RESEARCH REPORT

Building an inclusive Dementia Friendly Community (iDFC) in Kebun Baru

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Foreword

NUS Chua Thian Poh Community Leadership Centre (CTPCLC) offers a Community Development Practicum module through which students have the opportunity to collaborate with community organisations on research and evaluation projects. Over the years, CTPCLC students have partnered with a range of social purpose driven organisations (e.g. government agencies, voluntary welfare organisations, social enterprises) on projects that addressed pressing social and community issues.

In this study, Jazreel Low Ju Li, Jocelyn Joy Gwee, Lau Wan Ling, and Tan Jiayi partnered with Alzheimer’s Disease Association (ADA) to conduct a ground-sensing study in Kebun Baru as part of ADA’s efforts to use an asset-based approach to build an inclusive dementia friendly community. They conducted: a) surveys to determine residents’ knowledge of and attitudes toward dementia, b) focus group discussions with caregivers of persons with dementia to identify the challenges they face, the assets within the community and the support they need, and c) walking interviews with persons with dementia and their caregivers to understand their lived experiences within the community.

Findings from the study enabled ADA to identify and implement interventions that helped create an inclusive dementia friendly community in Kebun Baru by increasing dementia awareness, improving wayfinding, and enabling community through informal activities.

Dr. Angeline Lim
Lecturer
Chua Thian Poh Community Leadership Centre
ABOUT ALZHEIMER’S DISEASE ASSOCIATION

Alzheimer’s Disease Association (ADA) was formed in 1990 because of a growing concern for the needs of persons with dementia and their caregivers. Through their work, ADA hopes to reduce stigma by increasing awareness and understanding of dementia; enable and involve persons with dementia to be integrated and accepted in the community; and lead in the quality of dementia care services for persons with dementia and their families.

ADA aims to strive towards a dementia inclusive society through its four strategic service pillars: centre-based care; caregiver support; the Academy and community enabling. Their work allows them to be recognised as Singapore’s leading organisation in dementia care — a catalyst, enabler, educator and advocate — that inspires society to regard and respect persons living with dementia as individuals who lead purposeful and meaningful lives.
ABOUT THE PROJECT

In Singapore, it is estimated that one in ten seniors aged 60 and above currently have dementia, and the number increases to one in two seniors aged 80 and above. By 2030, dementia is expected to affect more than 100,000. Given the increasing prevalence of dementia, there must be adequate support for persons with dementia in the community to ensure that their quality of life is not adversely impacted.

Several communities have been declared dementia friendly in Singapore. However, existing local approaches adopt a technical assistance approach with government and social service agencies providing assistance to persons with dementia and their caregivers. While useful, this approach heavily taxes state resources and may not meet the needs and aspirations of persons with dementia and their caregivers. Following the asset-based and inclusive approach used to build a dementia friendly Kiama and learning from the efforts in building a dementia friendly Chong Pang under the Forget Us Not campaign, this project attempts to build an inclusive dementia friendly community (iDFC) in Kebun Baru (KB), a residential district in the north-eastern part of Singapore using the Community-Based Participatory Action Research (CBPAR) framework. KB was chosen for its high population of elderly, where two in five of its residents are above age 60.

To capture the nuances of an iDFC that the KB residents can identify with, and to support the KB grassroots in its creation of an inclusive dementia friendly community, we conducted a ground-sensing study to:

1. Understand the knowledge and attitudes Kebun Baru residents have towards dementia;
2. Uncover what a dementia friendly community means to them;
3. Explore what can be done to make Kebun Baru dementia friendly

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1 News article by The Straits Times in 2018 titled “More help at hand for dementia patients”:
https://www.straitstimes.com/singapore/health/more-help-at-hand-for-dementia-patients
2 Journal article by Subramaniam et.al. (2015) in J Alzheimers Dis 45(4) pp1127-38: Prevalence of Dementia in People Aged 60 Years and Above: Results From the WISE Study
3 Journal article by Ting and Lim (2016) in European Psychiatry 33 Supplement S474: Weathering the Silver Tsunami: Dementia Community Services in Singapore
4 News article by The New Paper on 25 Nov 2019 titled “Woodlands to engage young in dementia outreach initiatives”:
5 Dementia friendly Singapore website: https://dementiafriendly.sg/
6 Journal article by Phillipson et.al. (2018) in Dementia pp1-16: Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project
7 News articles by Today Online on 20 Jan 2019 titled “Forget Us Not’ campaign aims to build dementia-friendly communities”:
METHODS

The ground-sensing study was conducted using three community research methods to engage different groups of stakeholders. Specifically:

1. A **community survey** of 133 Kebun Baru residents was conducted to capture residents' knowledge of dementia, attitudes towards dementia and perceptions of a dementia friendly community.

