Deaf Culture
HC challenges
Public & Patient Involvement
Deaf in Malaysia
HEARD projects
HEAlth caRe needs of the Deaf (HEARD) in Malaysia:
Patient & Public involvement
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MONASH University
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Deafness

&

Deaf Individuals ?

Model 1

Model 2

Medical /Pathological

- lack auditory capability
- focuses on what they cannot do
- require help/aid
- disregard positive attributes

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small "d "

small "d" deaf

...don't always have a strong connection to the Deaf community and don't always use sign language... prefer to communicate with speech

small "d" deaf

...don't always have a strong connection to the Deaf community and don't always use sign language... prefer to communicate with speech

Cultural Model

- Embrace deafness as a unique difference- Deaf pride
- Does not focus on the disability aspect.
- Sign language is accepted

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- Sign language is accepted

Cultural Model

Big "D"

- Embrace deafness as a unique difference- Deaf pride
- Does not focus on the disability aspect.
- Sign language is accepted

Big "D" Deaf

a group that shares a cultural identity and a common language - Sign Language

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Facts about the Deaf in Malaysia

Facts about the Deaf in Malaysia

50,000 are Deaf

Facts about the Deaf in Malaysia

50,000 are Deaf

Malaysian Sign Language (BIM)

Facts about the Deaf in Malaysia

50,000 are Deaf

Malaysian Sign Language (BIM)

Facts about the Deaf in Malaysia

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Malaysian Sign Language (BIM)

Deaf : JBIM (Jurubahasa BIM) 1:800

Facts about the Deaf in Malaysia

50,000 are Deaf

Malaysian Sign Language (BIM)

Deaf : JBIM (Jurubahasa BIM) 1:800

Disability Act

.....states that disabled people should have equal rights and access to HC like other members of society.

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Healthcare Challenges

Poor health literacy

Poor health literacy

Communication barrier

Poor health literacy

Communication barrier

Misdiagnosis & Med errors

Healthcare Challenges

Poor health literacy

Communication barrier

Misdiagnosis & Med errors

Poor health outcomes

Healthcare Challenges

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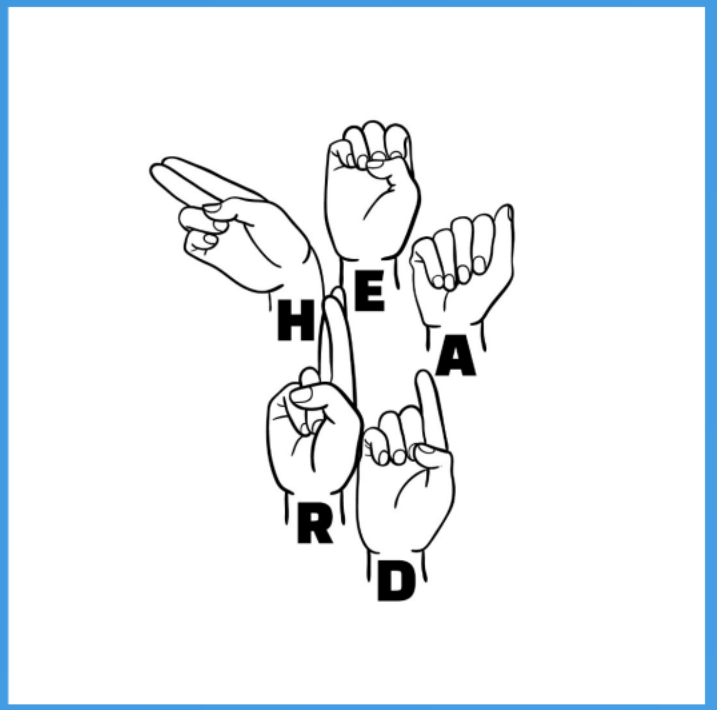

HEAlthca**R**e needs of the **D**eaf

Our Projects

Stakeholders & Collaborators

MFD

MyBIM
Persatuan Bahasa Isyarat Malaysia dan Pengalian Pekak
Malaysian Sign Language and Deaf Studies Association

myASLI

Kami Sedia Membantu
KEMENTERIAN KESIHATAN MALAYSIA

MOH

MUA

Maastricht University

HERIOT WATT UNIVERSITY

DITE app

Other projects

Deaf In Touch Everywhere

ACCEPT EMERGENCY REQUEST - JBIM

Deaf In Touch Everywhere

Book a BIM interpreter in advance or on-demand

ACCEPT EMERGENCY REQUEST - JBIM

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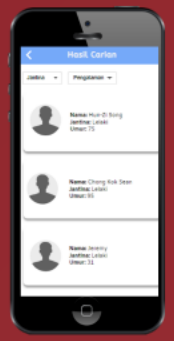


