

A Practical Guide to Promoting Social Participation in Seniors

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A Community-based Approach

By

Teoh Gaik Kin, Tan Maw Pin
and Chong Mei Chan

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PREFACE

Asia houses the largest population of older persons globally. The bulk of research studies on ageing has, however, primarily emerged from Western Europe and North America. There is therefore an urgent need to redress this imbalance. Asia is a highly diverse continent regarding ethnicity, religion, economics, and demography. In addition, many countries within Asia are ageing at an accelerated rate, with limited time and resources to develop ecosystems to address the needs of an ageing population. The benefits of social participation that promote active and healthy ageing are manifold – not just to the older persons, but to different levels of the society. Promoting social participation is also one of the prioritized action plans for sustainable population ageing, according to the United Nations Economic and Social Commission for Asia and the Pacific.

Considering the diverse cultures among Asian countries, adopting a one-size-fits-all initiative to promote social participation among older community dwellers would be impossible. In the hierarchical social context, the top-down approach which is government or funder driven is prevalent in many community initiatives. The experiences and perspectives of community members are often overlooked. This deters the sustainability of most community projects according to the Ministry of Health Malaysia (2010). Taken together, building a broad-based framework for community partnership that upholds diversity should be prioritized over seeking to implement or even impose a top-down, standardized framework on any community. In order to broaden the framework of community collaboration or partnership, the principles of participatory action research should be emphasized, and following the areas of emphasis are promising for empowering the community based on the experience of community members: being community-centred, building a trusting relationship between the initiator and community, sensitivity to the power of the privileged, co-learning between initiator and the community, building an equitable partnership, cultural relevancy and capacity building.

This book attempts to serve two purposes: (a) expand the experience of the cross-cultural adaptation of participatory action research, particularly focusing on the process of implementing its principles, which are still needed; and (b) instead of providing a standardized guide for community

engagement in developing nations, which will then be imposed on upcoming community initiatives, we hope this guide will contribute to and usher in a broader framework of knowledge which will prove useful to engendering community partnerships.

A few words on the terminology used

Although the phrase “community-based initiative” connotes something different from community initiative, the meaning of both is still blurry to many in our context here. To make a simple distinction for the readers of this guide, we differentiate the terms as such: community-based refers to a community program or initiative which is grounded on community-centred guiding principles (more discussion on this can be found in chapter two) of both community-based participatory research and participatory action research, whereas a community initiative or program connotes a general term for any forms of community engagement or community collaboration without adopting the principles of participatory research.

We use participatory action research and community-based participatory research interchangeably as we share the common values and principles of both.

For other technical terms, footnotes have been provided at the reader’s convenience.

CHAPTER ONE

INTRODUCTION

TAN MAW PIN

The world is seeing the rapid expansion of its older population. This started at the turn of the last century in Europe, followed by North America and Australia. Improved wealth, better nutrition and sanitation, and the discovery of penicillin which paved the way for modern healthcare have all led to increased life expectancy and a growth in the older population. The introduction of family planning, which was seen as key to population control and improved wealth, however reduced population growth, which was first compensated for by reduced fetomaternal deaths, but this eventually turned into the actual shrinkage of the child population. This saw to the emergence of demographic transition and population ageing, one of the main big shifts that will mark the twenty-first century (Lutz, Sanderson, & Scherbov, 2008).

In the second half of the twentieth century, many East Asian economies, led by Japan, started to emerge. The demographic transition that occurred in Japan, and later Korea, Hong Kong, Singapore and Taiwan, however, occurred over a far shorter period compared to the Western economies. In fact, Japan now boasts the oldest population in the world, with a life expectancy at birth exceeding eighty-three years. These countries, however, were able to complement rapid economic growth with changes in health and social care systems to ensure that their economy continues to develop in a superaged society (Cheng et al., 2015).