2. A **focus group discussion** with eight caregivers of persons with dementia was conducted to understand the dementia-related experiences and challenges encountered by persons with dementia and their caregivers, and their perceptions of a dementia friendly community.

3. **Walking interviews** were conducted with two pairs of persons with dementia and their caregivers to observe and more keenly understand their experiences and interactions with the physical, social and service environment within Kebun Baru.

Table 1 below presents the demographic profiles of the participants in each study.

<table>
<thead>
<tr>
<th>Community Survey</th>
<th>Focus Group Discussion</th>
<th>Walking Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 133 Kebun Baru residents</td>
<td>• 8 caregivers of persons with dementia</td>
<td>• 2 pairs of persons with dementia and their caregivers</td>
</tr>
<tr>
<td>• 12-16 from each of the 10 zones in KB</td>
<td>• 2 males; 6 females</td>
<td>• Pair 1: daughter-in-law / mother-in-law</td>
</tr>
<tr>
<td>• 74.8% live in HDB flats; 25.2% live in private housing</td>
<td>• Persons with dementia were their parents / parents-in-law (7), spouse (1)</td>
<td>• Pair 2: married couple</td>
</tr>
<tr>
<td>• 33.6% male; 66.4% female</td>
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<tr>
<td>• Age: Under 18 (6.1%), 18-24 (6.9%), 25-44 (22.9%), 45-64 (32.1%), 65-84 (30.5%), 85 and above (1.5%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Table 1: Description of samples across studies*

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8 Each precinct in Singapore is subdivided into smaller zones; each zone is supported by a committee made up of residents living in that zone.
FINDINGS

From the ground-sensing study, several key findings emerged:

1) Moderate level of knowledge and understanding of dementia

In the community survey, we asked Kebun Baru residents about their understanding of dementia and its implications on the daily functioning of persons with dementia. We found that approximately half of the surveyed respondents claimed to have a good understanding of dementia (responding positively to the item “I have a good understanding about dementia and how it affects people.”) However, nearly a quarter of respondents held stereotypes of persons with dementia and nearly half of the respondents neither agreed nor disagreed with such stereotypes, suggesting only a moderate level of knowledge and understanding of dementia (see Figure 1).

![Figure 1: Knowledge and understanding of dementia](image-url)
2) Overall positive attitudes towards persons with dementia

We also assessed respondents’ attitudes towards persons with dementia using a series of statements related to social exclusion of persons with dementia. As shown in Figure 2 below, majority of the respondents disagreed with statements such as “People with dementia should minimise contact with others”, “I wouldn’t visit or befriend a person with dementia because they wouldn’t remember”, “People with dementia don’t really need to use our community facilities and services”, and “I would prefer not to join a social activity or group if people with dementia are also invited”. More than half also disagreed with the statement “It is best that people with dementia live in Nursing Homes”, with 28% neither agreeing nor disagreeing with the statement. The significantly lower percentage of people disagreeing with this statement as compared to the other statements could perhaps be more of an indication of a lack of knowledge of dementia care and nursing homes and a concern for providing professional care for persons with dementia than a less positive attitude towards persons with dementia.

Figure 2: Attitudes toward Persons with Dementia
3) Characteristics of an inclusive Dementia Friendly Community

Based on the community survey, focus group, and walking interviews, three key characteristics of an inclusive Dementia Friendly Community (iDFC) emerged (see Figure 3). First, community members need to have greater awareness of dementia and dementia friendly resources within the community. Second, community members need to understand and cater for differences in individual experiences of dementia. A person-centred approach to dementia is necessary because dementia manifests itself differently in people – some persons with dementia become quiet and reclusive and some become agitated and violent. Our findings suggest the importance of a community that is able to provide individualised concern for its members with dementia and their caregivers. Third, an iDFC should be one with more services (both formal and informal) for persons with dementia and their caregivers. These services could range from specialised dementia care to services that enhance the daily lived experiences of persons with dementia and their caregivers. For instance, services that would allow caregivers some respite from caregiving and help them restore and replenish their positive energy.

