Title	**0040**
	by **Uma Palanisamy** in **Inclusive Health Research 2022**

Original Submission

1. The Entry	n/a
1 1. Lead organisation or Institution chiefly responsible for submitting this entry	**Monash University Malaysia**
Registered Address	**Jalan Lagoon Selatan** **Bandar Sunway** **Subang Jaya** **Selangor** **47500** **MY**
Type of Organisation	**Academic/research institution**
Website URL	**https://www.monash.edu.my/**
1.2 Chief Contact Person	**Uma Devi** **Palanisamy**

1.3 Name of project or programme	**HEAlth caRe needs of the Deaf (HEARD) project**
1.4 Date that the project or programme began	**July 2016**
1.5 Countries in which research / implementation was undertaken	**Malaysia**
1.6 About partners and collaborators	**Here you should name up to three collaborating organisations and provide a contact email address for each one that you name. We will then send a request for a supporting statement, which will be taken into account in the scoring of this application.**
Partner organisation/institution #1	**Malaysian Federation of the Deaf (MFD)**
Type of Organisation	**Patient Advocacy Organisation**
Website URL	**https://www.mymfdeaf.org/, https://www.facebook.com/legacy/notes/281527161875969**

Partner organisation/institution #2	**Malaysian Sign Language and Deaf Studies Association (myBIM)**
Type of Organisation	**Patient Advocacy Organisation**
Website URL	**http://mybimorg.blogspot.com/**

Partner organisation/institution #3	**Organization: Interpreters and Translation Association for Deaf Community Selangor and KL (JUPEBIM)**
Type of Organisation	**Other**
Website URL	**https://www.jupebim.com/, https://www.facebook.com/profile.php?id=100070310741863**

The Case Study	n/a
1.8 The Title of Your Case Study	**Addressing Healthcare Needs of People who are Deaf; their healthcare communication, access and health promotion**
1.9 Simple Summary	**Deaf people avoid seeking healthcare services due to issues of access. They have low health literacy levels, placing them at high risk for health problems. Many countries stipulate healthcare organisations provide a sign language interpreter (SLI) for Deaf patients. However, for the 55,000 or more Deaf Malaysians, no such legislation exists. There is a severe lack of trained SLIs in Malaysia. Our team through a series of research have developed an mHealth app, DITE, which connects the Deaf with a pool of off-site SLIs through secure video conferencing. DITE will also house a medical sign language (SL) dictionary, a repository of current health promotion videos in SL, and GIFS for healthcare personnel communicate with the Deaf. Furthermore, healthcare practitioners lack the training to provide linguistically and culturally-competent care for these patients. To address this issue, several cultural competency training workshops for healthcare students and practitioners have been developed.**
1.10 Introduction	**A nationwide study to understand the health seeking behaviour of Deaf community and pharmacists' comfort level in interacting with Deaf people was initiated. The outcome of this study led us to design and develop the mHealth app. An app that allows a Deaf person to book a sign language interpreter (SLI) for healthcare consultation and have the interpreter present virtually. Its design and development was carried out after feedback, consultation, and many tests with the Deaf, SLI, and healthcare practitioners (HCP). The app also houses COVID-19 screening and management tools in Malaysian Sign language (BIM), health promotion videos in BIM, GIFS of medical signs, among others. Also working with our partners, after identifying its need, we developed workshops and best practices for HCP on Deaf culture and their healthcare need. MFD was our link with the Deaf community, interpreted our research tools and provided feedback on the app. myBIM contextualisation the research questionnaires, carried out interviews with the Deaf, provided feedback on the app, ensured the correct BIM terms were used and helped with the Deaf cultural competency workshops. JUPEBIM provided feedback in the development of the DITE app as well as interpreters during the testing stages of the app.**
1.11 Key Words	**Deaf, Malaysia, Cultural Competency, Healthcare Access, Health Literacy, Mobile Health, Health Promotion**
Which category best fits this project or programme?	**Addressing a specific unmet health need**