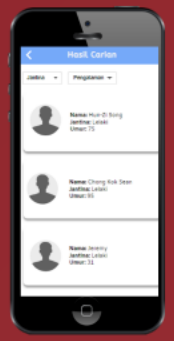
Access to a pool of certified BIM interpreters

ACCEPT EMERGENCY REQUEST - JBIM

Deaf In Touch Everywhere

DITE
Deaf In Touch Everywhere

Book a BIM interpreter in advance or on-demand



Access to a pool of certified BIM interpreters

Communicate through videoconferencing

ACCEPT EMERGENCY REQUEST - JBIM

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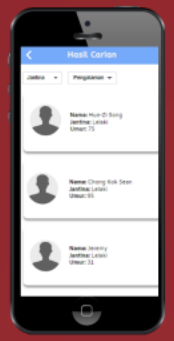

Access to a pool of certified BIM interpreters

Communicate through videoconferencing

Telemedicine features (3 way VC)

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Deaf In Touch Everywhere

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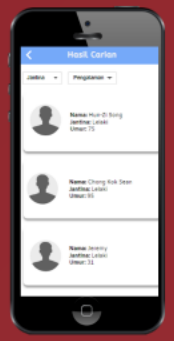

Access to a pool of certified BIM interpreters

Communicate through videoconferencing

BIM GIFs

Telemedicine features (3 way VC)

ACCEPT EMERGENCY REQUEST - JBIM

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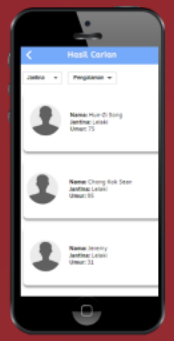


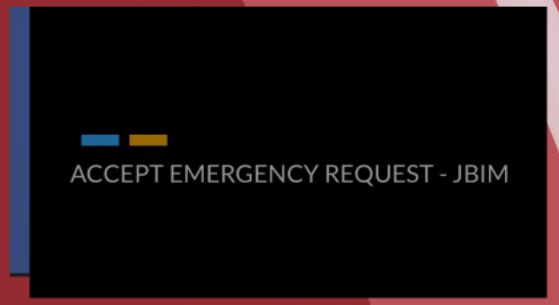
Access to a pool of certified BIM interpreters

Communicate through videoconferencing

BIM GIFs

Health Promotion Videos in BIM

Telemedicine features (3 way VC)



Medical Sign Bank (290)

Medical Departments (62)

Medical Sign Bank (290)

pain | chest pain | shoulder pain | flashes of light

Medical Departments (62)

Medical Sign Bank (290)

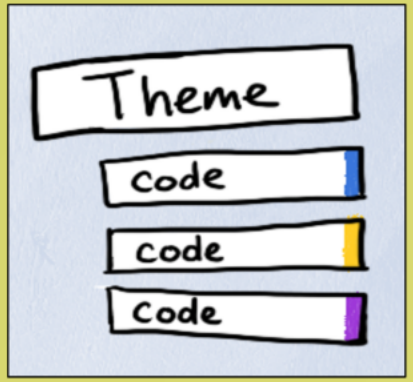
pain | chest pain | shoulder pain | flashes of light

Medical Departments (62)

medical | paediatrics | surgical | Obs & Gynae

Health promotion videos in BIM

Interviews with Deaf



Thematic analysis

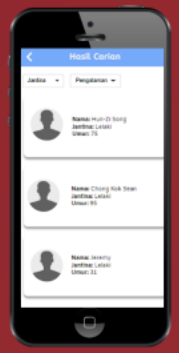
Large scale survey with Deaf

Contextualize available videos

Deaf In Touch Everywhere

DITE
Deaf In Touch Everywhere

Book a BIM interpreter in advance or on-demand



Access to a pool of certified BIM interpreters

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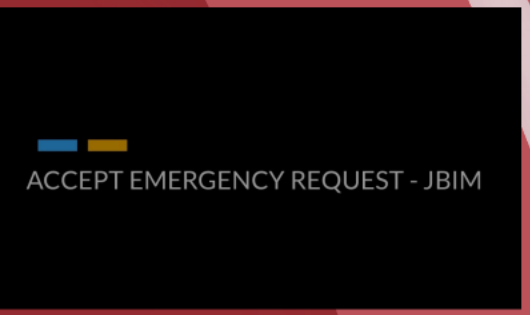

