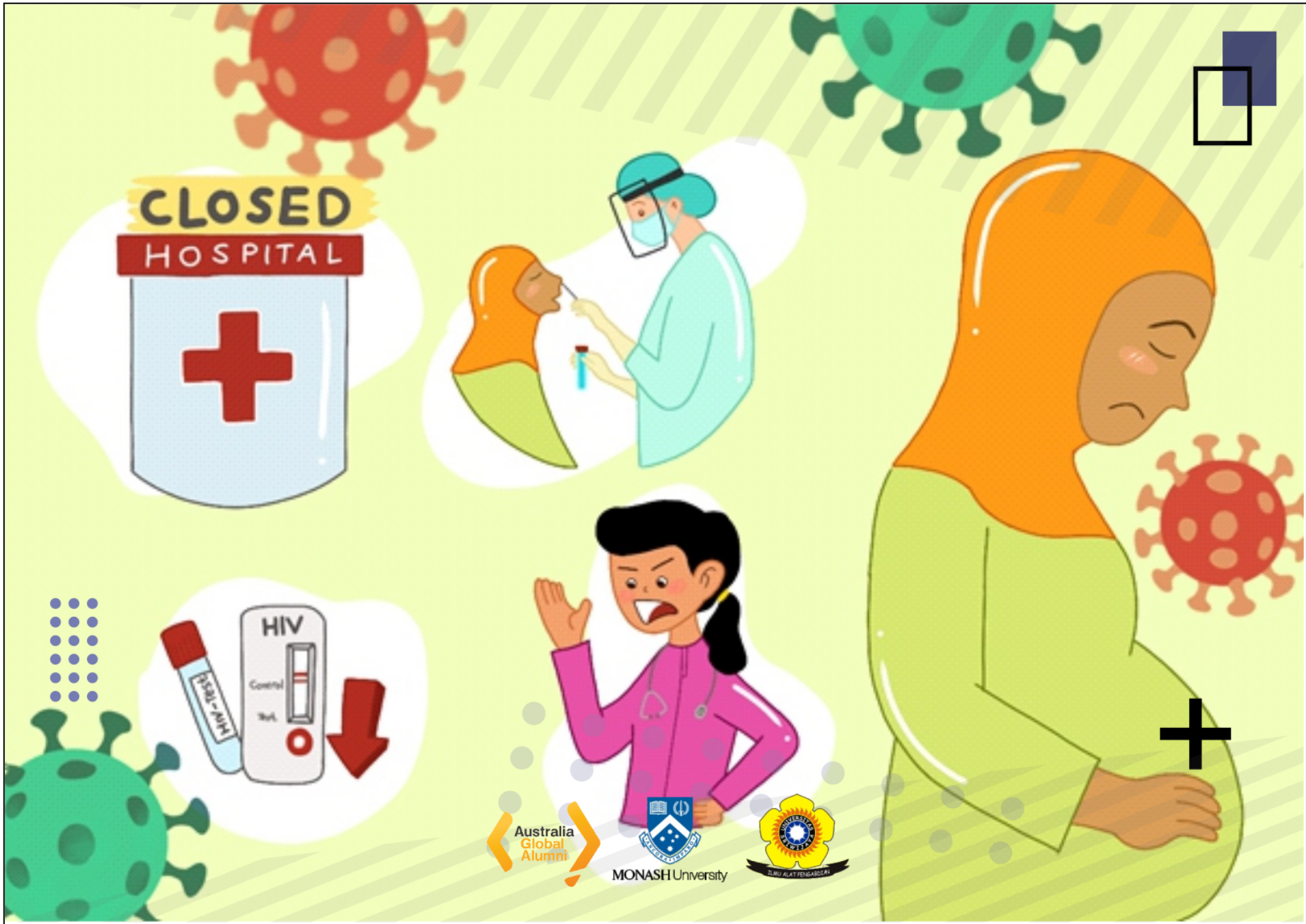


2 Figure 1: Some factors that may intersect with the New Normal perception of COVID-19



Developed by Najmah et al.
Copyright Najmah, et al 2021





CLOSED
HOSPITAL



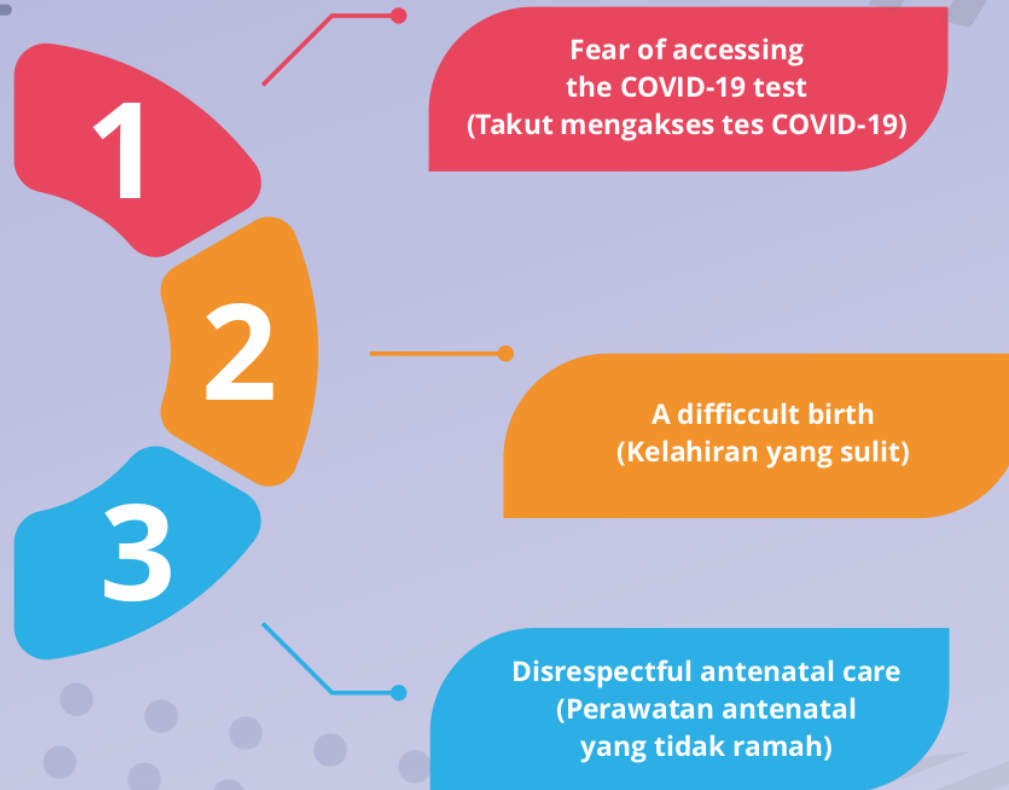
Disrupted Routine Materinty in South Sumatera, Indonesia

