

Community Engagement and Involvement in Research: A Local Experiences



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Forward

I am happy to give this message for the initiative taken by Dr. Surendrakumaran and his team. It is very creditable and the courage of the team for writing a book on 'Community Engagement and Involvement in Research: A local Experiences. Two of the Senior Lecturers attached to the Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna with the help of other the experts, have written this. And this task is undertaken at the most appropriate time.

'Community Engagement and Involvement in Research: A local Experiences' provides appropriate details and provided clear information for those seek advices to carry out Community based Research and explains how the community engagement can be obtained to conduct research and to get firsthand information with the community participation.

In the current context many researchers are trying to find the avenues of obtaining financial assistance and to have foreign collaborators. Further many researchers have problems in sustaining the collaborations and maintain good rapport with the collaborators. This book shall give some basic idea to the researchers.

In conclusion this Book shall provide some basic ideas to the researchers to initiate and develop research projects in sustainable and successful manner.

December, 2020

Prof. V. Arasaratnam,
Senior Professor of Biochemistry,
Faculty of Medicine,
University of Jaffna.

Preface

Global health research provides an opportunity for researchers in the developing world to work with researchers in the developed world. Majority of the global health research funding comes from the developed world. The nature of funding may impose the obligation for the partners from the developing world to follow high-income country researchers and agencies' agenda. Most of the research dissemination are also oriented with International Research Journals and Conferences rather than local knowledge translation. It is essential to have an equal level of power between the collaborators and the collaborators from the developed countries to understand the different cultural backgrounds of the people and the effect of the diseases. Many models for equitably shared partnership by the global researchers and agencies have been adopted to handle the issue.

The researchers got a global funding opportunity through the National Institute of Health Research (NIHR-UK) Global research on Atrial Fibrillation with the University of Birmingham and the University of Liverpool UK. The funding opportunity allowed the Sri Lankan researchers to understand the concept of "Community Engagement & Involvement (CEI)" together with the people involved in the research. The Sri Lankan research team gained extensive experience during the early implementation research on CEI. The team thought to share the experiences that could be useful for researchers involved in similar research.

The book describes the NIHR UK concepts of "Public Patient Involvement (PPI) and CEI. The details describe the adaptation of the suggested framework for the local context and the outcome.

We hope this could be a useful guide for public health and community-based researchers.

R.Surenthirakumaran

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December 2020

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Our extraordinary acknowledgement goes to the NIHR UK for the funding and the technical support by the principal investigators Professor. Gregory LIP, Professor. Neil Thomas and the Global AF research team from University of Birmingham and University of Liverpool UK. The support made us to get the project and guide us to learn the concept.

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Abbreviation

AF	-	Atrial Fibrillation
CEI	-	community engagement involvement
DS	-	Divisional Secretary
ECG	-	Electro cardio gram
FGDs	-	Focus Group Discussion
GN	-	Grama Niladhari
HCP	-	Health care provider
INHR	-	National Institute for Health Research
INR	-	International Normality Ration
LMIC	-	Low and Middle income Countries
MOS	-	Medical officer of Health
NHS	-	National Health Service
NICE	-	National Institute Health Care and Excellence
NOAL	-	Noval Oral Anticoagulants
ODA	-	Overseas Development Assistance
PAR	-	Participatory Action Research
PHI	-	Public Health Inspector
PPI	-	Patient and public involvement
QALY	-	Quality Adjusted Life Years
SSI	-	Semi Structured Interview
THJ	-	Teaching Hospital Jaffna
UOB	-	University of Birmingham
WP	-	Work Package

Chapter : 01

1. Introduction

Globally health inequalities are continuously escalating. Both high and low-income countries are faced with challenges such as ageing populations, deteriorating environments, deepening poverty and social exclusion, increasing prevalence of non-communicable and chronic diseases, new and resurgent infectious disease, and maldistribution of health. These challenges make it difficult for the countries to ensure accessibility and high quality of health services for their populations. Collaborative research provides the opportunity to learn the different strategies adopted by global partners who face challenges.

The collaboration or partnership may range from just sharing the information to getting to know each other [1] the fostering of partnerships and collaborative research have been promoted as playing a critical role in tackling health inequities and health system problems worldwide. Since 2004, the Canadian Coalition for Global Health Research [CCGHR].

Global health research collaboration creates the concept of partnership between North and South as central to the foundations of this academic field. Indeed, the collaboration should bring equal positioning of Northern and Southern actors. The partnership should ensure the autonomy and independence of each partnering entity [1] the fostering of partnerships and collaborative research have been promoted as playing a critical role in tackling health inequities and health system problems worldwide. Since 2004, the Canadian Coalition for Global Health Research [CCGHR]. Another term used for the Northern actors is “Western actors”, i.e., institutions and individuals representing the USA and Canada, Europe, Australia and New Zealand, whereas Southern actors represent low-and middle-income countries mainly from Asia, Africa and South America [2].

Some researchers criticise that most of the time the collaborations are dominated by the research agenda of high-income country researchers and agencies [3]. It further denounces that most of the research dissemination are oriented with

International Research Journals and Conferences rather than local knowledge translation. Another important allegation was that global partnerships failed to bring the expected global change to address the challenges.

Such criticisms have prompted a series of efforts and strategies to adopt different models for equitably shared partnership by the global researchers and the agencies [2].

It is important to ensure the participation of the local community in collaborative research and make them partners and help the collaborators with different languages and cultural backgrounds to understand the study. Usually, in the research, participatory research methods are used extensively to get the real insight of the community on a particular issue under investigation. But biomedical researches, developed on any specific disease should ensure the participation of the communities affected by the disease under investigation. This is especially the case in global health research.

In this process, it is good to define the community. The community could be defined in many ways.

The definition of National Institute for Health and Care Excellence [NICE], UK is as follows. “A community is a group of people who have common characteristics or interests. Communities can be defined by: geographical location, race, ethnicity, age, occupation, a shared interest or affinity (such as religion and faith) or other common bonds, such as health need or disadvantage. People who are socially isolated are also considered to be a community group” [4].

Different terminologies are used to explain the models adopted for the purpose.

Engagement, involvement and participation are the terms commonly used to describe the inclusion of the community in the research. Although these terms are used interchangeably, the words do not represent the same level of inclusion [5].

Community engagement could be defined as “a process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations, with respect to issues affecting their well-being” [5].

Community engagement is considered as a common and vital component of research, policymaking, ethical review and technology design. Most of the funding agencies and research institutions give priority for community representation and community participation. Community engagement approaches are quite useful to improve health and wellbeing and to reduce inequalities by helping the community identify their needs and by working with them to create and implement their initiatives [6].

Effective community engagement is crucial to ensure the instrumental objectives and moral ideals of scientific research, particularly research that is conducted with socially, culturally and economically diverse populations. Majority of the global health research initiatives are from the Global North, and the local researchers, practitioners, who heavily implement the initiatives are in the Global south [7].

The following listed benefits are recorded;

1. Redress past harms;
2. Dissolve long-standing mistrust and suspicion;
3. Minimise the risk of further exploitation;
4. Compensate for or resolve existing differences in power;
5. Privilege and positionality;
6. Allow for marginalised voices and experiences to be represented in the production of scientific knowledge;
7. Ensure that the research is relevant and impactful.

The advocates for engagement always emphasise that the engagement must aim to create meaningful partnerships between the researchers and those who live where research is being conducted [8].

1.1. Patient and public involvement

Another terminology used by NIHR is Patient and Public Involvement (PPI). PPI means that research is being carried out ‘with’ or ‘by’ members of the public, rather than ‘to’, ‘about’ or ‘for’ them [9].

PPI in research is an active partnership between patients and /or members of the public and researchers [6].

PPI creates an opportunity for the active participation of patients and the public, to work with the researchers, work in the research process as advisers and sometimes even as co-researchers.