2. Unmet Health Need Case Study	These will typically fall in to one of three groups: Group 1: Understanding needs and context Group 2: Designing and conducting research Group 3: Translating research into impact The various suggested sections which follow will not be equally applicable to all groups. We have given an indication of which sections may be most crucial to each but you should use your own discretion and judgement. We are seeking case studies that can be published, so please write your entry assummary, rather than a series of statements addressing the questions. You do not need to repeat information across sections. We do not expect everyone to be able to address all of the questions, as not all will be relevant.
2.1 Who should benefit from the project or programme? (Applicable to groups 1, 2, & 3)	Our research involves the Malaysian Deaf community who use the Malaysian Sign Language (BIM) to communicate. There are approximately 55000 people in Malaysia who are registered as Deaf but it is estimated this number could be higher. The Deaf community here avoid seeking healthcare due to the severe shortage of sign language interpreters (SLI) and face communication barriers with healthcare professionals, who lack linguistic and cultural competence. Healthcare professionals and services here are not legally bound to provide an SLI or make adjustments to their practice or premises to accommodate the Deaf. The Deaf also face discrimination from the public as well as healthcare professionals due to their perceived disability. This is compounded by the fact that available health information is not in a format accessible to the Deaf, placing them at a severe disadvantage. The healthcare needs of this community have been largely neglected and research in this area, particularly in Malaysia, is scarce. Healthcare administrators are only now beginning to realise the depth of the issues faced by this community. Crucial financial deployment, inclusive education, and appropriate training to healthcare practitioners can help improve this situation. Addressing this unmet need is crucial to ensure the basic healthcare accessibility rights of this community. The Deaf community in many regions in LMICs are equally marginalised in terms of their healthcare access. We believe our research; particularly on the development of the DITE app, can be used by many other countries. The cultural competency training and best practices workshops can also be contextualised for use by any other LMIC. This unmet need of the Deaf community was initially identified through a student-led Health Promotion project. Results from the pilot study was an impetus for us to request funding to study the issues in-depth. This was the start of our health equity research. Our initial focus (2018) was to understand the health-seeking behaviour of the Deaf community and learn how health care professionals can better serve them. We have since moved on to design and develop an app (DITE), create health promotion videos in BIM, and developed GIFS in BIM of the COVID 19 screening and management tools. Workshops on Deaf cultural competency and best practices to empower healthcare professionals better serve this population were also carried out. We have since recruited a number of healthcare practitioners, IT, Deaf studies. and health promotion experts into our team.

2.2. Engagement (applicable to groups 1, 2, & 3)	**We adopted a community-based participatory method where members of the Deaf community (MFD, myBIM) were involved at different stages of the research. This included research design and development, recruitment of participants, and dissemination of results. We ensured that the rights of the Deaf community were protected and that research undertaken would meet the actual versus perceived needs of the Deaf. We also hired a Postdoc and a Research assistant who are Deaf in our projects. Sign language interpreters (JUPEBIM) are a crucial link to the Deaf community, as such it was important to involve them at various stages in our projects. They provided crucial feedback on app development and interpretation requirement during meetings and workshops. This led to the development of an app that is not only relevant but caters to the needs of both the Deaf community and SLI.**

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To ensure that we address all aspects of healthcare accessibility for the Deaf, healthcare practitioners (clinicians and pharmacists) and medical students were also consulted at times when their feedback and input were required. We also engaged with a medical student-led organisation (MMI) in research involving medical students. We observed a lack of Deaf cultural competency and confidence in consulting Deaf patients among HCP and medical students. As a result we carried out workshops on Deaf cultural competency and learning signs relevant in medical consultation.

In our efforts to understand the Deaf community and develop relevant and equitable health inclusion projects, and innovative ways to train healthcare students serve the Deaf community, we consulted foreign experts in the area of Deaf studies (Prof Jemina Napier, Herriot Watt University) and medical education (Associate Prof Danielle Verstegen, Maastrict University)

To promote awareness on Deaf cultural competency and Malaysian sign language (BIM) at our campus, we organised several yearly events during the International Deaf week. Some such events include; food carts run by people who are Deaf, posters and basic signs to communicate with food vendors, talks, and awareness campaigns. Events as such have created a greater awareness among staff and students in Monash on Deaf culture and ways to communicate with them.

The HEARD team has also been featured by a local radio station (BFM) where the healthcare needs of the Deaf community and our health inclusion research was highlighted. MFD, myBIM, and JUPEBIM are collaborators in our research projects and have ownership to the outcome of research (data, app, workshops).