**Figure 3: Characteristics of an inclusive Dementia Friendly Kebun Baru**
4) Suggestions to develop Kebun Baru into an iDFC

Several suggestions on how to make Kebun Baru dementia friendly emerged from the study. These suggestions can be grouped into three aspects – physical, social and service – and are reflected in Figure 4 below.

**Physical**

When asked for suggestions on how to make Kebun Baru dementia friendly, respondents highlighted a need to improve wayfinding and walkability in the neighbourhood. The focus group discussion and walking interviews revealed a lack of visible signage or familiar landmarks within the Kebun Baru community that make it hard for persons with dementia to find their way. For instance, block numbers are only listed at lift lobbies, stairwells and on the external façades of HDB blocks. This may make it hard for persons with dementia to navigate their way through the blocks as the pillars and walls at the void decks look similar. Also, as Kebun Baru is undergoing extensive renovations due to the construction of an MRT station, a number of familiar landmarks have been boarded up and new temporary walkways have been created. This adds on to problems with wayfinding and walkability.
Furthermore, caregivers shared that while ramps are available within the HDB estates for those who are wheelchair-bound, often, these ramps are hidden out of sight or require walking a fair distance to access. There is also a need to improve lighting as visibility is low in some areas. Within the private housing areas, foot paths are often blocked (e.g. by dustbins, recycling bins, etc.), resulting in the need for those on wheelchairs to move out to the main road (where there are cars and the road may be less even). Such little inconveniences to the average pedestrian are magnified when encountered by seniors or persons with dementia who are less mobile.

**Social**

Our respondents also suggested more social activities to engage persons with dementia and to increase opportunities for social interactions among persons with dementia, their caregivers and the rest of the community. Such social activities may help delay the progression of dementia, and positive intergroup interactions can reduce stigma, enhance knowledge dementia and forge greater interpersonal connections.

**Service**

While there are some dementia-specific and dementia friendly services in Kebun Baru, respondents articulated a lack of awareness of such services and the need for more services that cater to this community. A focus group participant suggested an online portal that can be a “one-stop shop” for all dementia-related services. She highlighted the difficulty in searching for information on dementia and for activities that can help to engage her parent who has dementia.

Overall, the key findings from our ground-sensing study suggest a generally positive attitude towards persons with dementia among Kebun Baru residents and the potential for greater engagement of the community to improve their understanding of dementia. While some physical, social and service aspects of Kebun Baru do cater to persons with dementia and their caregivers, more can be done to enhance the inclusivity within Kebun Baru and transform it into a truly inclusive dementia friendly community.
RECOMMENDATIONS

Increase dementia awareness, knowledge and support

From our community survey, those who have a family member with dementia were more likely to treat persons with dementia positively, agreeing to spend time with and talk to a person with dementia. Thus, it seems that to reduce the stigma around dementia, one of the best methods is for Kebun Baru residents themselves to personally get to know, or at least have contact with a person with dementia, which would increase dementia awareness and knowledge as well as reduce dementia stigma. Other awareness initiatives such as roadshows and media outreach can also be utilised to increase dementia awareness and knowledge.

The rapport built during the focus group discussion with caregivers can be leveraged to establish a committed support group. Other possible stakeholders in this support group can also include persons with mild dementia. Additionally, having inclusive activities customised to a person with dementia that accounts for their abilities and interests is crucial.

Improve communication of dementia friendly resources

Based on our study, there was not only a need for more dementia-specific and dementia friendly services, there was also a need for greater awareness of the existence of such services and other available resources. As such, we recommend the development of a website or app that consolidates the list of dementia friendly activities, businesses and service providers in and around Kebun Baru. Service providers should also be more intentional in marketing the dementia friendly resources and efforts.