The World Health Organization, however, warns that governments in developing countries are not doing enough to prepare for population ageing. The rest of South East Asia, for instance, is now also experiencing population ageing, with Thailand, Vietnam, and even Malaysia seeing it occur at a blistering pace, matching or even outdoing the wealthier East Asian nations. However, these governments remain too preoccupied with the unfinished set- tropical infectious diseases – with some, such as dengue,

now seeing a re-emergence – to even deal with the new set-non-communicable diseases, let alone address the emerging set-age-related conditions. Unlike the rich Western countries such the United States and France or the East Asian economic powers which have continued to grow richer, developing countries are now growing older without first getting rich (Bloom et al., 2015). The lack of preparation for the changing health demands associated with urbanization and population ageing in these countries may lead to these emerging economies experiencing the middle-income trap.

Urbanization and industrialization have long been associated with a reduction in family networks. All the country types mentioned above, whether well-established high economies, newly established high-income countries, or emerging economies, now have nuclear families rather than large extended family networks. In addition, with urban and international migration, some economies are seeing geographical separation between the older generations and the middle and younger generations. With dwindling family networks, citizens of ageing nations are having to resort to work colleagues and friends for social networks. The concept of communal living that occurs in rural areas in poorer countries is also often abandoned in urbanized and more wealthy countries which cherish ownership and individualism. Therefore, older persons in populations which are ageing are also in danger of increasing social exclusion and social isolation.

Ageing, Health, and Social Participation

The rapid growth in medical discoveries, starting with the discovery of penicillin by Alexander Fleming in 1928, has led to a shift in healthcare approaches to becoming increasingly scientific and technical. It is all too easy to believe that all conditions can be treated by pills and operations. In fact, while more and more medical treatments are being discovered each day by increasingly expensive trials involving thousands of patients, it remains undeniable that the actual benefits of each treatment often vary between individuals. This had led to a large number of studies into genetic explanations for these variations as well as other factors that may determine such differences in responses to treatment.

The pattern of diseases that influence lifespan, health, and wellbeing has also shifted significantly in the last century. The most common causes of death worldwide now include heart disease, chronic obstructive pulmonary disease, stroke, cancer, and dementia. To date, few of these conditions can be cured. For non-communicable diseases such as heart disease, chronic

obstructive pulmonary disease, and cancer, the available treatment mainly keeps the disease processes in control or remission. The underlying disease processes relapses intermittently requiring regular interventions, with maintenance treatment required to reduce the number and severity of relapses. The patient eventually succumbs if the relapse episode no longer responds to treatment, unless of course other diseases or mishaps interrupt the disease trajectory. In strokes, the deterioration is sudden, hence the name, and the individual potentially suffers severe disabilities after the acute attack, with variable rates and levels of recovery which are often difficult to predict.

Dementia, sometimes considered the cruellest disease of them all, is a slowly progressive condition affecting the brain. The individual with dementia deteriorates gradually, depending on the type. Alzheimer's disease is the most common cause of dementia, accounting for sixty percent of all types. In Alzheimer's disease, the person typically lives for a decade after the point of diagnosis, slowly losing the use of their faculties and eventually needing help in all activities of daily living. During the disease process, difficult behavioural symptoms may emerge, ranging from violent uncontrollable outbursts to apathy and social withdrawal. The emotional toll of having a loved one continue to breathe but living as an empty shell devoid of appropriate human responses weighs heavily on family members. The needs of these individuals are immense, and are often not fully met by family members, social care, and healthcare systems. In this brain disorder which now affects one in five of all individuals aged eighty years and over, the variations in the illness experience of the person and their caregivers can be vast. Some experience distressing behavioural disturbances, turn away all assistance, and are eventually forcibly removed from squalor and locked away in institutions where they experience abuse by care workers. Others continue to contribute towards family life and community living, with family members and friends continuing to enjoy their presence until the very end. What truly accounts for these differences in the illness experience is not entirely understood and is now a hotbed for research.

It still holds true, however, that prevention is better than cure. Vaccinations have been a major turning point in preventing large populations being wiped out by the highly contagious viral diseases of smallpox, polio, measles, whooping cough, and most recently influenza. It is now well recognized that heart disease, stroke, cancer, chronic lung disease, and dementia are preventable. In addition to being called non-communicable diseases, they are also termed lifestyle diseases. All these lifestyle conditions appear to share common risk factors. These risk factors, which increase the

individual's likelihood of developing any of these long-term conditions, include smoking, obesity, sedentary behaviour, saturated fats, and inadequate exercise. Major public health initiatives have therefore been launched to reduce such high-risk behaviours, with many developed countries now seeing a reduction in death from these lifestyle conditions.