- Deaf Cultural Competency training for HC practitioners
- Mental health awareness etc videos in BIM
- Workshop on recognising mental helath and where to seek help for the Deaf

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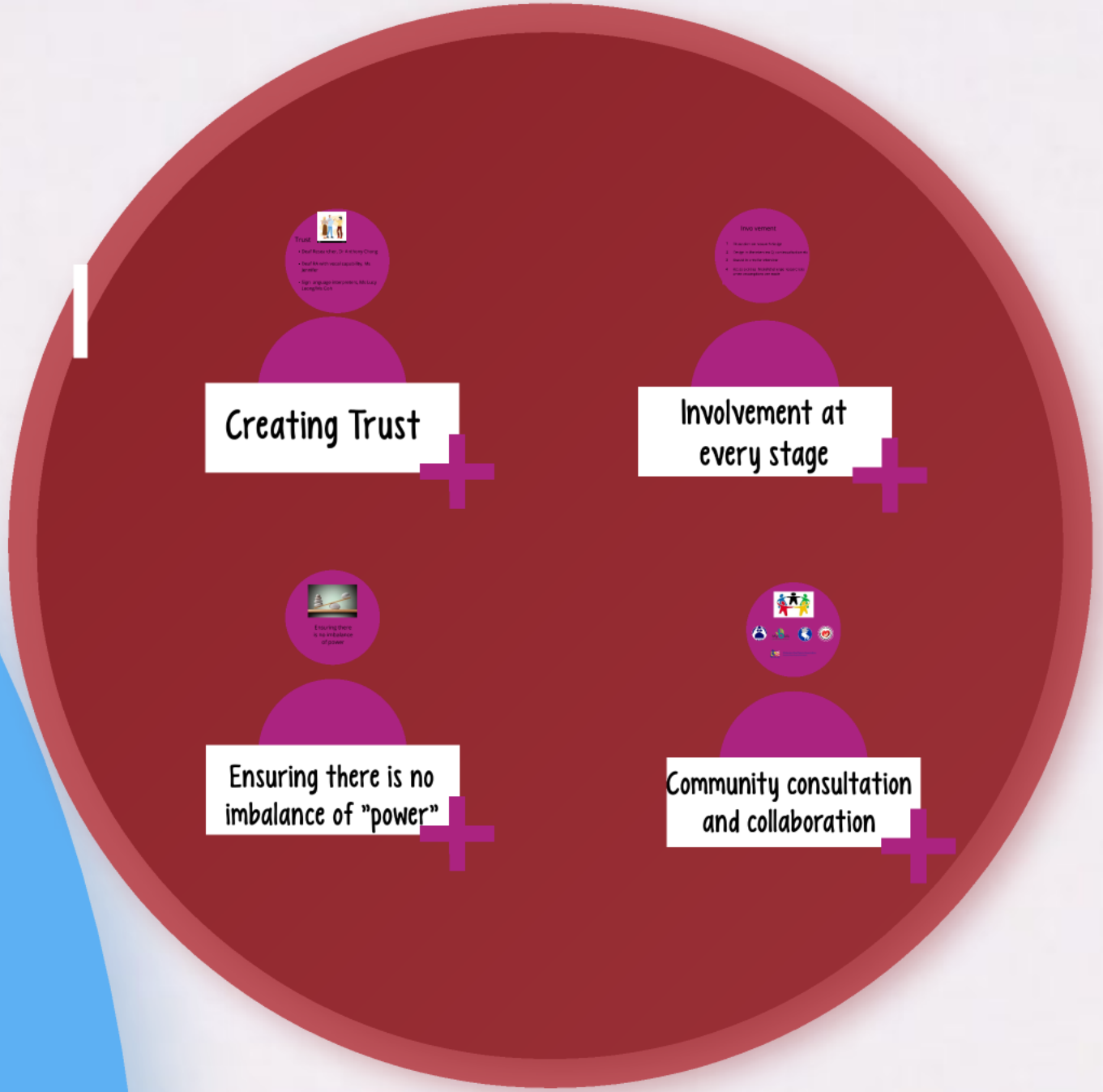
- PPI among sign language communities
- Our experience, 2016-2018
- Deaf people involved in the initiation, execution and translational phases of our projects