Usually, in most instances, unless researchers and clinicians have first-hand experience of the illness, disease or health condition, they will face stiff challenges with the research. PPI is the best option to provide insights about the particular disease, illness or health condition to the researchers. These insights can help health researchers to plan the research studies that is more relevant to the needs of patients, care givers and service users. Active involvement of the patient and the public is a vital part of PPI. PPI in the following steps of the research is required [6].

- Prioritisation of studies
- Design and management of studies
- Data collection and analysis
- Dissemination of findings.

The term PPI covers a wide variety of individuals as well as groups and organisations such as;

- People who receive health or social care services or have received previously;
- Informal care givers and family members;
- Parents;
- Members of the general public;
- Organisations who engage in specific health conditions;
- Individuals with interest in the topic being researched.

PPI is essential because it.

- Gives alternative views.
- Gives insight into the disease.
- Helps the patients to make judgements.
- Helps the affected party to understand their condition based on the Research results.

1.2. Community engagement and ethics

All the scientific studies should safeguard the rights of the participants and should follow the basic ethical principles. Informing or consulting a wider community on the ongoing research is an additional protection to ensure the ethical conduct of the research. Informed community can act in a better way to guarantee that the researcher follows the principles of respect for persons, beneficence, and justice. They can also protect the participants from potential harm by the research, by judging the appropriateness and relevance of the research topic, by assessing if the research measures meets the standard of care, by ensuring that the research benefits are shared with the community, by supporting the activities of local research ethics committees and also by detecting and mitigating non-obvious risks [10] communities, regulatory agencies, and funders with the aim of reinforcing subjects' protection and improving research efficiency. Community involvement also has the potential to improve dissemination, uptake, and implementation of research findings. The fields of community based participatory research conducted with indigenous populations and of participatory action research offer a large base of experience in community involvement in research. Rules on involving the population affected when conducting research have been established in these fields. But what is the role of community engagement in clinical research and observational studies conducted in biomedical research outside of these specific areas? Main body of the abstract: More than 20 years ago, in the field of HIV medicine, regulatory bodies and funding agencies [such as the US National Institutes of Health].

If the researchers fail to develop the proper community involvement, the community may carefully observe the important consequences of the research and culturally unacceptable results may affect the uptake and could result in poor acceptability of proposed interventions [10] communities, regulatory agencies, and funders with the aim of reinforcing subjects' protection and improving research efficiency. Community involvement also has the potential to improve dissemination, uptake, and implementation of research findings. The fields of community based participatory research conducted with indigenous populations and of participatory action research offer a large base of experience in community

involvement in research. Rules on involving the population affected when conducting research have been established in these fields. But what is the role of community engagement in clinical research and observational studies conducted in biomedical research outside of these specific areas? Main body of the abstract: More than 20 years ago, in the field of HIV medicine, regulatory bodies and funding agencies [such as the US National Institutes of Health].

1.3. Benefits of community engagement involvement

Community Engagement Involvement (CEI) increases research efficiency in many ways. Recruitment of the informed participants is easy and reduces the non-respondent rate. The community can meet and discuss on how to continue the research and about successful completion. Dissemination of results with the support of community members will encourage the uptake of the research findings. This will minimise the wastage of resources for the implementation of the research findings. Further to this, the involvement will help the trust-building activity between the researchers and the community. The trust will be useful in managing the situation if people are affected by the research.

In global health research, researchers speak different languages and are from diverse cultural backgrounds and beliefs. Involvement of the community and frequently meeting and sharing their perceptions and understanding of research will make the researchers understand local needs and plan research that is beneficial for the local context [10] communities, regulatory agencies, and funders with the aim of reinforcing subjects' protection and improving research efficiency. Community involvement also has the potential to improve dissemination, uptake, and implementation of research findings. The fields of community based participatory research conducted with indigenous populations and of participatory action research offer a large base of experience in community involvement in research. Rules on involving the population affected when conducting research have been established in these fields. But what is the role of community engagement in clinical research and observational studies conducted in biomedical research outside of these specific areas? Main body of the abstract:

More than 20 years ago, in the field of HIV medicine, regulatory bodies and funding agencies [such as the US National Institutes of Health].

In contrast to the benefits, there are increased concerns regarding community engagement. One of the critical concerns is the possible abuse of marginalised communities, especially any research problem which is highly prevalent, organisation with a high risk of having a particular disease. The best example would be, any illness with a genetic predisposition. Targeting a specific community for the particular research issue will also result in stigmatising the community, as that community could be more vulnerable for the specific health issue or problem. Another adverse concern would be that the research process could get delayed and be unequipped to face the critical challenges in building community involvement [10] communities, regulatory agencies, and funders with the aim of reinforcing subjects' protection and improving research efficiency. Community involvement also has the potential to improve dissemination, uptake, and implementation of research findings. The fields of community based participatory research conducted with indigenous populations and of participatory action research offer a large base of experience in community involvement in research. Rules on involving the population affected when conducting research have been established in these fields. But what is the role of community engagement in clinical research and observational studies conducted in biomedical research outside of these specific areas? Main body of the abstract: More than 20 years ago, in the field of HIV medicine, regulatory bodies and funding agencies (such as the US National Institutes of Health).

While having benefits, there are also concerns relating to community engagement. One of the critical concerns is the possible stigmatisation of marginalised communities, especially any research problem which is highly prevalent, or an organisation addressing a particular disease. The best example, any illness with a genetic predisposition. Another adverse concern would be that the research process could get delayed and may be insufficiently equipped to face the critical challenges in building community involvement [10] communities, regulatory

agencies, and funders with the aim of reinforcing subjects' protection and improving research efficiency. Community involvement also has the potential to improve dissemination, uptake, and implementation of research findings. The fields of community based participatory research conducted with indigenous populations and of participatory action research offer a large base of experience in community involvement in research. Rules on involving the population affected when conducting research have been established in these fields. But what is the role of community engagement in clinical research and observational studies conducted in biomedical research outside of these specific areas? Main body of the abstract: More than 20 years ago, in the field of HIV medicine, regulatory bodies and funding agencies [such as the US National Institutes of Health].

Combining community dimension in research will improve the human subject protection.

1.4. Model of community engagement involvement

There are many models proposed for CEI in research, including community-based participator research, empowerment evaluation, participator or community action research and rapid participatory appraisal. As indicated above, different researchers define community engagement differently. In most instances it is interchangeable [11] .

Engagement of the community in research may take different forms spanning from community consultation in a specific stage of the research, to representation throughout the research's whole process and even to a long-term and more complex partnership. Depending on the need, the appropriate level of involvement could be adopted, i.e., in some studies informal discussions with the community may be enough but, if more vulnerable populations are affected, there could be cause for more formal consultations or partnerships.

1.5. How to start the process

Carrying out community engagement and involvement is not straight forward. There is no guide to follow the complicated process. There are many methods proposed to achieve equal sharing of power between the researchers and the community.

The first step of the process is to identify the community. Clear definition of the community should cover the broader aspects of the research.

Selecting the community purely based on geographic or place-based terms is the standard error implicated in public health research and global health project implementation [12].

It is critical to consider the tensions that could be created through participatory methods between differently situated actors with differing levels of power.

Considering the complexities of the process the NIHR proposed a model called ‘empowerment framework’ and ‘learning by doing’ approach [12]. The model seeks to, “mobilise community members to participate in the decision-making, planning, implementation, and evaluation of programs, with the aim of empowering marginalised groups to have greater control over the decisions” [12].