Social isolation has now emerged as a major risk factor for death (Holt-Lunstad et al., 2015), rivalling cigarette smoking in its impact on ill health. Quite how this has emerged has yet to be teased out scientifically. Once mentioned, however, it would appear blatantly obvious at all levels of access to healthcare that being socially connected must have a major influence on the older person's health status.

However, being socially connected is likely to require attributes that exist prior to old age, such as a willingness to get along with others, available family networks, and social status, among others. In addition, what is known to occur with increasing age is loss of peers through illness and disease, and increased disability from the accumulation of medical conditions that become more common with ageing. In addition, even in well-developed economies, retirement is associated with a reduction in income, which continues to dwindle in real terms as pensions tend not to increase through retirement. In developing countries, however, pensions tend to be available to a small proportion of the population who worked for the civil service. The enforced savings schemes available in some countries do not usually last beyond a decade from retirement. Therefore, old age is often associated with dwindling wealth and poverty. In many developing countries, it also signifies a return to dependency on adult children's contributions. With the accumulation of health and financial factors alongside social factors which influence social participation, the odds therefore appear to be stacked against the older person in being able to achieve social participation.

Furthermore, despite strong evidence linking social isolation with poor health, and emerging evidence linking social participation with better health, it remains unclear whether social isolation is a modifiable risk factor for ill-health. To date, published scientific papers on enhancing social participation are still considered to be of inadequately robust design, and have yet to provide convincing evidence that social participation can be improved in older adults, let alone evidence directly linking the reversal of social isolation with improved health (Sander et al., 2015). The difficulties in generating such evidence are apparent. There are simply too many factors which determine social isolation, and far more needs to be done to overcome isolation than just enforced visits to day centres once a week, in a company

not of one's own choosing, for instance. The scientific world may, for now, have to be content in the knowledge that existing study designs do not lend to the evaluation of interventions for social participation and their actual effects on the health of individuals.

A Guide to Participatory Action Research for Social Participation

Until more robust methods of measuring alterations in social participation and their overall effects on health of communities are developed, ongoing efforts are still required to determine optimal methods of engendering social participation within communities. To date, few published papers address this issue globally, let alone within emerging economies and developing nations.

With population ageing now predominant in countries of the developing world, all of which have no more than three decades to prepare for this rapid demographic transition, it is now an imperative that these countries address social participation within their older communities in order to avert the potential catastrophic consequences which may ensue from the increasing health burden associated with social isolation resulting from population ageing.

This book is an instruction manual for conducting participatory action research on social participation in community-dwelling older persons. The authors of this book embarked on a journey to work with local communities in a middle-income developing country in Asia, and share their experience as well as the formula they have developed through this experience. We have learnt, however, that collaborative working with communities is not a prescriptive but a dynamic process, and requires intuition and patience. This guide therefore serves to help the researcher get started and brings to their attention issues which may arise, as well as what to look out for. We hope that, by producing such a guidebook, future researchers do not have to repeat our mistakes, but will have the opportunity to build on where we left off. With the urgency for developing rapid solutions for population ageing, we are optimistic that by using this instruction manual the efforts to develop community-based interventions to enhance social participation for older persons will be accelerated. Through initiatives such as these, the global community may yet have the chance to avert any catastrophe which may arise from the looming issues of population ageing, which would otherwise

lead to hardship from unaffordable, escalating healthcare costs and loss of income from social care costs.

Empowering Our Communities to Develop Their Own Solutions

The need to empower the older community may at first appear to be a contradictory statement in deeply hierarchical societies. However, developing countries are experiencing rapid demographic shifts alongside rapid development. As a result, the balance of roles between the younger and older segments of the population is changing rapidly. As the younger population receives higher educational attainments than their older relations, older persons experience difficulties in remaining relevant. In addition, the younger generation has become result-oriented in a fast-paced world – the dreaded generational gap. With an increasing number of retired older individuals within each community, resources becoming are increasingly stretched. The culture of filial piety in Asian cultures adds further dimensions to this complex relation, in which: (a) the older generation hands over all physically strenuous tasks to their adult children; (b) the older person remains detached, fearful that they are a burden to their children; (c) the older person exerts control over everything to avoid being hurt or prove their usefulness; and (d) the older person tries to engage by contributing or offering services to the younger generations.