Embedding PPI

What worked & Our recommendations


Creating Trust
Involvement at every stage
Ensuring there is no imbalance of "power"
Community consultation and collaboration

Trust

- Deaf Researcher, Dr Anthony Chong
- Deaf RA with vocal capability, Ms Jennifer
- Sign language interpreters, Ms Lucy Leong/Ms Goh

Creating Trust

Involvement

1. Discussion on research design
2. Design in the interview Q, contextualisation etc
3. Assist in prep for interview
4. Act as a critical friend/challenge researcher is when assumptions are made

Involvement at every stage

Ensuring there is no imbalance of power

Ensuring there is no imbalance of "power"

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Ensuring there is no imbalance of power

Malaysian Deaf Sports Association

Persatuan Sukan Orang Pekak Malaysia

Recommendations for Inclusive PPI with the Deaf

Cultural & Linguistic Sensitivity

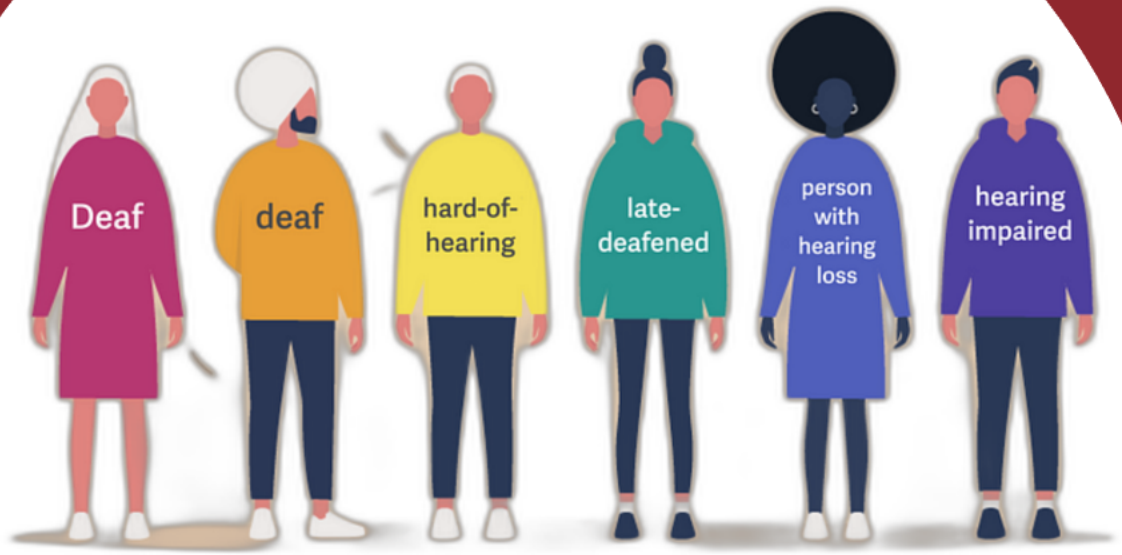
Removing Linguistic Barriers

Importance of a Knowledgeable Deaf Researcher

Ongoing Partnerships

Conduct PPI in Culturally Significant Places

Addressing Genera Health Concerns



Cultural & Linguistic Sensitivity

"Understand and build trust with the community"

Removing Linguistic Barriers

"Direct communication enables open discussion."

Importance of a Knowledgeable Deaf Researcher

"A direct link between participants and a researcher can be transformative."

Ongoing Partnerships

"Don’t just seek feedback once—build lasting relationships."

Conduct PPI in Culturally Significant Places

"Location matters—meet people where they are comfortable."

Addressing General Health Concerns

"People may have broader health concerns—addressing them builds trust."

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Helen Keller has said. . .

"Blindness separates us from things,
but deafness separates us from people."