1.6. The rationale for CEI in present research collaboration

The National Institute of Health Research (NIHR), UK global health funding, aims to leverage the research capacity of institutions based in UK and Low and Middle-Income Countries (LMICs) to directly impact health and well-being of vulnerable and marginalised populations within countries eligible for Overseas Development Assistance (ODA). Considering the Sustainable Development Goals with the call of, “Leave No One Behind”, the NIHR made CEI a mandatory core component of the research strategy, planning, implementation and evaluation process for all funded projects. CEI is a priority for the NIHR in all its funding projects. Considering the complexity of and relative newness of the concept, the need for a guide was felt. The NIHR UK prepared a resource guide for community engagement and involvement in global health research. The guide proposes that the researchers adopt an ‘empowerment framework’ and ‘learning by doing’ approach [12]. The model guides the community members’ engagement as beneficiaries of the programme to improve health services delivery. It is imperative to ensure the community members participate in decision-making, planning, implementation and evaluation of the programme. The guide gives particular emphasis to empowering marginalised groups to have greater control over the decisions that most affect their lives.

The design of project activities should incorporate reflexivity and flexibility which are essential for the ‘learning by doing’ approach. There should be a slot in the timeframe of the project to set up and reflect together with community members, the members can reflex on what is working, what isn’t and how to address shared challenges.

A better understanding of the approaches is further guided by the handbook on “Participatory Action Research in Health Systems: A Methods Reader” [12].

1.7. NIHR - ‘INVOLVE’

NIHR UK established INVOLVE to support active public involvement in NHS, public health and social care research [13]. INVOLVE defines public involvement in research as being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. The definition includes working with research funders to prioritise research, offer advice as members of a project steering group, comment on and develop research materials, understand interviews with research participants.

INVOLVE elaborates that the term ‘public’ includes; patients, potential patients, care givers and people who use health and social care services as well as people from organisations that represent people who use such services.

INVOLVE also clarifies that the terms involvement, engagement and participation are distinct, but often linked and can complement each other [5], [14].

Table 1.1.: Definition and examples of terms involvement, participation, engagement by INVOLVE.

Involvement	Participation	Engagement
<p>Def: where members of the public are actively involved in research projects and in research organisations</p> <p>E.g:</p> <ul style="list-style-type: none"> • as joint grant holders or co-applicants on a research project • involvement in identifying research priorities • as members of a project advisory or steering group • commenting and developing patient information leaflets or other research materials • undertaking interviews with research participants • user and/or carer researchers are carrying out the research. 	<p>Def: Where people take part in a research study</p> <p>E.g:</p> <ul style="list-style-type: none"> • people being recruited to a clinical trial or another research study to take part in the research • completing a questionnaire or participating in a focus group as part of a research study. 	<p>Def. Where information and knowledge about research is provided and disseminated</p> <p>E.g:</p> <ul style="list-style-type: none"> • science festivals open to the public with debates and discussions on research • open day at a research centre where members of the public are invited to find out about research • raising awareness of research through media such as television programmes, newspapers and social media • dissemination to research participants, colleagues or members of the public on the findings of a study

Source: INVOLVE NIHR UK [14]

1.8. Rationale to assess the involvement with standards

Research teams should always try to understand how good public involvement is, if there is enough public involvement in the ongoing research activity and if enough is being done. Researchers should always want to improve or evolve the process. So, there is a need to have standards or framework for the evaluation and reflection. There are many frameworks available for this purpose from NIHR and others.

Based on the standards and guidance, the research team can plan the community engagement and involvement activities.

The representatives from important research and public health agencies of Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (Northern Ireland) and the National Institute for Health and Research (England) got together and established the UK Public Involvement Standards Development Partnership in July 2016. The following six key standards were identified for the community involvement in research

1. Inclusive Opportunities
2. Working Together
3. Support and Learning
4. Governance
5. Communications
6. Impact

1.8.1. Inclusive opportunities

Diverse public opinion is essential to understanding the real issues in the community. The communities that are prone to the diseases under research should be given broader opportunities of access to participate in the research. Research should cover the diversified public experiences and insight to understand the research needs that will be useful for the treatment and services. The key standard development team identified specific questions for the research teams to reflect whether they achieved the involvement process.

The following standards will help to reflect on the achievements made by the research team:

- Early-stage involvement of people interested in the research and affected by the research;
- Identifying and addressing the potential barriers to involvement, such as payments for time or accessible locations for meetings;
- The ways adopted to share the opportunities and whether it appeals to different communities;
- Whether people are included in research through fair and transparent processes and whether it reflects the equality and diversity duties?
- Availability of choice and flexibility in opportunities offered to the public

1.8.2. Working together

In a participatory kind of work, the great challenge is in power-sharing. Valuing the contribution provided by the community will help to develop a mutually respectful and productive relationship between the researchers and the different actors of the community. The relationship will create an environment of working together and respect for each other. It could be reflected in terms of whether; public involvement was jointly defined and recorded, whether the practical requirements and arrangements for working together was addressed, if the potential different ways of working together was explored and whether it was jointly planned and decided, whether there is shared understanding of roles, responsibilities and expectations of public involvement and whether individuals' influence, ideas and contributions are recognised and addressed.

1.8.3. Support and learning

There must be an inbuilt planned arrangement to identify the learning needs of the community that would help build their confidence and skills. This will further help to remove the practical and social barriers in the active involvement of the people. The research team should evaluate whether the community involvement programme can address the following:

- The available range of support to address the identified needs;
- Allocation of designated support learning and development opportunities for both the public, researchers and staff;
- Public awareness regarding where to seek information and support about public involvement
- Availability of the culture of learning by doing, building on and sharing that learning with researchers, staff and the public

1.8.4. Governance

Public involvement in the research governance which comprises, research management, regulation, leadership and decision making to improve the transparent conduct of research and achieve trust in the research implementation and outcome. This could be assessed by looking at the following aspects:

- Evidence of public voices heard, valued and respected in every aspect of the research;
- Regular monitoring, reviewing and reporting of public involvement plans;
- Availability of visible and accountable responsibility for public involvement throughout the organisation;
- Allocation of realistic resources (including money, staff, time) for public involvement;
- Protect the privacy of the personal information by collecting and using it in a suitable way.

1.8.5. Communications

Successful comprehensive involvement of the community highly depends on how the community is communicated with, by using a broad range of accessible and appealing approaches. Involvement plan and activities should include the details of the communication, language to be used and when to use it. Following criteria were suggested to see whether the research team meets the standards:

- Including the communication plan in the involvement activities;
- Addressing the needs of different people through inclusive and flexible communication methods;
- Processes in place to offer, gather, act on and share feedback with the public;

- Sharing both positive and negative learning and achievements of the public involvement.

1.8.6. Impact

Understand the changes, benefits and learning achieved from the insights and shared by the patients, carers and the public. The research team should pursue improvement by recognising and sharing the changes that public involvement brought to the research.

The following will guide to reflect if the standards are met:

- Ensure the public's involvement in deciding the aspects and approaches to be focused in the impact assessment;
- Assess impact through clear identification of information to collect, person involved and method used to collect the information;
- Act on the changes, benefits and learning that results from public involvement.

Chapter : 02

2. Background

After the success of obtaining the grant from the National Institute for Health Research (NIHR) UK, Global Health Research Group on Atrial Fibrillation Management, University of Birmingham was formed in April 2018 and is led by Professors Gregory Lip and Neil Thomas and a team of academics from University of Birmingham (UOB) UK.

Partnerships with three LMICs – Brazil, China and Sri Lanka were developed. The partnership helped to share the knowledge and experience of UOB with the partners in these countries to develop tailored research to improve Atrial fibrillation (AF) management.

AF, the most common arrhythmia globally, is a major cause of morbidity and mortality but is often under-diagnosed and inadequately treated. The collaboration is planned to build and establish long-term, sustainable partnerships. This will allow the countries to increase research capacity and AF education/awareness amongst key stakeholders (patients, families, healthcare providers and commissioners) in these countries through co-developed, culturally-adapted, community-based approaches. The program is planned to deliver locally-focused evidence-based research investigating developments of pragmatic patient pathways to generate further funding opportunities. This research would facilitate models of best care to reduce healthcare inequalities by improving the well-being and health outcomes of patients with AF.