*Rutinitas Pelayanan Antenatal (Bersalin) yang Terganggu
di Sumatera Selatan, Indonesia*



This disrupted contributed to anxiety and fear among pregnant women as well as creating mothers' resilience in obtaining health services in Indonesia

Gangguan ini turut menimbulkan kecemasan dan ketakutan pada ibu hamil serta menciptakan ketahanan ibu dalam memperoleh pelayanan kesehatan di Indonesia



Fear of Accessing the COVID-19 Test

Takut mengakses Tes COVID-19



Hai COVID
Hai COVID
Dia tidak mematikan
Jangan takut
Jangan ragu untuk tes COVID (2x)

Kalau mau sehat
Mari kita tes
Kita harus berani
Melakukan tesnya tidak sendiri
Dengan masyarakat tak perlu rasa takut


Hai COVID
Hai COVID
Dia tidak mematikan
Jangan takut
Jangan ragu kita harus sehat (2x)

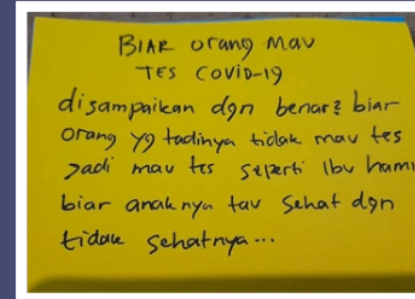
Hai COVID
Hai COVID
Dia tidak mematikan
Dengan masyarakat melakukannya
Dengan senyum ceria
Indahnya apabila tes COVID gratis

Hey COVID, Hey COVID,
It's not deadly
Don't be afraid
Don't hesitate for COVID-test [2x]

If you want to be healthy,
Let's undertake test, we have to be brave,
We do the test not alone, but together with society
There is no need for fear of COVID-19

Hey COVID, Hey COVID,
It's not deadly
Don't be afraid
Don't hesitate for COVID-test [2x]

Hey COVID, Hey COVID
It's not deadly
With the community, doing it with a chee  I smile
That would be nice if the COVID-19 test is free



Video Link: https://www.youtube.com/watch?v=_eoXqicsKwI



Disrespectful Antenatal Care

Perawatan Antenatal Yang Tidak Sopan



(Rina's, 23 years old, a mother and wife, diary notes, 2021).

Nurse : do you want [a covid] check, mom?

Rini : I want to check my pregnancy.

Nurse : Do you have any [covid] symptoms?

Rini : I feel nausea.

Nurse : [Regarding her pregnancy.] We cannot check you. [I]f you felt getting worse, such as having bleeding, then you can come to the puskesmas again.

Rini : Then I['] directly go home, and felt disappointed afterwards. I decided to access a private midwifery practice 'till my delivery.

(Rina's, 23 Tahun, Ibu Dan Istri, Catatan Harian, 2021).

Perawat : mau cek [covid] bu?

Rini : Saya ingin memeriksakan kehamilan saya.

Perawat : Apakah ada gejala [covid]?

Rini : Saya merasa mual.

Perawat : [Mengenai kehamilannya.] Kami tidak bisa memeriksa Anda. [Saya] jika Anda merasa semakin buruk, seperti mengalami pendarahan, maka Anda bisa datang ke puskesmas lagi.

Rini : Kalau begitu saya langsung pulang, dan merasa kecewa setelahnya. Saya memutuskan untuk mengakses praktik kebidanan swasta 'sampai saya melahirkan'.



Disrespectful Antenatal Care

Perawatan Antenatal Yang Tidak Sopan



SULITNYA PERIKSA KEHAMILAN DI MASA PANDEMI KARNA BANYAK KLINIK YANG LIBUR !!!

It is difficult to check pregnancy during the pandemic because many clinics are closed

BEROBAT JANGAN DIPERSULIT

Don't complicate treatments

Jiha, 23 years old, a mother and a wife, FGD

PENUHI AKSES TERHADAP LAYANAN KESEHATAN IBU / ANAK

Please, fulfill all health services for mothers and kids



A Difficult Birth *Kelahiran Yang Sulit*



PELAYANAN
KESEHATAN
HARUS
RAMAH TAMAH

Friendlier health services
[during pandemic]

HAMIL YANG
MENGKHAWATIRKAN
DI MASA PANDEMI
COVID-19

Worrying about pregnancy during
the COVID-19 pandemic.