Improve wayfinding and neighbourhood walkability

In the focus group discussion, caregivers highlighted the lack of accessible ramps for persons with dementia who are wheelchair-bound and the lack of proper, visible signage to aid persons with dementia with wayfinding within the community (e.g. the lack of visible block numbers at void decks, similarity in design of void decks across blocks.) From the walking interviews, we found that there was a lack of inclusive activity spaces and exercise areas, as well as obstructions in pathways (especially in private housing estates.) A proper environmental audit can be done to identify the exact areas in which wayfinding and walkability can be improved to provide a more inclusive physical environment for persons with dementia.
INTerventions

With the completion of the ground-sensing with the residents in KB, ADA embarked on several initiatives with the KB grassroots and community partners based on the recommendations to build an inclusive dementia friendly KB together. These actions may be broadly categorised into (1) Raising dementia awareness; (2) Enabling the community with informal activities; and (3) Improving wayfinding in the neighbourhood.

raising dementia awareness

Organised by the KB grassroots, dementia awareness and screening in two Residents’ Committees (RCs) in KB namely Heights RC and Bestari RC were done, allowing us to reach out to more than 100 residents. This initial effort enabled us to embark on several other initiatives to identify and engage with residents with dementia in the two neighbourhoods. These include monthly recycled arts activities with 10 residents with dementia at Heights RC Centre, run entirely by trained volunteers, and our first Memories Café programme9 in KB on 18 January 2020 which had 15 residents with dementia benefitting from the session. These informal monthly activities benefit residents with dementia, providing them a platform for social interaction and psychosocial activities

Other dementia awareness initiatives include two dementia awareness talks at Sembawang Bible-Presbyterian Church on 30 May and 23 July 2019, which was initiated and organised mainly by a resident and attended by more than 100 of her fellow residents from Thomson Neighbourhood Committee (NC), as well as dementia awareness exhibitions held at Kebun Baru Community Club in September and October 2019, and another round from January to March 2020.

In collaboration with KB CCMC, Child@Street 11 and St Luke’s ElderCare in Kebun Baru, we also developed a series of videos featuring conversations between seniors with dementia and children. These videos are developed to raise dementia awareness and reduce the negative stereotypes of dementia, and will be screened on TV panels set up at HDB lift lobbies in KB.

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9 Memories Café by Alzheimer’s Disease Association is a programme for persons with dementia and their caregivers, conducted at external partner cafés and restaurants. The programme provides a normalised café setting for participants to interact through activities and conversations in a safe, supportive and conducive environment.
Enabling the community with informal activities

A team of more than 20 volunteers from Salem Chapel in Thomson Hills NC underwent training with ADA to be equipped with the knowledge and skills to run caregiver-accompanied programmes and activities for persons with dementia. This initiative has been running monthly since June 2019, benefitting a regular pool of more than 10 families with loved ones with dementia.

An informal support group (House of Joy) was also started in KB in collaboration with KB grassroots, Tan Tock Seng Hospital and St Luke’s ElderCare (SLEC) in KB. The group of five caregivers had their first get-together and introduction on 2 November 2019 and decided to meet once every six weeks to support one another.

Improve wayfinding in the neighbourhood

On 14 November 2019, ADA organised a closed-door dialogue session between the MP for Kebun Baru Constituency, Mr. Henry Kwek, and persons with dementia and their carers. The group touched on many aspects of building dementia friendly communities during the session - from services and drug costs to infrastructure and environment. This dialogue led to their involvement in the void deck mural painting project in KB to aid in wayfinding for persons with dementia. Besides helping the KB grassroots select appropriate icons for painting, two persons living with dementia also assisted to identify the locations under the void decks for painting to prevent confusion for residents with dementia. Residents were then roped in to help with the painting process to instil a sense of ownership and participation in the project.
Building An Inclusive Dementia Friendly Community in Kebun Baru

OVERALL GOAL
To contribute to an inclusive Dementia Friendly Community (IDFC) in Singapore where persons with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential.

PURPOSE
To build an inclusive dementia friendly Kebun Baru (KB) where persons with dementia and their carers are included and supported to age in place.