Further, it is proposed to co-develop community-based research to increase awareness and management of AF patients in underprivileged communities to improve their quality-of-life and greatly reduce inequalities and AF burden and meet UN Sustainable Development Goals 3, 8, 10.

2.1. Co-developed objectives and work packages

Co-developed objectives:

1. Develop & consolidate sustainable collaboration, shared vision and links with patients policymakers to sustainably improve local services

2. Strengthen community-based research culture, including public involvement (PPI), and capacity to improve our AF understanding and improve health outcomes
3. To adapt, with PPI, and assess feasibility of prioritised evidence-based sustainable pharmacological and behavioural approaches for integrated AF management within the resource confines of local health systems
4. To develop, with PPI, and test feasibility of culturally-adapted, community-based approaches to increase education/awareness and to provide sufficient knowledge (patient, families, health care practitioners) about AF and its complications to empower patients
5. To provide evidence and develop local models of best care for local policy makers to improve well-being of AF patients and provide a template for extending this work to other chronic conditions
6. To build a sustainable research platform within partner countries for future collaborations

Work packages

Four Work Packages (WP) developed to implement the objectives.

WP 1: Current knowledge and state of AF management:

Systematic review of previous studies to understand ‘local’ approaches to AF, eg IMPACT-AF. Two focus group discussions with AF patients and health care providers (HCPs, n=6-10/group) in each country setting to understand barriers to awareness, detection and implementation of stroke prevention strategies. Partner countries will document current AF management pathways and access to care.

WP 2: Stroke and risk factor control and symptom management

WP 3: Behavioural interventions to improve AF management

WP 4: AF decision modelling

2.2. Country level implementation

The research proposal further explains the country level implementation. After developing the themes and packages based on the objectives developed for the grant proposal application by the local team with the support of UOB team

and the international advisory group, the country level prioritisation, will be consulted with local policy-makers, healthcare professionals and AF patients to consider different dimensions (fit with local policy goals, perceived importance among local AF patients & clinicians, logistic complexity of delivery, technical feasibility, available resources). Findings will be presented and a final decision made in consultation with all co-applicants and input from international advisory groups. Final decisions will also be discussed with the local community and their views will be incorporated. Also, all the projects would be planned to adopt mixed-methods (quantitative & qualitative) and include a health economic modelling (eg measurement of resource use/health benefits, WP4), with the patient and public involvement/advice (eg patient groups including AF Association, Stopafib.org). These aspects should also be planned to be adopted in the country-level planning and build the country level teams' capacity to carry 'added value' to LMICs with training and research opportunities.

2.3. Sri Lankan team and the research projects

The Northern province of Sri Lanka, currently recovering from a devastating civil war which spanned over 3 decades, has minimal data on its health status. The prevalence of many illnesses is unknown including AF, although a significant portion is likely to be related to valvular heart disease given the prevalence of chronic rheumatic heart disease.

Teaching Hospital, Jaffna is the only tertiary care hospital in the Northern Province caring for a population of >1.2 million, taking referrals from all five districts in the Northern Province. It is a 1,236 bedded hospital, catering for 4500 patients a day. Warfarin is the only anticoagulant available, and monitoring with International Normalised Ratio (INR) is available only at district main hospitals. None of the Noval Oral Anticoagulants (NOAC) is available in Sri Lankan state sector hospitals.

Sri Lankan team consisting of five research team members identified three thematic areas to achieve the Global AF group's research objectives. The National Intensive Care Surveillance-Mahidol-Oxford Research Unit (NICS-MORU) team also supports the Sri Lankan team.

2.3.1. Theme one

The objective of the theme is to evaluate AF prevalence, risk factors and the feasibility acceptability/cost-effectiveness of different case-finding strategies and subsequent care pathways among adults in the Northern Province.

The objectives are planned to be delivered in three work packages:

Work package 1 (WP 1):To determine the prevalence and risk factors associated with AF among the adult population in the Northern Province, Sri Lanka.

Work package 2 (WP 2):To model and compare the cost-effectiveness of three case finding strategies for AF in Northern Province, Sri Lanka.

Work package 3 (WP 3):To determine the usability and acceptability of a smartphone based AF case-finding strategy amongst health care providers and recipients.

2.3.2. Theme two

Theme 2: Streamlining the management of atrial fibrillation using a mHealth real-time decision support platform in the Jaffna District: a feasibility study.

The project includes the mapping of the existing care pathway and creates IT-based mhealth platform to develop an efficient care pathway between the primary care and secondary care (cardiology clinic) for AF and assess the feasibility and acceptability by the stakeholders.

2.3.3. Theme three

An investigation of atrial fibrillation management in a hospital setting.

A retrospective and prospective study will be carried out to describe the demography and risk factors of patients with AF attending clinics at Teaching Hospital Jaffna (THJ).

Identify proportion of patients who have had a CHA₂DS₂-VASC score and HASBLED score documented. Calculate the risk scores for all patients and audit appropriateness of initiation of anticoagulation.

2.4. Details of work package one

It will be a cross-sectional descriptive study through household surveys in the Northern Province of Sri Lanka. The study population will be non-institutionalised permanent residents of age 50 years and above in the Northern Province. The study will recruit 10,000 participants using multistage cluster sampling. The data collecting instruments will be interviewer administered questionnaire and smart phone-based single lead (Lead I) ECG Electrodes called AliveCor. An IT platform will be developed to collect, store, retrieve and exchange real-time data to minimise inaccurate entries. Statistical analysis would be carried out using the Stata 14 or SPSS Version 20 software. A direct standardisation technique will be used to obtain Province level prevalence data from the District level results. Data analysis will include descriptive statistics to report prevalence of AF, associated comorbidities & risk factors and multiple regression analysis to estimate the strength of the association with AF.

2.5. Details of work package two

This package will model and compare the cost-effectiveness of three case-finding strategies (systematic population-based screening, systematic targeted screening and opportunistic screening strategies) for AF in Northern Province.

The systematic population-based case-finding strategy will be directly based on the data obtained from the household survey in **WP 1**, where essentially all participants are screened.

The other two case finding strategies will be modelled based on the information obtained from the WP 1. For targeted screening we will use information on risk factors and assess the best option to define the target population. For example, this may be people with more than one risk factor or have a high CHADS-VASC risk score. For opportunistic screening we will use information on attendance to health care facilities in the last year and estimate the effectiveness of an approach to only screen those patients attending these facilities.

This work-package consists of two distinct parts: study-based cost-effectiveness analysis and a model-based cost-effectiveness analysis. Study based cost-effectiveness analysis will be performed alongside **WP 1**. It will be an incremental approach which will assess the additional costs and benefits associated with each case finding strategies. The cost of case finding methods will be the sum of

expenses in-relation to the respective strategies and out of pocket expenditure by the patients. The out of pocket expenditure will be estimated by administering patient cost questionnaire to a selected number of patients who attend the AF clinic conducted by cardiologist at the Teaching Hospital Jaffna, described in the introduction section.

Model-based analysis or long-term analysis will be carried out through Markov model which will be constructed to determine the long-term costs and outcomes of alternative case finding strategies. The model structure will be informed by reviewing previously published modelling studies and eliciting opinions from clinical experts. The model will determine the cost per life year gained and cost per additional Quality-Adjusted Life Year (QALY) gained for each alternative case-finding strategy. The Markov model is the most appropriate decision analytical model type for this analysis. The model can represent a clinical situation where patients change health states or experience recurrent events over a long time.