*Deva, 23 years old, a mother and a wife,
access to caesarian section*

Jangan Kucilkan
Orang yang positif
Covid-19, tapi harus
di beri dukungan baik
di RUMAH MAUPUN
di R.S. 😊

Please, do not stigmatise people
who get infected with COVID-19,
they need a moral support at
home and hospital. 😊



A Difficult Birth *Kelahiran Yang Sulit*



I am traumatised by COVID-19, my two children and my husband also contracted COVID-19. I was also infected with COVID-19 during my last term of pregnancy. No one wanted to take care of my children because I had to be referred to the Palembang to delivery my baby. Finally, my brother-in-law got up the courage to take care of my asymptomatic children. I was referred to a different hospital from my husband in Palembang. I gave birth to my third child when my husband was unconscious and struggling in the ICU. In the hospital, the nurse only came into my room when injecting the medicine and immediately left me alone in the isolation room. After I delivered my baby, I was separated to my baby directly to prevent COVID-19 transmission. Thanks God (Alhamdulillah), my husband and my family were still given a second chance to live and we have been declared negative for COVID-19. I am traumatised, I am traumatised. For now, I am still closing my midwifery practice in my house.

(Ani, a working mother, 40 years old, access to caesarian section, online chatting through WhatsApp).

Saya trauma dengan COVID-19, kedua anak saya dan suami saya juga tertular COVID-19. Saya juga terinfeksi COVID-19 selama masa kehamilan terakhir saya. Tidak ada yang mau mengasuh anak saya karena saya harus dirujuk ke Palembang untuk melahirkan bayi saya. Akhirnya, kakak ipar saya memberanikan diri untuk merawat anak-anak saya yang asimtomatik. Saya dirujuk ke rumah sakit yang berbeda dari suami saya di Palembang. Saya melahirkan anak ketiga saya ketika suami saya tidak sadarkan diri dan berjuang di ICU. Di rumah sakit, perawat hanya masuk ke kamar saya saat menyuntikkan obat dan langsung meninggalkan saya sendirian di ruang isolasi. Setelah saya melahirkan bayi saya, saya langsung dipisahkan dengan bayi saya untuk mencegah penularan COVID-19. Puji Tuhan (Alhamdulillah), suami saya dan keluarga saya masih diberi kesempatan kedua untuk hidup dan kami dinyatakan negatif COVID-19. Saya trauma, saya trauma. Untuk saat ini, saya masih menutup praktik kebidanan di rumah saya.

(Ani, Ibu Pekerja, 40 Tahun, Akses Operasi Caesar, Chatting Online Melalui WhatsApp).



A Difficult Birth

Kelahiran Yang Sulit



(Dina, 32 years old, a working mother).

I am lucky, a nurse who treated me was also infected with COVID-19 during pregnancy. The nurse did not suffer any symptoms. The nurse was diligent to check my fetus in my womb three times a day. For me, I was lucky, the nurse did not be afraid of me and was friendly during my hospitalisation.

Saya beruntung, perawat yang menjaga saya di rumah sakit ketika terinfeksi COVID-19 saat hamil, juga positif COVID-19 tanpa gejala. Sang perawat cukup rajin memeriksa janin saya, 3x dalam sehari. Bagi saya, saya beruntung, sang perawat tidak merasa takut dan ramah dalam merawat saya.



What's Behind COVID-19

Vaccine Hesitancy In Indonesia

Ada Apa Di Balik Keragu-raguan Vaksin COVID-19 Di Indonesia?



MAU DI VAKSINI
COVID - 19 ???

Kenapa? →

- Tidak mau di vaksin karena tidak mau ambil resiko/dan merasa Sehat.
- Cukup protokol kesehatan dan jaga kesehatan, sudah cukup dan minum obat - vitamin istirahat di rumah.

do not want to take any risk [by having the vaccine]. I feel healthy and I am in a good condition. I just need to perform the health protocols [e.g. hand-washing] and maintain my immunity by taking vitamins.



Social media message saying: "I am ready to be vaccinated"
(Source: [Ministry of Health Indonesia](#))

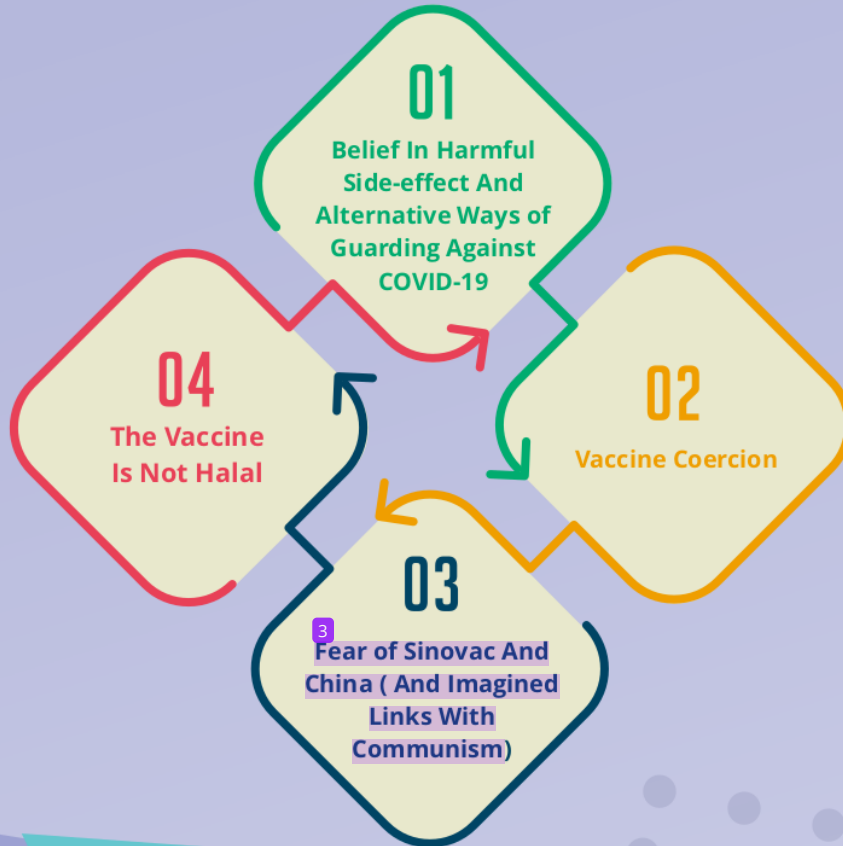
MAU DIVAKSINI
COVID-19 ??