PROJECT OUTCOMES
1. EDUCATED the people living, working and studying in Kebun Baru to have increased awareness and knowledge about dementia, and create more positive attitudes toward dementia and persons with dementia.
2. ENABLED the community in and around Kebun Baru to take action to support their neighbours with dementia and their carers.
3. EMPOWERED persons with dementia and their carers to be included in dementia friendly initiatives and to age-in-place in Kebun Baru, despite their condition.

KEY ACTIVITIES
1. EDUCATE: CONDUCT DEMENTIA AWARENESS ACTIVITIES IN KB
   - NOV 2018: Conducted dementia awareness talks and screenings during Active Ageing Carnival at KB CC
   - MAR 2019: Supported Walk2Remember (Walkathon) Event at Bishan Park to raise dementia awareness
   - MAY 2019: Conducted dementia awareness talks and screenings at Heights RC
   - MAY & JUL 2019: Conducted dementia awareness talks at Sembawang Bible-Presbyterian Church at Thomson NC
   - SEP 2019: Conducted dementia awareness talks and screenings at Bestari RC
   - SEP – OCT 2019: Displayed dementia awareness posters at KB CC
   - DEC 2019 – APR 2020: Displayed Walk2Remember dementia panels at KB CC

2. ENABLE: EVOLVE IDFC IN KB TO HAVE VISIBLE ACTIVITIES
   - Trained volunteers from Salem Chapel in Thomson Hills NC to run monthly caregiver-accompanied programme for persons with dementia
   - Developed monthly recycled arts programme for residents with dementia at Heights RC
   - Started informal caregiver support group at KB in collaboration with KB grassroots, Tan Tock Seng Hospital, Thye Hua Kwan Moral Charities and St Luke’s Eldercare at KB
   - Started monthly Memories Café programme for residents with dementia and carers at View RC (Under Onesimus Village@KB)

3. EMPOWER: INVOLVE PERSONS WITH DEMENTIA
   - NOV 2019: Conducted closed door dialogue between persons with dementia and Henry Kwek, MP of Kebun Baru Constituency
   - MAR 2020: Produced a series of videos in collaboration with KB grassroots, Child® Street11 and St Luke’s Eldercare at KB. Videos featured seniors with dementia to raise dementia awareness and address negative dementia stereotypes
   - MAR 2020: Completed mural painting under selected void decks to aid in way-finding for residents with dementia. Persons living with dementia were roped in as advisers for the project
CONCLUSION

We used a CBPAR approach to engage various stakeholders within Kebun Baru to: a) identify existing knowledge levels and attitudes of Kebun Baru residents, b) find out what a dementia friendly community means to them, c) explore the experiences of caregivers and persons with dementia, and d) identify ways in which Kebun Baru can develop into a dementia friendly community.

While Kebun Baru residents acknowledge some good physical aspects, by considering a person with dementia’s holistic experience, a consistently more mobility friendly and dementia friendly community that instils confidence and motivation in persons with dementia to navigate the neighbourhood independently, can be built.

Socially, while there is already a relatively friendly community and persons with dementia have varying levels of social connections, more social opportunities and a kinder community can be encouraged to forge residents’ interpersonal connections with persons with dementia, going hand-in-hand with initiatives that aim to increase awareness of dementia.

Lastly, more inclusive and personalised dementia-specific services can be initiated and made known to support caregivers and persons with dementia.

We recommend the usage of the CBPAR approach to further involve the community in dementia-related research in Kebun Baru. The untapped potential of assets that persons with dementia and their caregivers have can also be harnessed to build an inclusive dementia friendly community that consistently takes into account a person-centred understanding of a person with dementia when interacting with the physical, social and service environments.
PARTNER REFLECTIONS

“Dementia is not a problem unique to Singapore, but rather, a global phenomenon. Studies have found that many persons with dementia face social isolation. Yet, change is already happening in some developed countries, like Australia, where they have included people living with dementia not just into the community, but also into the local government and other decision-making councils.

Take for instance the Dementia Friendly Kiama Project based in the coastal town of Kiama, New South Wales. The project brings together various people living with dementia, their carers, supporters, residents and local businesses to ensure that not only are the needs of persons with dementia met, their opinions and views are sought and taken into consideration in the process. Notably, the Advisory Group supporting this project in Australia is chaired by Mr Dennis Frost, who is diagnosed with young onset dementia, highlighting that the opinions of persons with dementia can still be valued.