2.6. Work package three outline

The package includes a descriptive qualitative study to determine the usability and acceptability of a smart phone-based AF case-finding strategy amongst health care providers and recipients. The qualitative study will consist of Semi-Structured Interviews (SSIs) Focus Groups Discussions (FGDs). The focus group discussion will cover the following topics: user-friendliness of Alivecor, and confidence with the results obtained from Alivecor.

2.7. Process of developing and finalising the themes and work packages

The initial international meeting was held in July 2018 at UOB with the participation of the UOB research team, international advisors, collaborators and representative from the funding agency. Research team of each country worked out the initial country-level themes and discussed with the meeting participants. Initial themes were finalised. Initial finalised themes are presented in annexure (Annexure 1). After developing the themes, Sri Lankan team developed a country level mechanism to get the community involved to develop and improve the themes based on the local needs and experiences. Following methodology was adopted to get the public involvement in the research based on INVOLVE, NIHR UK and CEI guide NIHR.

Chapter : 03

3. Methodology

The research team followed the guidance provided by the NIHR guide for patient and public involvement in health and social care research: a handbook for researchers [6]. Involvement of the public would be facilitated by following these research steps: Identifying & prioritising the research problems and issues, design the study, development of the grant proposal, undertaking and managing the research, analysing and interpreting the results, dissemination of the findings, implementation and monitoring and evaluation.

This document describes the community involvement on an ongoing basis for research. The document describes the role of community involvement and engagement in identifying and prioritising the research problems and issues, design of the study, development of the grant proposal and undertaking and managing the research.

3.1. Defining the community

Based on the themes developed in the first partnership meeting at UOB, the Sri Lankan team considered the following features in defining the term “community “ for the research:

1. Sociodemographic and economic factors: age, sex, geographical location, race, ethnicity, religion, occupation, place of work, person or family member with disease/ risk factors for AF, hypertension, diabetes, stroke etc.;
2. Health service workers, social service workers and administrators;
3. Non-governmental organisations: national, local, religious and community-based;
4. People representing the disadvantaged community; mothers clubs, disabled peoples organisations, elders clubs etc.;
5. People interested in AF, hypertension, stroke, diabetes, cardiovascular diseases;

The following factors were considered in the selection of the above groups:

- a. Diversity
- b. Equality
- c. Experience
- d. Involvement

3.2. Mapping the community partners

Important part of community engagement and involvement is identification and mapping of possible partners. Community consists of many kinds of parties who differ in their levels of power and interest. Usually, the voices of powerless people are not heard in the forums, their interests are not considered in designing the projects, but these are the more vulnerable people. By carefully identifying and mapping the community members, the interest levels of different stakeholders could be understood. This will help to design the project to empower the target group of the research.

A two way approach was adopted. While simultaneously working with the bottom up approach, top to bottom approach was also adopted to get the support of high level officials such as decision makers, administrators and professionals. This helped to manage the power dynamics which could affect the public involvement and research. To identify the key people personal meetings and professional discussions were arranged. This was really helpful in identifying the key people to engage in the research at an early stage of the development of the research proposal. The team was very keen to not to miss any relevant and important community partners. Having considered the needs, the potential organisations were listed and the focus group discussions and brain storming sessions were arranged to identify all the possible community partners. Then a profile was developed for every community partner who revealed their interest areas. The snowball mechanism was also adopted to identify more relevant people with the support of the people who had already started to work. Community partners were categorised into private sector, public sector and civil society stakeholders. The categorisation was helpful in preparing the complete list of people for identification. The list has been updated periodically with the input of the community. Details of the people identified for the involvement is annexed **(Annexure 1)**.

3.3. Developing communication

While preparing the list of people to be invited for involvement in the research, the team started to plan effective communication methods to ensure the involvement of the identified groups. This was essential in getting the target groups to agree to be involved and also to encourage their active involvement. Further, communication plan is important in identifying the required resources for public involvement.

3.3.1. Use of templates to invite community partners

Different strategies were used to invite different types of public. According to the categorisation - private sector, public sector, Land civil society members - a sector-specific approach was developed. Periodical monitoring and evaluation of the plan was developed based on the method of reflexivity and flexibility, as suggested by NIHR. First, we tried to create an opportunity to interact with people. After initiating the interaction, measures were taken to develop a good rapport with them. The team tried their best to understand their perspectives, such as; their level of understanding of the problem, ability to understand the language and their knowledge etc. Based on that, different types of templates were developed to invite their involvement in the research.

For the government officers like Divisional Secretaries (DS), Grama Niladhari (GN), Medical Officer of Health (MOH), and Public Health Inspectors (PHI), a group who are key social and public health officials that make essential decisions at divisional and village levels, the team, offered to provide a few health promotion activities for their staff and the community they work with. A stress management programme was also introduced with trained volunteers and incorporated it with the health promotion programme. During the programme, the health issues were discussed, and tried out the best to help the community by mobilising the necessary resources or connecting the needed people with the relevant resources. Through this process, the research topic was gradually introduced by discussing the economic burden of non-communicable diseases such as heart attack, diabetes and hypertension and the possibility of preventing the complication by early detection and treatment. It was also emphasised that the treatment will improve

the quality of life, and that patients could carry on with their day to day activities without any difficulties. It was observed that community response – verbal and nonverbal cues - based on their feedback, communication templates were modified. The team also found that most people were not aware of Atrial Fibrillation (AF), but they were concerned about stroke, so our template discussed stroke and then moved on to the need to detect AF for the prevention of stroke. It was also emphasised that how the early detection will improve quality of life and how that will enhance productivity and contentment.



Photos: Community sessions to prepare templates

For the private sector partners, mainly non-profit sectors, the team approached them through some field health programs. Some health education dramas were conducted and the volunteers from nearby villages participated in these dramas. These programs were successful tools to educate the audience and actors. At the end of the drama, a discussion was initiated; through which the ideas were exchanged. This helped to build trust with the people. Then the importance of

early diagnosis and prevention of complications were discussed. An idea of the issues that the community face were obtained and instructed them on how to improve the management of the patients in the community. Community and Family Medicine website and YouTube videos that offer many health education and learning materials were introduced for the general public. Social media groups were created to interact with each other about health issues, especially AF and its risk factors. This process helped them to contribute in the development of the template to invite more people for involvement. Their continuous contribution through social media was used to update the templates.

An increasing number of people and patients were reached with the help of forum discussions. A couple of interactive sessions were conducted with five identified community groups. Healthy food habits were discussed for the existing community groups like patient welfare society, elders club and volunteers of the community centres. This was an interactive session to understand their food habits and the factors influencing it, especially the availability and accessibility of the food and other services. The process again helped us to build relationship and created a platform to understand each other more. The officials who were already in the network with the groups were connected to support their needs. The discussion was concentrated on the food habits of the people, the current food habits were discussed and an imaginary exercise was conducted about a healthy future with healthy diet and lifestyle. Relationship between healthy food habits and reduction in the occurrence of the non-communicable diseases were clearly explained. The community has a basic idea about fatty, unhealthy foods. Most of the participants were aware of the benefits of a healthy lifestyle and disease prevention, however, their main problem was to maintain sustainable behaviour changes. The possible solutions were discussed and also provided learning opportunities to gain knowledge. Community input was also included in the template. In relation to food and disease prevention, the feedback were obtained and improved the template for invitation. In the subsequent sessions, with a better understanding, their views further were discussed on the prevention of cardiovascular diseases, and healthy lifestyle. Possibilities of preventing the complications were explained through some interactive sessions. The community

members became fairly convinced and also discussed the problems they face in the community to adopt preventive measures, especially highlighted were the issues in the availability of services and utilisation. Based on the discussions the templates were developed to invite more people from broader geographical areas.