2.3. The Research (Particularly relevant for groups 2 & 3)	**Understanding needs and context**

Understanding needs and context

In 2016, a pilot study to identify challenges faced by the Deaf when seeking pharmaceutical care was initiated. Following which a nationwide study to identify the communication barriers and needs of the Deaf, and how to prepare pharmacies to better serve this population was initiated (2018). Our findings indicated that the Malaysian Deaf community avoid seeking healthcare due to the lack of access to services of SLI, which is further exacerbated by the severe shortage of SLI. The idea of the DITE app was conceptualised.

Designing and conducting research

Qualitative studies were conducted to gather perspectives of the Deaf community and design suggestions to facilitate their healthcare communication (2018). The development of the app, DITE, was initiated (2020). In order to explore the existing communication modalities and factors influencing its usage in medical consultations with Deaf patients, a scoping review was initiated (2021). We found that professional SLI is the preferred modality but writing and lip-reading were commonly used in healthcare settings. The review highlighted several implications for practice which we initiated as translational research.

Healthcare providers (HCP) are ill-prepared to serve this population and should be more culturally competent. Our review highlighted the need for cultural competency programs within health care education (2021). HCPs who received training in cultural competency showed increased knowledge and confidence in interacting with deaf signers. To understand Malaysian HCPs and medical students' exposure to Deaf culture and knowledge of available communication modalities with the Deaf, surveys were initiated (2021/22). We observed that medical students and doctors alike lack exposure to Deaf culture, experience with the community and best communication practices. They agreed that their medical training did not prepare them to interact with the Deaf. Majority of doctors felt discomfort and challenged when communicating with Deaf patients and feared misdiagnosis and mismanagement. They had predominantly relied on writing, using hand gestures, and family members to communicate with their patients. Doctors indicated that there is virtually no available resource at their HC facility which enabled their communication with Deaf patients. We concluded that doctors faced communication challenges and were ill-prepared to serve Deaf patients. Medical schools should attempt to incorporate Deaf cultural competency training in their curriculum. This will ensure we produce culturally competent physicians, who will make the healthcare system more "Deaf-friendly". The recent completion of workshops on Deaf cultural competency and best practices is a result of this finding.

Design & development of the DITET app (2020-)

Having an interpreter present is deemed the best communication mode in a healthcare setting for the Deaf. Taking this into account our team developed a mobile app, DITETM (Deaf In Touch Everywhere) which aims to connect the Deaf with a pool of off-site interpreters through secure video conferencing. The main functionality of DITETM is to help Deaf individuals book a BIM interpreter in advance or on demand at their convenience. The design and development was carried out in a community-based participatory manner working with key partners; the Deaf (MFD, myBIM), BIM interpreters (JUPEBIM), and medical practitioners (Ministry of Health). We initially sought the input of the Deaf community and BIM interpreters following the Unified Theory of Acceptance and Use of Technology (UTAUT2) model. The pilot study employed a cross-sectional quantitative survey and qualitative focus groups. We observed that both the Deaf and BIM interpreters have high behavioural intention to use the DITE app, and they provided areas for improvements and recommendations. The process of engaging end users in the design process provided extremely valuable insights and helped ensure the DITE app continues to address true needs for both the Deaf community and BIM interpreters in Malaysia.

Development of Health Promotion videos in BIM (ongoing)
The healthcare access challenges they face, compounded by their lower health literacy levels place them at higher risk of worsening their condition, lower health status, and poorer health outcomes. Health information is rarely tailored for the Deaf community. The DITE app will also house a repository for health promotion videos in BIM. To inform the design of health promotion (HP) videos, a qualitative interview was undertaken with the Deaf community to determine their health literacy levels. Relevant HP videos are being contextualised and developed in BIM

BIM Graphics Interchange Format (GIFS) for COVID-19 screening and management (2020)
In collaboration with MFD and myBIM, GIF translations of the Malaysian Ministry of Health's guidelines on COVID-19 screening questions was developed.

Deaf Cultural competency training for Medical students and healthcare practitioners (2022)
The HEARD team together with myBIM and Malaysian Medics International (MMI) carried out a series of Deaf Cultural competency training, best practices when consulting a Deaf patient and basic BIM workshops. The workshops were conducted virtually over a period of 6 months from May to October 2022 by a Deaf person.