Let's be smart and do all we can to <u>never</u> let hearing loss separate us from those that we love and spend time with.

The team

Thank you!

Team Members & Collaborators

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SoL MUA

Sazali Shaari,
MFD

Anthony Chong,
MyBIM

Wan Zuraidah,
myAsli

Jennifer Ng
Monash

Lucy Leong
JUPEBIM

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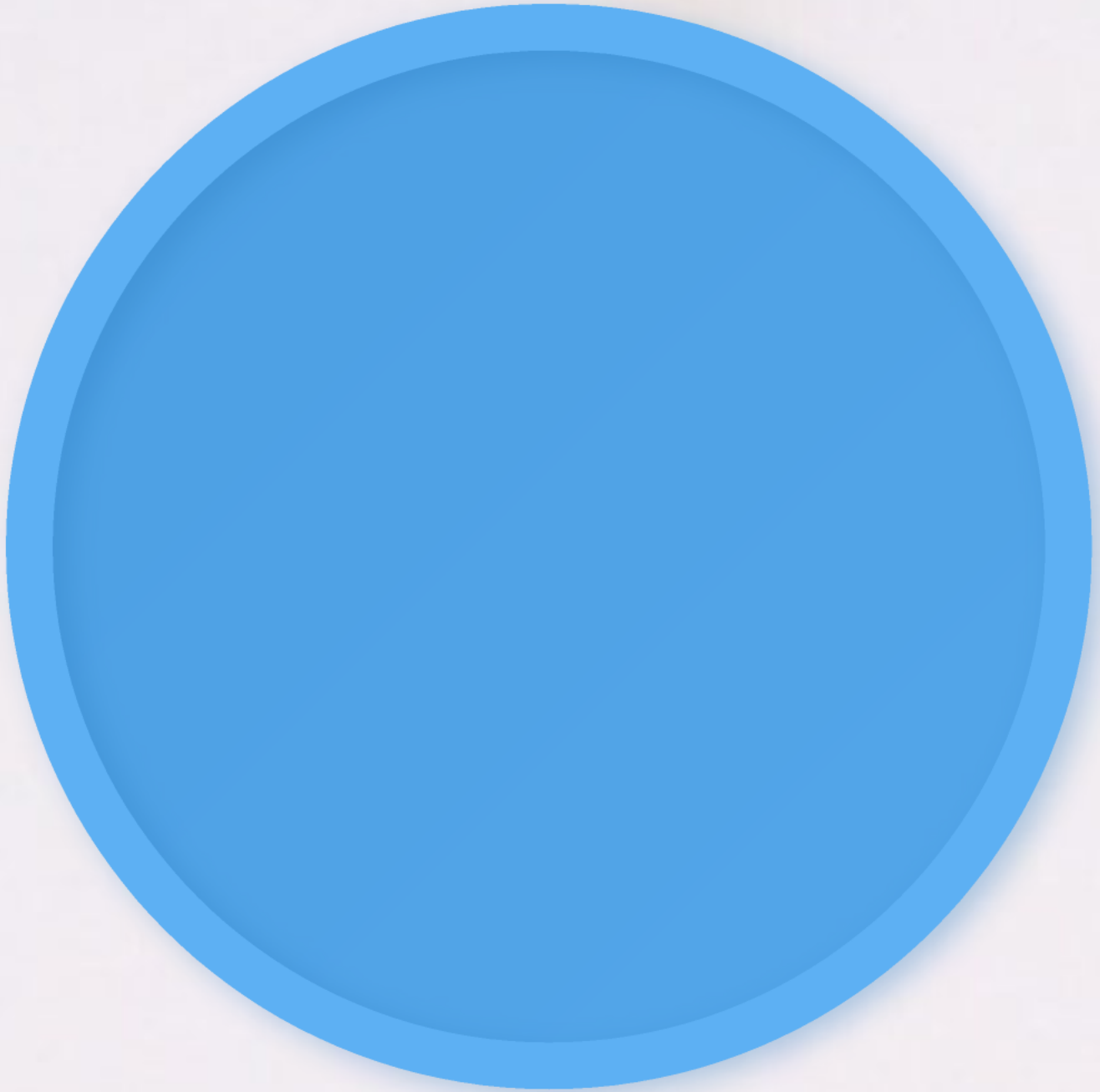

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