3.3.2. Template role and description

Using a template makes communication easy and effective [6]. Different community members have different levels of knowledge and experiences. The communication template was carefully designed with the support of people from the different sectors as described above. The templates were updated periodically with feedback from the people. Few of the members from the community sector also helped us modify the templates. For the success of the project, necessary information should be clearly communicated to the relevant parties and it should be precise. Otherwise unnecessary information can lead to misunderstandings and fear among the invitees. Especially in this part of the world, the research studies are very minimal as the Northern Province was severely impacted by the civil war of more than thirty years. The people also face many challenges to run their day to day activities. Communication absorption mostly depends on the oratory skills of a person, so it is very important to select a suitable person to provide the necessary information with the aim of achieving maximum reach and impact. Having an appropriate template will support effective communication and thus facilitate better grasping power.

Communication with the government sector staff was carried out by the logistics coordinator. She is a doctor with clear communication skills. Government staff were mostly concerned about the economic impact of the diseases. Welfare expenditure of the government mainly goes to the health services. By providing an effective preventive health care service, curative and palliative health care service expenditure can be cut down. By understanding the age of onset of these non-communicable diseases, the impact on the productivity of the staff was made clear. Emphasis was made on the usefulness of the preventive approaches to improve the quality of life of the patients and improve economic productivity. The template we used to communicate with this group, conveyed these messages clearly and was able to convince them to get involved with us. Increasing the

interest of the government staff made the process of conducting the research easy. Many were convinced and offered their support and the Grama Niladharis helped in identifying the volunteers. These youth volunteers helped us to identify the participants and to introduce our data collectors to them. This step increased the trust and consent level of the participants.

Relationships with the private sector staff mainly non-profit organisations like, Green Memorial Hospital staff, was handled by the community engagement team. Staff who were directly dealing with patient care were targeted. Then added burden caused by non-communicable diseases were communicated, as in most cases the burden is already heavy. So, staff already knew the effects of these diseases on the quality of life of the patients and the time spent by the relatives of the patients for the care of their loved ones. Hence, preventing diseases like stroke was very much desirable for them and this helped to get their active involvement in our research. They helped to identify the patients to develop and pretest the questionnaires. A template was developed through the communications that had with participants. This template proved useful in communications with other relevant private sector partners.

Communication with the community members were handled by the youth volunteers. Previous experience they got from social work also helped the volunteers to understand the different perspectives of the community members. Community members wanted to include the low educational level and cultural beliefs of the villagers into the template. The volunteers were also from the same social background, so they provided valuable input to understand the existing beliefs and thus correctly interpret the response. The communication was planned around the food habits and healthy lifestyle. The volunteers came up with the idea of doing an organic home gardening to support healthy food and lifestyle plan. Benefits identified by the community members included getting enough supply of fresh vegetables without any contamination of toxic agrochemicals, increased physical activity and building family harmony.

The template which was introduced by NIHR for PPI was used. It has the following structure; **Title/ Headline, key questions, background of the study, what this means for people getting involved, roles and responsibilities of**

user representative (duties, qualities, essential criteria, desirable criteria, remuneration, support), **further details and contact information**. English and Tamil version of different templates prepared after the consultation annexed with the book. (Annexure 2)

3.4. Making links

Many paths to invite people for involvement in the research; government officers like DS, GN and their supportive volunteers, clinicians at rural hospitals and teaching hospital, Jaffna, research participants and community forums were used.

Government administrative structures have a very good network within the community. The officers have lists of active social services and community oriented organisations. As a first step the Divisional Secretary was contacted and the relationship was built. Divisional Secretary is the top Administrative Officer at Divisional level of a District Administration. The cordial relationship with the Divisional Secretaries would be very useful in expanding the network and inviting people for involvement. As described above, in the early part of the research and template development, support was given to organise a Health Education Program and a COVID 19 Prevention Program. The Divisional Secretary had a good awareness and understanding about the Project. Provincial Director of Health gave a recommendation letter for this project and a recommendation letter from the District Secretary was also obtained as well. Then every Divisional Secretaries were contacted and through them the support of Grama Niladhari (GN) were obtained, subsequently, through the help of the GN the volunteers were obtained. Potential partnership organisations and participants were contacted with the help of the volunteers.

Doctors from the local Hospitals and Cardiologist at the Teaching Hospital, Jaffna were engaged in the development of the research. AF patients and other cardiac disease patients were connected with the research through these doctors. Cardiologists and other clinicians were involved in the creation of the questionnaire. Cardiology Clinic patients were recruited for the pretest under the guidance of the Cardiologists. Feedback given by the Cardiologists was useful in improving the questionnaire. Local hospital patients were also recruited for the

pretesting. Thereafter, the pilot study was carried out in five Divisions with the support of DS Offices and local hospitals.

Participants who were recruited for the research were of great help. Many local organisations and supportive social groups were identified through the participants. While collecting the data, the data collectors identified the supportive participants. The supportive participants are the people who wish to protect others from the disease. They worked together with the research team to promote healthy food habits among other participants.

Forums conducted with Patient Welfare Societies, Farmer Organisations and other Community Organisations helped the research team to bring forth the different worldviews of Community Members. In these forums food habits were discussed, and inquired about current and possible future food habits. These forum discussions encouraged other community members to engage in the discussions. Oppressed people of the community were given chances to express their opinions. When they were given the opportunity, they became more actively involved and engaged.

3.5. Developing involvement and engagement plan

Community engagement and involvement was planned on the methodology of Participatory Action Research (PAR). PAR is a Public Health Research Methodology. PAR overcomes the separation between subject and object, thus the researcher is part of the affected community or a facilitator of the change process in the affected community. Collective inquires, reflection and cock-screw cyclical discussions were done to determine the actions to be done with researched population which will help to study the population and align with the common theme. The 2nd part of the common theme is changing the world through the findings which were gathered through the discussions [15].

3.5.1. An effective research method in public health

Public health is determined by several factors such as biological, psychological & economical dimensions and social and/or power relationships of the population. For example, in 3rd world countries, poverty is the main determinant of the health

status of the population. Low economic status is a barrier for gaining knowledge and skills. Lack of awareness and poor skills leads to improper practices, which paves the way towards a vicious cycle of communicable and/or non-communicable diseases amongst the impoverished community. Therefore, the success of public health research depends on understanding the influencing factors of the health status of the population. In the 2008 report of the Commission on Social Determinants of Health [16], significant evidence shows that social processes and differentials in power and resources contribute to health outcomes. PAR approach gives the researched population an opportunity to become researchers by empowering them to find a solution which is suitable to their local context. This approach was addressed in recent health related studies as the most effective and efficient in transforming or adapting the researched population to the new paradigm [17].

3.5.2. PAR process

Participatory action research is a spiral of repetitive cycles. The new learning from actions and real life experiences become the input for the new round of collective, self-reflective inquiry which is broadly categorised into five phases - systematising experience, collectively analysing and problematising, reflecting on and choosing an action, taking and evaluating action and finally systematising learning. It is an adult learning technique where the action (by doing) and reflection (while learning) goes together and leads to transformation and/or adaptation to the change [18].

Empowering the researched population helps not only to break the vicious cycle of the local contextual issues, but also gives tailor made sustainable solutions as well. Action and reflection technique of adult learning is goal-oriented towards a change, therefore, PAR can be used for cognitive and behavioural changes. Apart from finding solutions, this way of learning develops and enhances the human values, teamwork, unity, power dynamics as well as resources and psychological relief through empathy.

PAR is an effective research method for public health because it aims for a change in societal power as the control of knowledge creation and shifting the action

towards those affected by problems, thus leading towards long-lasting change.