2.5. The Future (Applicable to groups 1, 2, & 3.)	**Our ultimate goal is to improve the health outcomes of this largely underserved community in Malaysia. Working with our community partners, we hope to achieve the above through the many ongoing and planned programs.**
	1. A local company delivering primary healthcare has shown interest on DITE. Together with the company and our partners; MFD, myBIM and JUPEBIM, we plan to beta test DITE. We also have plans to include a telemedicine feature, among others, into DITE.
	2. We recently applied for a local government grant to develop health promotion (HP) videos on mental health literacy in BIM (Malaysian Sign language). If successful, these videos will be developed after determining the mental health literacy levels of the Deaf population in Malaysia. Effectiveness of the HP videos will be determined at several times points post intervention.
	3. As healthcare educators we believe we are in a unique position to advocate and implement curriculum relevant to healthcare students on Deaf cultural and linguistic competency. Together with our international medical educator collaborators, University Maastricht, we plan to develop MOOCs for healthcare professionals on engagement with the Deaf during healthcare consultations
	4. Taking inspiration from the Auslan Signbank, setting up a BIM medical Signbank would serve as a stepping stone in developing human capital. This will allow for the standardisation of medical terminologies and spoken medical terms in BIM, hence preventing miscommunication and misinterpretation in medical practice. It's important that the development of the BIM medical Signbank is done in close collaboration with the Deaf community and healthcare professionals. Having a designated BIM Medical Signbank will also allow for easier access and training among the Deaf community and BIM interpreters, Together with myBIM, and an Australian university, we plan to apply for a grant to develop the BIM medical Signbank.
	5. Having a trained interpreter present has been deemed the best communication modality for the Deaf in a healthcare setting. Many countries stipulate the provision of sign language interpreters for healthcare consultation, however no such legislation exists in Malaysia. A policy paper to the Malaysian government is imperative to strongly advocate for the provision of BIM interpreters in hospital settings.
4. The Prize Fund	**Since 2017, the HEARD program has been funded by several grants from Monash and Rotary. The prize money will be most helpful in many of the projects we have in our pipeline, particularly the development of a policy paper and BIM Medical Signbank. While we have some data, to advocate for the provision of BIM interpreters in hospital settings, we also need specific case studies and cost benefit analysis. Another project which is crucial and much needed is the development of a BIM Medical Signbank. We are already in discussion with international experts and are sourcing for potential grantors.**
5. Your advice to others	**I have been the coordinator of Community Engagement programs at Monash since 2008. Here students are sent to various NGO's to develop health promotion projects that address issues of health inequalities. I have seen amazingly positive changes in students upon completion of this program. I have always strongly advocated to students and my academic colleagues the need to use their research resources to address the many health inequalities that exist in our society today. Apart from academic returns (publications, grants, research students) and positive outcome to the beneficiaries such research has also inculcated active citizenship among our students.**
6. Supporting Evidence	n/a