In our efforts to mirror the approach in Kiama and build a truly inclusive dementia friendly community in Kebun Baru, Angeline and her team of students from CTPCLC assisted us in several ground-sensing projects to uncover what it means to be dementia friendly from both the residents’ and businesses’ point of view. The entire process from the scoping of projects, to recruitment of students, all the way to the presentation of the survey findings to community partners was clear and pleasant. It is personally very inspiring and motivating to encounter students and lecturers so vested and committed to make meaningful contributions to our community.

Ms. Mary-Ann Khoo
Consultant, Community Enabling
Alzheimer’s Disease Association
STUDENT FELLOWS’ REFLECTIONS

“As an engineering student, I have never really engaged in social science research and thus the opportunity to work on this project was a special one! Having lived in Kebun Baru previously, I was already familiar with Kebun Baru but through this project, I saw another side of Kebun Baru, one that is often less talked about and more intangible. I learnt what residents on the ground understand of dementia, their assets, what they hope to see in their dementia friendly community and what they think can be improved. I hope that the project’s results could translate into practical societal recommendations like more dementia friendly spaces that would have a long-lasting and tangible impact on dementia friendly communities in Kebun Baru and beyond.”

Jazreel Low Ju Li
Engineering ‘21

“This project helped me to understand the importance of eliciting key insights from stakeholders (caregivers) in understanding what a dementia friendly neighbourhood meant. Every caregiver has their own rendition of what a dementia friendly community would look like to their loved one based on personal lived experiences, and every experience shared was deeply insightful in understanding community needs. We cannot just gloss over issues with a blanket explanation or understanding. The ground-up, community-centric approach that ADA envisioned and pushed for was also an admirable endeavour. “Ground-up” means walking alongside the community as they cultivate a growing level of ownership for the efforts involved and the changes they would like to see. I really valued this learning experience.”

Jocelyn Joy Gwee
Arts and Social Sciences ‘19
This project has given me the opportunity to better understand the dynamism and complexity of what it means to suffer from dementia, what it means to care for persons with dementia and what it means for the stakeholders involved. Throughout the process, I personally felt the significance of a ground up approach which my team adopted; I saw how it truly encouraged the sharing of honest and heartfelt experiences and ideas. Truly, dementia in Singapore, likewise ageing population, should not be seen as a liability and burden, but rather a golden opportunity for Singaporeans to learn to draw in the gap and foster more genuine conversations, to become more empathetic, more concerned and committed citizens.

Lau Wan Ling
Arts and Social Sciences ‘19

This research experience has been truly enriching and fruitful. It was satisfying seeing the impact of our research on the community, with recommendations that can be implemented to build a dementia friendly Kebun Baru. During the project, I learnt about the Community Based Participatory Action Research (CBPAR) model and the in-depth challenges faced by persons with dementia and their caregivers. We managed to apply the CBPAR model and really engage residents, persons with dementia and their caregivers on the ground, to be inclusive in the research process and capture their voices such that any interventions made are relevant and based on their lived experiences. I am extremely grateful for this opportunity to embark on this research project.

Tan Jiayi
Arts and Social Sciences ‘21
About Chua Thian Poh Community Leadership Centre

Located at NUS University Town, the Chua Thian Poh Community Leadership Centre is named in recognition of Mr Chua’s generous gifts to the University. At the Centre, we aim to nurture Singapore’s next generation of community leaders, who will not only be intellectually engaged in social and community issues, but will also be passionate about addressing social and community challenges in Singapore.

Each year, we admit a select number of NUS undergraduates from different disciplines as student fellows. Together with faculty members and organisational partners, the student fellows learn to adopt a multi-disciplinary approach and conduct social research such as needs assessment, asset mapping, programme evaluation, social impact measurement and identification of sustainable solutions.

To date, our student fellows have worked with over 100 organisational partners serving different communities in Singapore; healthcare, family service, disadvantaged individuals, and many more. The programme has also inspired our student fellows and alumni to continue initiating ground-up community projects involving a wider NUS community. We hope to inspire young community leaders within and beyond NUS to contribute to a more caring, and resilient society.