Thus, the research targets the vulnerable society and brings them to the forum and empowers them to reveal their worldviews. Patients and marginalised societies were encouraged to join the discussion, where they discussed their issues and identified the problem. They developed the transformation they wish to achieve in the future. Different ideas were generated and a few were selected and analysed for their desirability and feasibility. Finally, a plan was made to implement the ideas through iterative cycles of learning

3.6. Implementation

After all the arrangements, implementation mechanism was developed with the support of research team members and research fellows recruited for the study. Initially, there were only two members of the public who were already involved with the team in the previous projects. Through our initial programme and through patients and their relatives, we were able to get a few more active members.

With the original group an implementation team was formed. A Research Fellow was appointed to coordinate the activity. The Research Fellow was supported by a trained nutritionist and a few professionals. Two community members representing the poor socio-economic strata were identified.

Communication mechanism was then developed. A social media group was formed to share their activities. Regular reporting about the activity was done by the research fellow. Few of the community members were from the age group that is unfamiliar with technology, hence, they had issues with handling social media. Hence, we used mobile phones to keep them involved in all the aspects of the research.

CEI activities were discussed in the weekly research progress meetings. Research team provided their feedback on the activities. Once in a month, community members were also invited for the meetings to give their observations and feedback about the research. The Team currently works with the CEI team to develop a sustainable prelateship. The phase one research one data collection has been completed, phase two data collection is to be done in a few months. It is very

important to keep the patients engaged with the research team. Research team also plans to build a long term programme with the community. Few important programmes have been identified. One of the observations of the team, was that community was keen on eating healthy food, but they had a lot of barriers. So, the team decided to work with the community to help them overcome the barriers. The home gardening project was to be implemented and this was a successful programme. The second important issue identified by the community was stress management and suicide prevention. The team introduced a programme that is locally acceptable, awareness through drama. The project was supported by the staff of the Charity Hospital and discussed the prevention and control of non-communicable diseases.

The ongoing activities need to be expanded with the support of the CEI from other areas. The team is now working on it.

3.7. COVID19 pandemic and implementation

During the implementation, the activities were interrupted by the COVID19 pandemic situation. During the months of March and April 2020, the whole country was under lockdown. The CEI members initiated education for the community on COVID 19 and they were working with the local health authorities in the contact tracing and quarantine process. They were also helping to run the 24-hour Hotline Services for the public to get services related to COVID 19. They also helped to deliver food and other essential items to the community. The experience was very helpful for the research team to continue the data collection during the COVID 19 pandemic. After the lockdown, there was a COVID19 free period. During that time, a lot of materials related to COVID19 education was prepared and shared with the public. When the second wave of infection started, it was very useful for the team to maintain the necessary precaution and work with the community. The community also accepted our data collectors collaborating with them. This was a very good experience.

Currently, data collection is happening without any major issues, this is possible only due to the successful CEI activities.

Chapter : 04

4. Experience in Community Engagement and Involvement

The success of this study depends on the active involvement and engagement of participants and relevant stakeholders. This, however, is not a straightforward task, hence, it is crucial to implement an appropriate trust-building activity to obtain active engagement and involvement of participants and stakeholders. Building that trust will not only help to conduct the current study effectively but also open the way forward for a potential cohort study in the future as well. Participatory Action Research (PAR) will be conducted to achieve the objective of the study. Community Engagement and Involvement are the two actions which contributes to PAR plan and that is integrated into all stages of the survey from the beginning of concept development for this study.

4.1. Research concept development

Community representatives such as Grama Niladari (GS / GN), Public Health Inspector (PHI), elderly people from the community and patients were considered as stakeholders. The stakeholders were formed into small groups based on their characteristics. The study started with a discussion with the stakeholders about the burden of cardiac diseases, stroke and its influences on quality of life. The participants queried about the ways of prevention and its benefits. A lot of interest was shown on prevention of disease. The suggestions for prevention from the participants comprised; intake of healthy food, regular exercise, regular follow-up and early detection or screening. Health professionals amongst the participants recommended early detection to delay the onset of complications.

The reason for stroke was explained as a complication of atrial fibrillation (AF). Early detection of AF and starting appropriate pharmacological and non-pharmacological management were illustrated as management strategies by the researchers. It was pointed out by some of the doctors amongst the participants that Electro Cardio Gram (ECG) facility is not easily handled and they queried about the situation in local hospitals. As a solution, after consultation with the health professionals and the patients, a single lead ECG device was selected based on its user friendliness. A community survey was formulated to identify the prevalence of the AF and to see the cost effectiveness of the single lead ECG device for early detection. At the end of the discussion, the groups promised to give their support for this project.

4.2. Questionnaire development

A questionnaire was developed for a community survey, based on the popular discussions among these groups. It was translated with the help of Mr and Mrs Balasingam, who are the patients at the Primary Care Centre. The questionnaire was modified to a more user-friendly version after considering the feedback of the patients.

4.3. Pre-test

The translated questionnaire was pretested with selected participants from Cardiac Clinic and Community Settings. The participants were selected based on various socio-economic, educational and cultural backgrounds. Each respondent was requested to debrief their understanding of the questionnaire and experience during the interview. During the debriefing, understanding of the respondents on the questions and the influence of the question on their response were mapped. It helped the investigators to assess the questions whether they were clearly articulated and if the response options were relevant, comprehensive and has no medical jargons. Usage of text free entry has been restricted to a maximum extent. Later, the modified questionnaire was analysed by a panel of experts to ensure its accuracy.

4.4. Pilot study

A pilot study was planned as a trial run of the entire study from start to end, in order to test the entire research process from a methodological standpoint (e.g., sampling and recruitment strategies, administration, data collection and analysis) in actual field conditions. The pilot study was conducted in a selected GN Division of five Divisional Secretariat (DS) divisions of Jaffna district. Data collection was conducted through face to face interviews with a hundred households. Data collectors were trained to obtain consent, interview the participants, handle the mobile based questionnaire and interpret medical information appropriately. They were trained with the support of community members and patients, with whom, they did some mock interviews. Then, they were grouped together as pairs, with one as a data collector and the other a data collection assistant. A mobile phone with REDCap application was used to collect the data.

Before the commencement of the pilot project, the team visited the relevant District Secretariat and had discussions with the GNs of that Division. A program was conducted to educate the staff of the relevant DS Divisions on how to handle the work-related stress and to build a good rapport. Youth volunteers were recruited through GNs to conduct the community survey. The Youth volunteers were contacted via mobile phone and the research was explained and they were then requested to support in conducting this research. The volunteers helped to identify the index households and introduced the data collectors to the households. This facilitated the acceptance of the research and most of the participants gave informed consent. Local community engagement was carried out on the entire pilot study data collection. Feedback was collected from the participants and community members regarding their perceptions about the research. The CEI team visited the same village where they conducted the data collection and discussed with the village community regarding their opinion about the research. This further helped to improve the process of data collection for the questionnaire. After the completion of the pilot study, a discussion was conducted among the researchers, experts, community members and patients. The feedback from the participants and suggestions from the forum were analysed. The feasible recommendations were selected by the research team.



Photo: Stakeholder meeting with local stakeholders

4.5. Pre data collection

Before starting data collection in the selected GN divisions, the CEI team visited the relevant Divisional Secretariats and conducted meetings with the DS, GNs and Samurthi Officers. This discussion was about stroke as a complication of AF and the possibility of prevention via early detection through use of single lead ECG device. The need for the prevalence study and the methodology for sample and data collection are also explained. This discussion involved the GNs, Samurthi Officers and Development Officers and they were requested to provide the selected volunteers to support in recruitment and data collection. Also, some health education programs were conducted in the DS office and Community Centers to engage the public and to enhance their involvement in the research project. The project was explained clearly to the Medical Officer of Health (MOH) and Public Health Inspector (PHI) and they were requested to provide details of the COVID 19 related isolated households. This helped to avoid unnecessary exposure to COVID-19.