KEMAPA ?

KARNA TAKUT TERIN
JADI MAU di PAKSIN
GRATIS yach...!

Do you want to access COVID-19 test?
Why? I am afraid to be infected COVID-19,
so I want to get a shot, but it has to be free of charge





01

³Kepercayaan pada efek samping yang berbahaya dan cara-cara alternatif untuk melindungi diri dari COVID-19.

02

Pemaksaan Vaksin

03

Ketakutan akan Sinovac dan China (dibayangkan berkaitan dengan komunisme)

04

Vaksin Tidak ³Halal





“I do not want to be vaccinated because the vaccine is from China, and there are pig parts in the ingredients. It is haram (forbidden) to put pig parts into my body. We will go to hell if we do it.”
(Yaya, a 50-year-old housewife)

*“Saya tidak mau divaksin karena vaksinnnya dari China, dan ada bagian babi di dalam bahannya. Haram (dilarang) memasukkan bagian tubuh babi ke dalam tubuhku. Kita akan masuk neraka jika melakukannya.”
(Yaya, seorang ibu rumah tangga berusia 50 tahun)*

Lala, a 30-year-old nurse, also mentioned that as a health worker she was obliged to get vaccinated and that her only choice was to agree to the vaccine or to lose her job. Lala also noted: “We are also afraid of accessing the COVID-19 vaccination. We are ordinary humans, we are afraid of taking the COVID-19 vaccine, but we need to take care of our own health.”

Lala, seorang perawat berusia 30 tahun, juga menyebutkan bahwa sebagai tenaga kesehatan ia wajib divaksinasi dan satu-satunya pilihannya adalah menyetujui vaksin atau kehilangan pekerjaannya. Lala juga mencatat: “Kami juga takut mengakses vaksinasi COVID-19. Kita adalah manusia biasa, kita takut mengambil vaksin COVID-19, tetapi kita perlu menjaga kesehatan kita sendiri.”





Endless Stigma of HIV and COVID-19



¹ Note: The English translation of the words in this picture is: We are great mothers (*kami Ibu Hebat*). HIV is not a death penalty (*HIV tidak mematikan*). We survive with HIV/AIDS (*kami tetap bertahan hidup meski dengan HIV/AIDS*). Let's get an HIV test (*mari kita tes HIV*). People living with HIV (PLWHIV) are not scary (*Penderita ODHA tidak menakutkan*). We wish for all HIV-positive people to always strive (*semoga ODHA sukses terus*). Please, stop discrimination against those living with HIV (*hapus diskriminasi HIV/AIDS*). Government needs to embrace PLWHIV (*pemerintah merangkul ODHA*); Keep your spirit up (*semangat!!*). Someday, we hope there will be a cure for HIV (*berharap suatu saat ditemukan obat untuk menyembuhkan HIV*). I am HIV-positive (*Saya HIV +*).



A Deep Voice From an HIV-Positive Pregnant Mother



² If you were tested for COVID-19, the result is more likely positive. I said, no, I am not COVID-19 positive, I am healthy. Please, do not pray me for that. If I get infected with COVID-19, you would be sick too. Then the health worker was silent.

² Then another doctor helps me, and said to one midwife who treated her “if you cannot finish your work to help this mother, it is better not to help her delivery”. The unprofessional treatment for HIV-positive pregnant women would kill the mother and baby, the doctor added.

² I have right, I can make a report for your unfair treatment, please don't treat me badly. For my HIV status, it is not my own willingness, I also did not want to be infected HIV too. My operation schedule failed as the date of prediction was on 15th December 2020. The health workers keep talking though I was in bleeding and in pain. My heart was broken. Help me, God



Suara yang Dalam Dari Ibu Hamil yang HIV-Positif



Nah kamu kalau tes, kamu bakalan positif katanya. Enggaklah bu kataku. Kalo aku emang, aku selama ini sehat-sehat aja aku bilang kayak itu. Eh jangan didoain juga lah bu kataku. Kalo aku kena corona ibu lebih ini. lalu langsung diem dia.

Jadi dimarahin lah dokter yang nanganin aku yang pertama itu sama bidan yang lain itu kan. Katanya ibarat kalo kamu kerja ga nyelesain itu, ga usah dipegang lah mending. Ini kayak gini, sama aja kamu kayak membunuh orang katanya

(Terus aku jawab, aku punya hak dong, aku jawab, aku bisa ngaduin kalian loch kataku, janganlah kayak gini ku gituin. Memang bukannya kehendak aku. Yang kemaren operasi gagal kataku. Prediksi ini bukan tanggal ini kubilang gitu kan. Seharusnya tanggal 15 kata dokternya pub kayak gitu ku bilang. Pokoknya bu ocehan bu. Pas darah itu aja aku masih pendarahan. Uuh sakit ati aku didalam dicaci inilah kataku. Ya Allah (Yana)