With this mess of changing family and community dynamics and ingrained cultural values, what do we now have? Some lucky older persons do maintain patriarchal or matriarchal roles in their families and larger communities, and these tend to be the ones with material wealth and pre-existing societal status. However, many are perceived as irrelevant, as they struggle to keep up with the rapidly changing society with its technological advances, digital economies, and complicated transportation systems, leaving some vulnerable to elder abuse. Many older persons in developing economies often find themselves dependent on their adult children financially and are a burden to their families in terms of healthcare spending, personal care, and social contact.

Therefore, empowerment differs from filial piety and the cultural values of respect for older persons. Respect and filial piety, as mentioned above, are interpreted as obeying and providing for the older person, which leads to an increasingly burdened sandwich generation which is obliged to provide for dependent children and ageing parents. In addition, “providing for” is

regularly interpreted as doing everything possible, and hence tasks are taken over by the adult children even before the parent has lost their ability to perform such tasks, and “love” is interpreted as letting the older person “take it easy” or “rest,” as they have previously worked hard to provide for their children. Unsuspectingly, some older adults may require financial support from their adult children as soon as the latter start earning salaries, but continues to live beyond the adult children’s working life, well into their adult children’s retirement. With limited savings to speak of, the second generation having exhausted all their funds on their parents’ medical bills and children’s education, the third generation is now faced with the unbelievable burden of providing for two generations of older persons with their own young offspring (the fourth generation) to care for, while the community looks on in admiration at the third generation’s “good fortune” in having four generations under one roof. Unaware of this non-sustainable cultural imposition, society begins to imply declining moral standards and demands their moral high ground to be enshrined in a “filial piety law.” Thankfully, even states which have such laws rarely see them enforced, as older parents would not challenge their adult children in court for maintenance.

Empowerment, on the other hand, implies an older generation which is able to remain productive and contribute to society. This calls for stamping out of age discriminatory practices and a culture shift from governments and social institutions “working for” to “working with” communities. The older individual needs to assume the responsibility of maintaining their own health and continue to contribute to their family and community throughout their life. The younger and older generations should demonstrate mutual respect for their individual societal contributions. The idea of enhancing social participation in the older community would empower older individuals, with the ultimate vision of building self-sufficient communities which continue to add value to their communities in potentially new and innovative ways. However, Rome was not built in a day. Though we do not have centuries to do this, just a couple of decades, this will be an iterative process which will need to start somewhere. This book, an instruction manual of sorts, should therefore help anyone with an interest to do so.

Suggested Readings

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CHAPTER TWO

PREPARATIONS PRIOR TO COLLABORATION

Community collaboration is often initiated and directed by funders or privileged groups (Reason, 1994). The government sectors or the academic institutions who initiate community collaboration play the high-authority role in the hierarchical social context. Their intention to conduct community collaboration often couples with a charitable mindset to help the community. Or sometimes, community collaboration is meant to initiate movement in which those of high authority believe that the community will benefit from it. Either with the charitable or directive approach, who benefits the most is neither often clearly stated nor even evaluated. Apart from this, some government sectors or academic institutions are obligated to fulfil part of their Key Performance Index through community engagement. Hence, the basis and the ultimate agenda for conducting community collaboration need to be critically examined, particularly among communities that had suffered a long history of abuse (Wells & Jones, 2009).

Thus, in this chapter on the prior preparations before a collaboration, core principles which ground community collaboration will be discussed. They are indispensable for three reasons: 1) community collaboration needs to be grounded on social justice¹, 2) when the approach to community collaboration is top-down, the process to know the community in terms of its strengths, resources, and gaps are usually overlooked, often leading to unsustainable community initiative due to mismatched expectations (Ministry of Health Malaysia, 2010), and 3) to enhance the integrity of conducting community collaboration, so abuse cannot be easily justified as charitable acts. In order to enhance the preparations prior to collaboration, three dimensions will be deliberated, namely, recognizing different types of community initiatives, getting to know the community, and understanding the process of change.