6.1. Funders	**Funder: Monash University Malaysia** **Grant title: Addressing Health Communication Needs of Deaf Sign Language Users with DITE (Deaf In Touch Everywhere). A submission from the HEARD (HEAlthcaRe needs of the Deaf) project** **Award period: 1 Jan 2021 – 31 June 2023** **Value in GBP equivalent: 50 668** **Weblink (if available)** **: https://www.monash.edu.my/pages/latest/articles/2021/Digital-health-projects-traverse-disciplines-to-address-health-inequalities** **Funder: Rotary Central Damansara Malaysia** **Grant title: :Youth Empowerment and Skills Training Workshop & the Deaf Communication Study** **Award period: 2018** **Value in GBP equivalent: 2 400** **Weblink (if available): https://rccd.org.my/**
6. 2. Academic/Professional Publications	**Publication title: Chong, E. Y., Jacob, S. A., Ramadas, A., Goh, P. H., & Thanabalasingam, D.,. (2021). Assessment of community pharmacists' communication and comfort levels when interacting with Deaf and hard of hearing patients. Pharmacy Practice (Granada), 19(2).** **Date of publication: 2021 (Apr-Jun)** **Article title: Assessment of community pharmacists' communication and comfort levels when interacting with Deaf and hard of hearing patients** **Names of any authors who are listed partners on this application: Elizabeth Y Chong, Sabrina A Jacob, Amutha Ramadas, Pei H Goh & Uma D Palanisamy** **Weblink (if available): doi: 10.18549/PharmPract.2021.2.2274** **Publication title: Jacob, S. A., Chong, E. Y. C., Goh, S. L., & Palanisamy, U. D. (2021). Design suggestions for an mHealth app to facilitate communication between pharmacists and the Deaf: perspective of the Deaf community (HEARD Project). Mhealth, 7.** **Date of publication: April 2021** **Article title: Design suggestions for an mHealth app to facilitate communication between pharmacists and the Deaf: perspective of the Deaf community (HEARD Project)** **Names of any authors who are listed partners on this application: Sabrina Anne Jacob, Elizabeth Yie-Chuen Chong, Soo Leng Goh, Uma Devi Palanisamy** **Weblink (if available): doi: 10.21037/mhealth.2020.01.04**
6.3. Other publications	**Date of publication: 2022** **Publisher: Wolters Kluwer Health** **Title of article: Health care needs of Deaf signers: The case for culturally competent health care providers.** **Weblink: doi: 10.1097/ACM.0000000000004181** **Jacob, S. A., Palanisamy, U. D., Napier, J., Verstegen, D., Dhanoa, A., & Chong, E. Y. C. (2022). Health care needs of Deaf signers: The case for culturally competent health care providers. Academic Medicine, 97(3), 335-340.** **Date of publication: 2022** **Publisher: Elsevier** **Title of article: Communication methods between physicians and Deaf patients: A scoping review** **Weblink: doi: 10.1016/j.pec.2022.05.001.** **Yet, A.X.J., Hapuhinne, V., Eu, W., Chong, E.Y. & Palanisamy. U.D. (2022).Communication methods between physicians and Deaf patients: A scoping review. Patient Educ Couns. Sep;105(9):2841-2849.**

6.4. Other forms of communication, including conferences	**Date : Sept 2020** **Publisher/host/programme: The business station BFM 89.9, Malaysia** **Title of article: Podcast of interview on COVID-19 SCREENING QUESTIONS IN MALAYSIAN SIGN LANGUAGE** **Weblink: https://bfm.my/podcast/the-bigger-picture/the-daily-digest/covid-19-screening-questions-malaysian-sign-language** **Date : 22/5/2021** **Publisher/host/programme: The Galen Centre for Health & Social Policy** **Title of article: A webinar on Listening to the Deaf Community for Better Health Literacy** **Weblink:** **https://www.facebook.com/galencentre/photos/a.1380010778762144/3884317258331471/?type=3** **https://www.youtube.com/watch?v=F3clXcgycGw**
6.5 Other Evidence	**Publications:** **1. A qualitative study on the design and development of an mHealth app to facilitate communication with the Deaf community: perspective of community pharmacists. Patient preference and adherence, 13, 195. 2019** **2. Knowledge and Perception of Malaysian Doctors and Medical Students on Deaf culture, how they communicate and expectation of medical curriculum. Journal of General Internal Medicine. (submitted)** **4. Acceptance and Use of the DITE app with people who are Deaf and Sign language Interpreters. JMIR mHealth and uHealth. (submitted).** **DITE app:** **https://www.monash.edu.my/jcsmhs/about/heard/dite** **https://www.businesstoday.com.my/2020/10/26/monash-university-approves-funding-for-7-digital-health-strategic-projects/** **https://focusmalaysia.my/monash-malaysia-and-amazon-collaborate-to-help-students-develop-impactful-apps/** **COVID-19 SCREENING QUESTIONS IN BIM** **https://www.monash.edu.my/jcsmhs/about/heard/bim-covid-19-screening-questions** **https://www.malaymail.com/news/life/2020/10/28/covid-19-to-help-the-deaf-malaysian-academics-translate-screening-questions/1917168** **Webinars on Deaf Cultural Competency** **https://www.facebook.com/malaysianmedics/photos/a.731868116933926/2878094325644(** **https://malaysianmedics.org/upcoming-events/mmi-de-healthcare-for-deaf-breaking-the-silence**