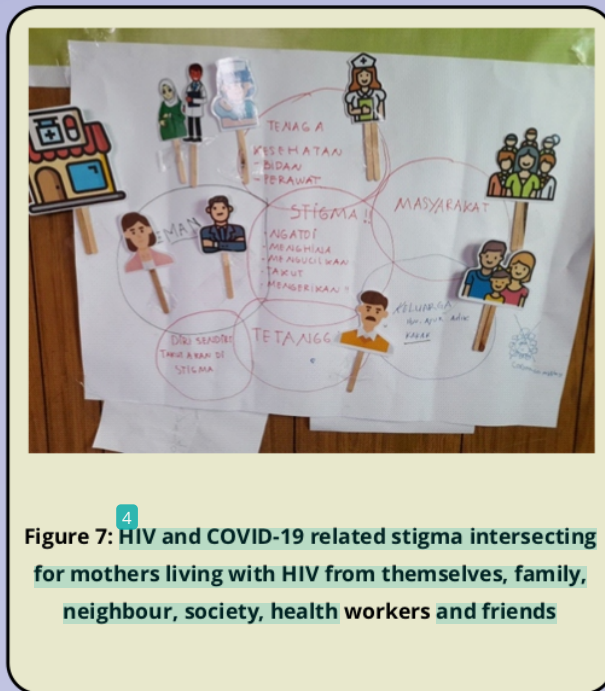


Figure 7: HIV and COVID-19 related stigma intersecting for mothers living with HIV from themselves, family, neighbour, society, health workers and friends

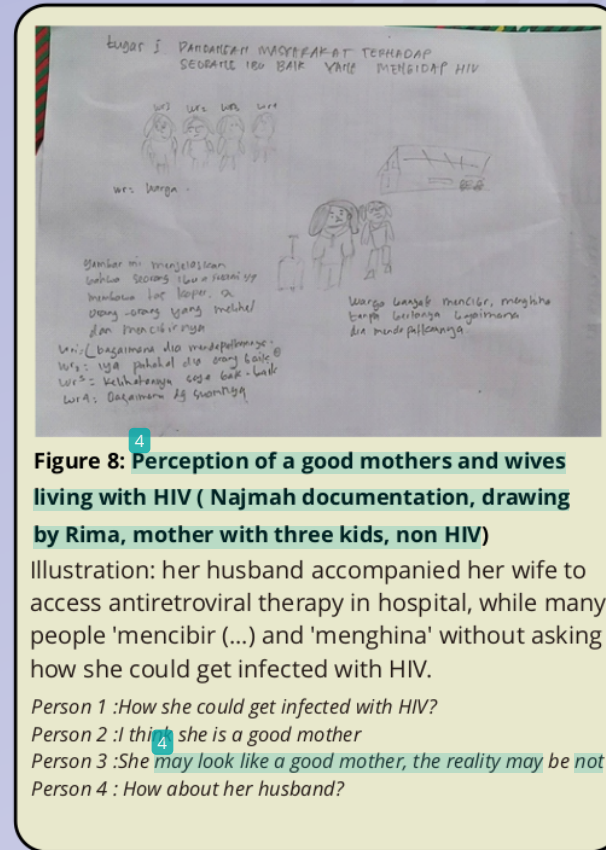


Figure 8: Perception of a good mothers and wives living with HIV (Najmah documentation, drawing by Rima, mother with three kids, non HIV)

Illustration: her husband accompanied her wife to access antiretroviral therapy in hospital, while many people 'mencibir (...)' and 'menghina' without asking how she could get infected with HIV.

Person 1 :How she could get infected with HIV?

Person 2 :I think she is a good mother

Person 3 :She may look like a good mother, the reality may be not

Person 4 : How about her husband?





PLEASE... HELP... PLEASE...