¹ Social justice is the equal access to wealth, opportunities, and privileges within a society.

Recognizing Different Types of Community Collaborations

Thorough prior preparation is essential in the context of developing nations. Western hegemony is prevailing in knowledge creation. Implementation of imported frameworks from developed nations often supersedes the recognition to value local practices and its relevancy. Unlike experimental intervention, the reality in community collaboration is relative. It is defined by intangible forms, such as emotions and values (Lincoln & Guba, 2013). The shapes of community-based initiatives are influenced by the political, historical, cultural, economic, and social context of the settings. In the context of a developing nation like Malaysia, the connotation of community collaboration might entail different meanings from the developed nations. In particular, the framework for community collaboration is expandable and emergent. Thus, broadening the framework of community engagement is strongly urged, rather than seeking replication of community collaboration protocol in an intricately diversified social context.

In other words, understanding the existing discussion on community collaboration and identifying the community embedded knowledge² are essential for creating knowledge that inclusively portrays the meaning of inclusivity, especially since the cross-cultural application of community collaboration is still scanty. Therefore, it is essential that in order to understand how community collaborations are shaped in a hierarchical social context, discussion of community intervention in the context of knowledge creation would shed light on how the forms of community collaboration came about.

Understand Community Collaboration through the Lens of Knowledge Creation

To deliberate community collaboration in the context of knowledge creation, the underpinning paradigms of knowledge creation will be discussed, as it often sets the stage for knowledge creation. There are four research paradigms which are broadly classified into positivist, post-positivist,

² Embedded knowledge “resides primarily in specialized relationships among individuals and groups and in the particular norms, attitudes, information flows and ways of making decisions that shape their dealings with each other” (Basaracco & Stevenson, 1991).

constructivist, and critical theory (Guba & Lincoln, 1994; Israel, Schulz, Parker, & Becker, 1998; Ponterotto, 2005).

(1) Positivism

The researcher and the participants are believed to be independent. The researcher is expected to stay clear from being influenced by the participants. The researcher's values and biases are not allowed. This paradigm entails hypotheses that are subjected to verification and confirmation. Confounding variables need to be controlled and manipulated so that contamination of the outcomes of study are prevented.

(2) Postpositivism

This stance arose out of the intention to eradicate the shortcomings of positivism. In order to improve on the positivist stance, a natural inquiry is pursued so that an emic view is elicited. Objectivity is emphasized. Triangulation of evidence to falsify hypotheses is underscored.

The commonalities between positivist and postpositivist stances include that objectivity is valued, the researcher's role is detached from the reality, and the study is etic-based³.

(3) Constructivism

In contrast to the objective stance that positivists and postpositivists hold, constructivists believe that 'objectivity is chimaera' (Lincoln & Guba, 2013, p. 41). Constructivism assumes that reality is co-created by both the researcher (or initiator) and the participants. The co-construction is alterable and is a work in progress. It follows 'a relativist position that assumes multiple, apprehendable, and equally valid realities' (Ponterotto, 2005, p. 129). Reflection and interactive dialogues between the researcher (or initiator) and participants are crucial to facilitate the co-construction of knowledge.

(4) Critical theory

Disturbance to the status quo is believed to be a part of the research. The researcher's values are fundamental to the purpose and method of the

³ The etic approach assumes Western constructs and models represent the universality and cross-cultural invariance (more discussions on Chapter 6).

study. Interactions and relationships between the researcher and participants are essential. It is based on the intention to convert ignorance into 'informed consciousness' (Guba & Lincoln, 1994, p. 110; Maguire, 1987). Empowerment, equality, and democratic change are highly upheld in this paradigm. Social justice is the core of this paradigm.

The continuum from positivism to critical theory depicts the developmental process of knowledge creation. The developmental process is influenced by the macro and micro dynamics of the social, cultural, political, economic, and historical context of the society. Ideally, an accountable community collaboration consists of the positivist's openness to deal with biases, the postpositivist's realism to inquire naturalistically, the constructivist's quest to reflect upon reality in multidimensional angles, and the ground of social justice which is founded upon critical theory. However, in developing nations, the underpinning paradigms for most knowledge creation process predominantly incline towards positivism and postpositivism, including many social science studies. Constructivism and critical theory are not usually given much emphasis, especially if the outcomes are incalculable. Researchers are not encouraged to inject their experience while they conduct their studies. Funders are still very interested in big data studies which can be quantified, especially since most of the stakeholders are from the fields of natural science, medical, and engineering. Thus, knowledge creation is heavily laden with positivism, and some with postpositivism. In other words, the spectrums of social justice and relativism are missing in our world of knowledge creation. As a result, the forms of community collaboration would likely rest, not on the interest of the community, but on the expectations of the funders, the researchers or the relevant stakeholders.

Existing Types of Community Collaborations

Based on observation, there are four types of community collaboration (summarized in Table 2.1), or perhaps more, which are researcher-driven or high-authority-driven:

- (1) outcome-based collaboration
- (2) experimental-based collaboration
- (3) active initiator and passive community members collaboration
- (4) participatory research collaboration without social justice base

Table 2.1 Types of community collaborations

Types of Community Collaboration	Emphasis on	Lack of Emphasis on
Outcome-based	<ul style="list-style-type: none"> ✓ General health status among community dwellers ✓ Informing policymakers ✓ Big data 	<ul style="list-style-type: none"> ✓ The variations among the community dwellers ✓ Intervention or change ✓ Community dwellers' experience and culture
Experimental-based	<ul style="list-style-type: none"> ✓ Gauging the effectiveness of a program/ intervention ✓ The outcomes of pre- and post-intervention 	<ul style="list-style-type: none"> ✓ Whether the pre- and post-assessments are culturally relevant ✓ The experience of the participants
Active initiator and passive community members	<ul style="list-style-type: none"> ✓ Initiator is more knowledgeable than the community members ✓ Initiator works for the community 	<ul style="list-style-type: none"> ✓ Engaging community ownership in the project
Participatory research collaboration without social justice base	<ul style="list-style-type: none"> ✓ Program or intervention is prioritized ✓ The values of conducting participatory research ✓ Reflection 	<ul style="list-style-type: none"> ✓ The process of engagement ✓ Social justice ✓ Sensitivity to the community's culture

The commonalities among the four high-authority-driven community collaborations are that the high authority works for the community, empowerment is not emphasized, initiator dominates the collaboration, and it is outcome-centred. The development of existing community collaboration is still predominantly hinged at positivist and postpositivist paradigms, with a slight inclination towards constructivism.

When the reflection and experience of researchers, the relationship with the community, and social justice are not valued in knowledge creation, community members can easily be treated as targets for measurement. The power imbalance between the initiators and the community members is ubiquitous and yet is often left unchecked. Therefore, understanding community collaboration in the context of knowledge creation, it explains why different types of community collaboration are conducted without the basis of social justice. Contrary, social justice should be the basis for all studies and community collaborations.

Pursuing Community Collaboration That Fits

With the current cultural contexts, institutional system, and availability of human resources, the diverse forms of community collaborations are inevitable. To turn initiator-driven community collaboration into community-centred collaboration requires shifting the paradigm of knowledge creation. Particularly, community is not a laboratory setting. Its reality is relative and multidimensional. The paradigms of constructivism and critical theory should be the foundation. This would involve changing the expectations of stakeholders and the culture of building community collaboration (Teoh, Tan, Tan, & Chong, 2018).

For developing, diverse, and hierarchical cultural contexts, implementing a top-down standardized approach in community collaboration is common, even though it is unsustainable. A bottom-up approach, which seeks to understand the needs of the community and to expand the framework of community collaboration, would be more suitable. We seek to propose principles that guide community collaboration, either empowerment-based or community-centred. The forms and methods used in empowerment-based community collaboration can be creatively crafted according to the capacity of the community and the availability of resources. However, it should entail the principles of community partnerships. These principles are grounded in social justice. They are adopted across participatory action research in different disciplines. They include:

- Cooperative and active involvement of the community members and the initiator in establishing partnerships
- emphasizing co-learning between the initiator and the community members
- recognizing the strengths, resources, and gaps of the community to enhance capacity building
- upholding a trusting relationship(s)