The low-middle income family



Stop COVID, Better Economy-

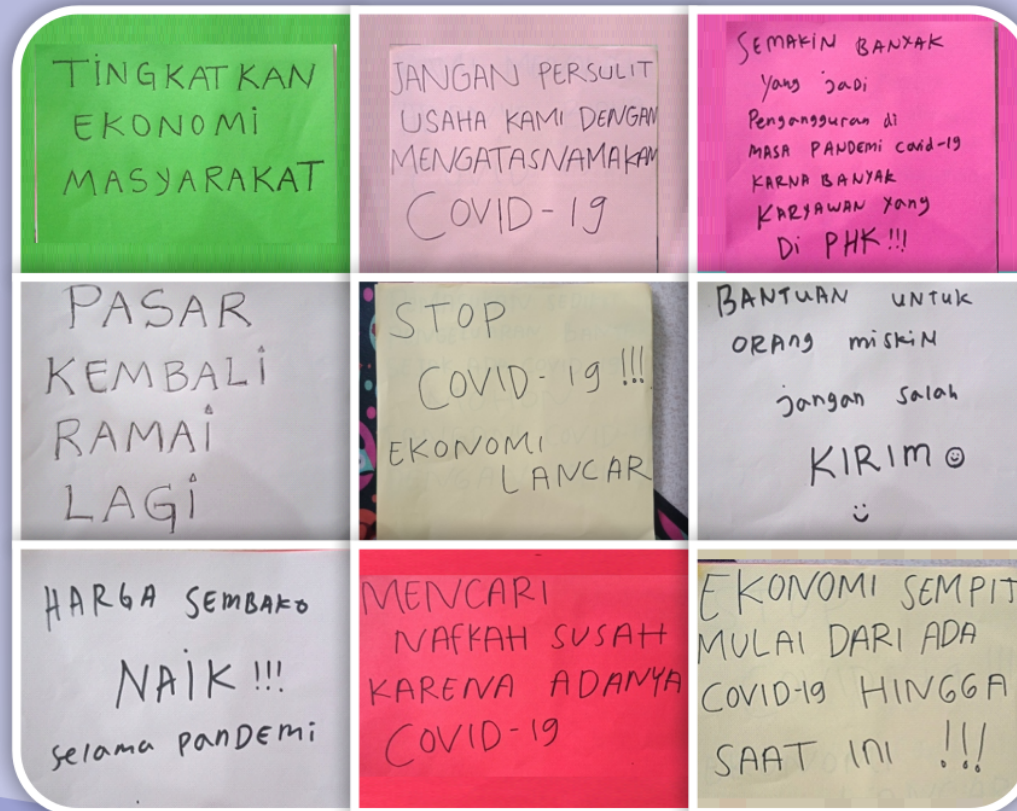
Voice From Mothers and Wives



Improve Society's economy	Don't Complicate our small business with a reason of COVID-19	The higher number of unemployment during COVID-19 pandemic because many employees have been laid off
The market is bustling again	Stop COVID-19 The Economy is smooth	Help the poor Help the right person, not wrong person
The Increasing price of nine basic food during pandemic	It is hard to make a living due to COVID-19	The economy is narrow, from the existence of COVID-19 to now



Stop COVID, Ekonomi Lancar- Suara Para Ibu dan Istri



Reflection and Conclusion



Reflection 1:

It is important to listen to women's stories, especially around HIV and Covid-19. While Covid-19 patients need to be prioritised this should not be at the expense of women living with HIV. Governments need to ensure that women living with HIV, especially mothers, can access the healthcare they need for themselves and their children. Indeed, a half mothers we spoke to, they received good HIV healthcare for themselves and their children and as such, it is possible for some, yet not for all in Indonesia to access HIV care.



Refleksi dan Kesimpulan



Refleksi 1:

Penting untuk mendengarkan cerita perempuan, terutama seputar HIV dan COVID-19. Sementara pasien COVID-19 perlu diprioritaskan, ini tidak boleh dengan mengorbankan perempuan positif HIV, terutama seorang ibu, untuk dapat mengakses layanan kesehatan yang mereka butuhkan untuk diri mereka dan anak mereka. Memang, sebagian dari ibu pada studi ini, mereka menerima pelayanan kesehatan yang baik, namun tidak semua mampu mengakses layanan HIV.

Menormalisasi stigma terkait HIV di masyarakat dan di layanan kesehatan

Takut tes COVID-19 dan stigma diCOVIDkan dilayanan kesehatan



The era of
COVID-19

Institutional and
Cultural barriers

a lack of standard
operating procedures
for HIV and COVID-19

Avoidance of
treating HIV-positive
women

Inadequate
communication
and coordination

Opportunity for
better HIV
treatment

Better preparation
for any future
outbreaks

Reflection 2:

What lessons can be learnt from this research?

Late diagnosis and testing of both HIV and COVID-19 reflect institutional and cultural barriers which surround the treatment of HIV in the era of COVID-19. They suggest ¹an interplay of inadequate communication and coordination between levels of government and the relevant health services, relative ¹avoidance of treating HIV-positive women by healthcare providers, and a lack of socialization of standard operating procedures for HIV and COVID-19 patients. COVID-19 has highlighted these issues in Indonesia, offering an opportunity to develop better treatment of HIV-positive women, as well as improving Indonesia's experience with meeting any future outbreaks of currently unknown diseases (and many existing ones that also face social stigmas).



Era Pandemi COVID-19

Hambatan budaya dan institusi (kelembagaan)

SOP terkait pelayanan pasien HIV dan COVID-19

Sikap menghindari ibu positif HIV

Kurangnya komunikasi dan koordinasi

Kesempatan untuk pelayanan HIV dan COVID-19 yang lebih baik

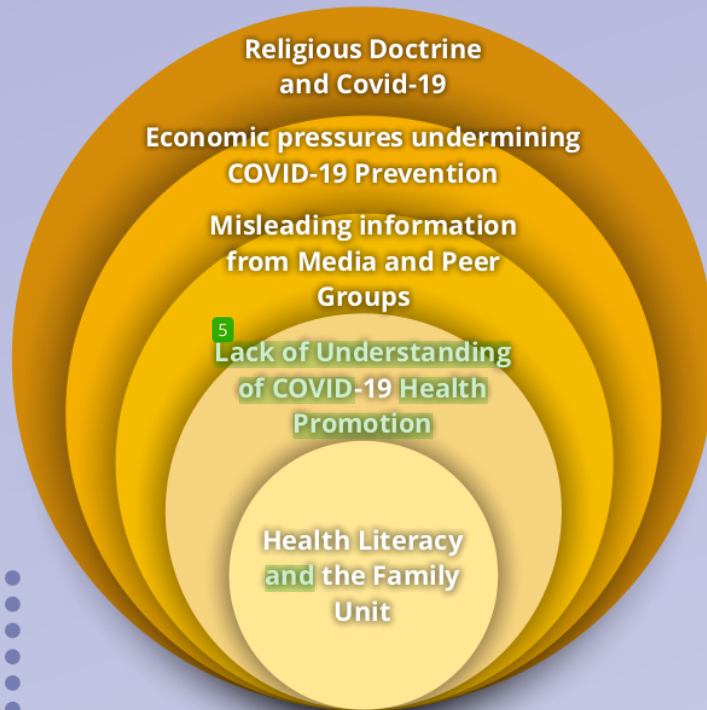
Persiapan mitigasi bencana pada penyakit yang tidak diketahui dimasa depan

Refleksi 2:

Pelajaran apa yang bisa dipetik dari penelitian ini?

Keterlambatan diagnosis dan tes HIV dan COVID-19 merefleksikan kendala budaya dan kelembagaan dalam akses layanan HIV dan COVID-19 di masa pandemic COVID-19. Studi ini mengamati adanya interaksi antara kurang memadainya komunikasi dan koordinasi antara pemerintah, layanan kesehatan terkait, sikap menghindari perawatan ibu positif HIV oleh layanan kesehatan dan kurangnya sosialisasi standar pelayanan operasional untuk pasien HIV dan COVID-19. Pandemi Covid-19 telah menyoroti berbagai tantangan di Indonesia, menawarkan kesempatan untuk mengembangkan pelayanan lebih baik untuk ibu positif HIV dan memberikan pengalaman berharga untuk Indonesia dalam menghadapi wabah di masa depan dengan penyakit yang tidak diketahui dimana akan berkaitan dengan stigma sosial juga.

Factors Influencing Perceived Threats



Description:

5 Given these factors, we have three recommendations for the government.

First, the government and official health institutions should collectively develop a coherent and consistent message delivered across all sectors of Indonesian society, particularly those in more deprived areas. Second, the government must improve their data collection practices, better identifying those who work in the informal sector. More accurate knowledge of the informal work sector should lead to better targeting of the wage subsidy, particularly for women. Finally, improved resourcing and distribution of personal protection equipment for frontline health staff and centres. If the national government can prioritise these key areas, Indonesia will be better equipped to deal with the ongoing impacts of the Covid-19 pandemic.



Faktor-faktor yang Mempengaruhi Ancaman yang Dirasakan



Keterangan:

Mengingat faktor-faktor ini, kami memiliki tiga rekomendasi untuk pemerintah :

Pertama, pemerintah dan institusi kesehatan resmi harus bersama-sama mengembangkan pesan yang koheren dan konsisten yang disampaikan di semua sektor masyarakat Indonesia, khususnya di wilayah dengan literasi rendah dan ekonomi terbatas. Kedua, pemerintah harus memperbaiki implementasi pengumpulan data, mengidentifikasi lebih baik pihak yang bekerja di sektor informal. Pengetahuan yang lebih mudah dicerna, terutama untuk pekerja di sektor pekerjaan informal dan juga subsidi pendapatan, terutama bagi perempuan. Ketiga, peningkatan sumber daya dan distribusi Alat Pelindung Diri untuk tenaga kesehatan sebagai garis terdepan. Jika pemerintah pusat dan daerah dapat memprioritaskan bidang-bidang utama ini, Indonesia akan lebih siap untuk menghadapi dampak pandemi Covid-19 yang berkelanjutan.





COVID-19
HOAX
Vaccine = Death

Quick change of
COVID-19
Regulation

I need Money
NOT ISOLATION

decrease
of
health worker

COVID-19
Vaccine

Socialization
Of COVID-19 &
HIV

herd immunity

COVID-19 Vaccine Certificate
**peduli
Lindungi**

↓ ↓ ↓
STRATEGIC PLAN

Australia
Global
Alumni



Strategies For COVID-19



Problem	Strategy
<ul style="list-style-type: none">● Unfixed regulations, not annulled with basic needs in the field, and lack of participation of related factors in the regulation● The refusal of the vaccine due to the lack of understanding of family members about COVID-19, as well as the lack of optimal religious support for the implementation of the COVID-19 vaccine● Limited inspection laboratory facilities at the beginning of the pandemic● Workers who are positive for COVID-19 still have to work● Health facilities determine that people with HIV are positive for COVID-19	<ul style="list-style-type: none">● Simplifying the regulations related to COVID-19 handling, making it clear and targeted for the basic needs of people with COVID-19● Increasing public understanding about the importance of vaccination and herd immunity● Strengthening the examination of pregnant women in first-level health facilities● Fulfillment of basic needs and rights that must be fulfilled by the leader for workers affected by COVID-19● Educate HIV sufferers by telling them that the symptoms felt by sufferers are included in the category of suspected COVID-19 so they need to self-isolate



Strategi-strategi untuk COVID-19



Permasalahan	Strategi
<ul style="list-style-type: none">● Regulasi yang berubah-ubah, tidak menganulir kebutuhan dasar di lapangan, dan kurang partisipatifnya faktor terkait dalam regulasi● Penolakan vaksin akibat dari kurangnya pemahaman anggota keluarga tentang COVID-19, serta kurang optimalnya dukungan agama terhadap pelaksanaan vaksin COVID-19● Terbatasnya fasilitas laboratorium pemeriksa pada awal pandemi● Pekerja yang positif COVID-19 tetap bekerja● Fasilitas kesehatan mengcovidkan penderita HIV	<ul style="list-style-type: none">● Penyederhanaan regulasi terkait penanganan COVID-19, membuat regulasi yang jelas dan tepat sasaran terhadap kebutuhan dasar penderita COVID-19● Peningkatan pemahaman masyarakat terhadap pentingnya vaksinasi dan herd immunity● Penguatan pemeriksaan ibu hamil di fasilitas kesehatan tingkat pertama● Pemenuhan kebutuhan dasar dan hak-hak yang harus dipenuhi pimpinan terhadap pekerja yang terdampak COVID-19● Edukasi ke penderita HIV bahwa gejala yang dialami oleh penderita termasuk dalam kategori suspek COVID-19 sehingga perlu dilakukan isolasi mandiri







Strategies to Improve ANC Service Outcomes

- Collaborate with health cadres and community leaders to provide counseling about ANC during the pandemic and mobilize the community for self-examination
- Conduct home visits according to data on pregnant women, infants and toddlers
- Create a WhatsApp group for pregnant women, mothers in labor and postpartum
- Cooperate with hospitals and health facilities in the work area in terms of health service data
- Provide government assistance/support in terms of distribution of PPE according to standards for health workers at PMB

Strategi dalam Meningkatkan Capaian Pelayanan ANC

- 18 • Bekerja sama dengan kader kesehatan dan tokoh masyarakat untuk memberikan penyuluhan tentang ANC selama masa pandemi dan menggerakkan masyarakat untuk memeriksakan diri
- Melakukan kunjungan rumah sesuai data ibu hamil, bayi, dan balita
- Membuat grup WhatsApp ibu hamil, ibu bersalin dan nifas
- Bekerja sama dengan rumah sakit dan fasilitas kesehatan di wilayah kerja dalam hal data pelayanan kesehatan
- Adanya bantuan/dukungan pemerintah dalam hal distribusi APD yang sesuai standar bagi tenaga kesehatan pada PMB





Strategies to Improve HIV Screening of Pregnant Women during the COVID-19 Pandemic



Problem	Strategy
<p>Man</p> <ul style="list-style-type: none"> • Limited human resources • WFH and WFO systems for health workers at public health centers or hospitals <p>Money</p> <ul style="list-style-type: none"> • Limited budget due to focus on COVID-19 budget <p>Material</p> <ul style="list-style-type: none"> • Rapid HIV 2, HIV 3, and syphilis RPR still not available <p>Machine</p> <ul style="list-style-type: none"> • Multiple use of laptop/computer • Low specification computer/laptop <p>Method</p> <ul style="list-style-type: none"> • Implementation of Large-Scale Social Restrictions (PSBB) and Community Activities Restrictions Enforcement (PPKM) so HIV screening decreases <p>Environment</p> <ul style="list-style-type: none"> • Compliance with taking medication for HIV patients • Complaints about taking ARV drugs • Family support • Fear of visiting the public health centre or hospital during pregnancy 	<p>Man</p> <ul style="list-style-type: none"> • Hospital or public health centers staff need to schedule HIV screening for pregnant women • Prepare substitute staff so that there is no shortage of HIV screening officers <p>Money</p> <ul style="list-style-type: none"> • Propose a specific budget for the HIV program <p>Material</p> <ul style="list-style-type: none"> • Propose to the Provincial Health Office regarding HIV rapid stock • Independent rapid procurement <p>Machine</p> <ul style="list-style-type: none"> • Submit reports on time • Propose the procurement of computers and laptops <p>Method</p> <ul style="list-style-type: none"> • Counseling via WhatsApp • Taking ARV • Taking drugs by delivery (gosend, etc.) • Provision of HIV screening • Make MoUs with BPS, private clinics, and BPM <p>Environment</p> <ul style="list-style-type: none"> • Supervision of taking medication (PMO) from the family • Support from NGOs • ARV adherence test using Cotrimoxazole

Strategi dalam Meningkatkan Capaian Skrining HIV pada Ibu Hamil selama Pandemi COVID-19



Permasalahan	Strategi
<p>Man</p> <ul style="list-style-type: none"> • SDM terbatas • Adanya sistem WFH dan WFO petugas kesehatan di puskesmas atau rumah sakit <p>Money</p> <ul style="list-style-type: none"> • Keterbatasan anggaran karena fokus untuk anggaran COVID-19 <p>Material</p> <ul style="list-style-type: none"> • Rapid HIV 2, HIV 3, dan RPR sifilis masih kosong <p>Machine</p> <ul style="list-style-type: none"> • Rangkap penggunaan laptop/komputer • Komputer/laptop berspesifikasi rendah <p>Method</p> <ul style="list-style-type: none"> • Pelaksanaan PSBB/PPKM sehingga skrining menurun <p>Environment</p> <ul style="list-style-type: none"> • Kepatuhan minum obat oasien HIV • Keluhan minum obat ARV • Dukungan keluarga • Takut mengunjungi puskesmas atau rumah sakit saat hamil 	<p>Man</p> <ul style="list-style-type: none"> • Petugas rumah sakit atau puskesmas membuat jadwal skrining HIV pada ibu hamil • Menyiapkan petugas pengganti sehingga tidak terjadi kekurangan petugas HIV <p>Money</p> <ul style="list-style-type: none"> • Pengajuan anggaran khususnya untuk program HIV <p>Material</p> <ul style="list-style-type: none"> • Pengajuan ke Dinas Kesehatan Provinsi terkait stok rapid HIV • Pengadaan rapid secara mandiri <p>Machine</p> <ul style="list-style-type: none"> • Mengirim laporan tepat waktu • Pengajuan pengadaan komputer dan laptop <p>Method</p> <ul style="list-style-type: none"> • Konseling melalui WhatsApp • Pengambilan ARV • Pengambilan obat secara delivery (gosend, dll) • Pengadaan skrining HIV • Membuat MoU dengan BPS, klinik swasta, dan BPM <p>Environment</p> <ul style="list-style-type: none"> • Adanya PMD dari pihak keluarga • Adanya dukungan dari LSM • Tes kepatuhan ARV menggunakan Cotrimoxazole

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Team



Najmah, PhD

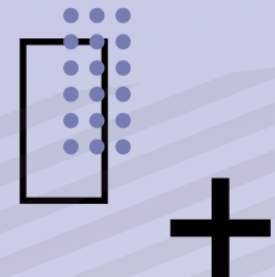


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Nadilla Nusirwan, S.KM



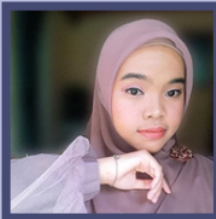
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