4.6. During the data collection



Photo: Engagement programme with DS office staff, data collectors and volunteers

During the data collection, support was sought from community center members, volunteers and GN. Youth volunteers and GNs were involved in introducing data collectors to the relevant households. A small incentive was provided to them. From the selected households, 50-year-old participants were selected for the data collection. A discussion was also carried out with the other members of the family about the health of the participant to identify the supportiveness to the participants. These supportive participants, were eager to prevent illnesses

in others, and were willing to contribute their time and support for the benefit of others. To get them fully engaged, the data collectors took the time to explain the outcome of this project, its benefits to the society and the health system. The data collection process helped to develop rapport with the GN, volunteers and community members. Feedback was collected from those involved. Every evening, after data collection, the feedback collected and the issues faced by the data collectors gets discussed. The feedback was regularly checked by the research fellows, as well as primary researchers, following which, recommendations are made during data collectors' fortnightly team meeting.



Photo: Team involvement in data collection

4.7. Post data collection

A team of data collectors with good communication skills and social concern, were selected for community engagement. A month after the completion of the community survey, the

Details of the photo

CEI team revisited the participants to discuss their health status and advise them on lifestyle improvements, especially healthy food habits and drug compliance and exercise. The CEI team, involved the whole family in these discussions, empathetically listened to their problems and answered their questions. The participants who needed additional support were put in touch with the relevant officers.

Interested participants were invited to participate in a forum where particular community representatives, volunteers, research team members and other relevant stakeholders were present. Supportive participants encouraged the main participants to join the forum. This forum discussion was initiated with questions about their food habits such as, what their current food habit is and how they want it to be in the future. Their ideas were recorded via rich picture and they were encouraged to develop action plans to resolve the identified issues. At the end of the forum, based on the desirability and feasibility, one or two action plans were chosen. Recurrent discussion sessions were conducted to reflect their implementation of action plans and improvements were made by adapting the new knowledge.

Active involvement and engagement of the local community and relevant stakeholders, together with the research team, will yield a pragmatic solution for the prioritised problem and generate a new set of knowledge.



Photo: Discussion and activity with local community

This CEI method was piloted in Kondavil village. The pilot study was conducted after a participatory meeting in the Kondavil Family Health Centre. The meeting was attended by voluntary participants from the study population and other relevant stakeholders, the presence of participants from marginalised sections of society was ensured. Health issues such as sedentary lifestyle, early onset of non-communicable diseases – diabetes mellitus, hypertension, cardiovascular diseases, stress, family problems and psychosocial problems were identified.

After a number of participatory discussions, it was found that, promoting healthy

eating and home gardening is one of the successful methods for participant engagement. A study done with more than sixty year old people in Stockholm, showed that the regular gardening can reduce the risk of heart attack or stroke and increase life span by 30% in the 60 plus age group [19]. Gardening improves the level of physical activity and reduces stress that creates harmony in the family. Harvesting organic vegetables enables healthy eating habits. In the pilot study, participants were grouped into clusters and encouraged to be involved in farming by providing support including seed distribution and trainings. Regular field visits, helped the participants to be engaged with the team. Provincial Department of Agriculture and agrarian service department were also involved in this project. This pilot study was successful, as it addressed many health-related issues, helped to improve the overall health, developed a good rapport with the participants and facilitated to keep them in the loop.



Photo: CEI Team involving in home gardening project



Photo: Healthy eating habits promotion in local community

4.8 Lessons learnt

The research collaboration is a new experience for the Sri Lankan Team. The Team could learn and implement the activities with the support of the UOB team and the international members. Initially, the concept of CEI was very new to the Team members in Sri Lanka. Regular meetings with collaborators and their visit to the research area and to the field helped us understand the concept better. Regular discussions enabled to develop comprehensive CEI process.

Once the implementation was commenced, the community was very receptive and enthusiastic, which gave encouragement to include many innovative ideas for the implementation. Involvement of the community was amazing and the community was always very supportive in every aspect of the research. The community was guiding in many aspects of the planning and implementation of the research. Community members were happy to volunteer their time. The grant was helpful for us to support the people involved with us in the research to a certain extent. Generally, people involved they were willing to support the research by using their own resources and time.

Sometime people had difficulties to understand the methodological aspects of the research. The research team tried their best to explained the complexed

issues in simplified manner. They were also interested to learn and provide input, which enable the research team to understand the real scenarios of the issues.

CEI provided a very valuable learning opportunity for the researchers and the community. This is well reflected in the response rate of participation. Community also encouraged the participants to be involved as subjects. Another success of the CEI process was being able to continue the data collection even during the COVID 19 pandemic. The greater experience should continue with more involvement and innovations.

Chapter : 05

5. Conclusion

The research collaboration is a new opportunity for researchers at the Faculty of Medicine, University of Jaffna. During the proposal writing phase, the term public patient involvement was introduced. The term was relatively new in the local context. The research team has immense experience in carrying out research and other activities with the community. With the previous experience and the support of the UOB and the international collaborators, the team at Jaffna University started the process of planning and implementing the community engagement and involvement in the NIHR funded Global Health research. Initial discussions at UOB and the subsequent meetings with the experts from UOB was very helpful for us to understand the process.

Based on the guidance provided by the NIHR and INVOLVE team, CEI framework was developed. It follows the six key indicators considered for the assessment of the implementation. The initial establishment of community involvement started in the early phase of the research development. The meetings were carried out with the stakeholders to identify the local needs based on the proposed research problem. Their inputs were included in the research, and final version of the research proposals were shared with them for their feedback before submitting to ethics and NIHR. A few consultative meetings were carried out to identify the people who could get involved in the research. Based on the discussion, three categories of stakeholders were identified. Communication templates were prepared to invite the mapped-out category of stakeholders: private sector, public sector and civil society. Relevant communication templates were prepared to link with them. Many pathways were adopted to link with the community based on their level of power and other socio-cultural aspects. The team put their maximum effort to incorporate the marginalised people and to empower them.

Regular reporting mechanism was developed. It was shared with the community involved with the research team. The community contributed to the planning and implementation of the research. Data collection is still in progress. Involvement of the community was remarkable, all the compartments of the community were

active and enthusiastic about supporting the research project. It brought exciting experiences for the researchers and the community. The excellent relationship was beneficial in carrying out the data collection during the COVID 19 pandemic situation. The community involved in the research was dynamic in understanding the benefits of the research and also in communicating well with the participants.

The research team is currently working with community groups to develop a few sustainable projects to support them to ensure continuous involvement and engagement. Already, healthy eating, home gardening, stress management and suicide prevention are identified by the community as their needs. The team is now able to start a few successful models with the support of the relevant state stakeholders.

Now the challenges are to continue maintaining the momentum created by the community themselves and the team and also to keep them engaged. The team also successfully identified a few community programmes such as, home gardening, stress management and suicidal prevention, these programmes are integrated with the ongoing government programme and also is planned to get more partners to work with the team.

The research collaboration is useful in introducing a new dimension for the researchers to work for the community in health promotion and management. The prevailing challenge is to maintain the momentum created. The team is looking for various avenues to sustain the achievements with stakeholders' support in the country, UOB team, and international collaborators.

Chapter : 06

6. Case Studies

1. Community engagement and involvement - case study 1

Mr & Mrs Balasingam were involved in the Atrial Fibrillation (AF) project from the beginning. Mr Balasingam is a retired technical staff from the University of Jaffna and his wife is a retired teacher. They live in Kondavil, a village close University of Jaffna. They are socially oriented and engaged in community empowerment activities. We were looking for community participants when we met the couple in Kondavil Family Health Centre. Mrs Balasingam attends clinic there and the couple voluntarily participated in the initial discussion about this AF project. We were looking for community members to help to identify the variables and to help us customise questions to the local context. It was found difficult to get the appropriate Tamil words used by the local community for the common medical terms used in the research. The couple helped to find more resources in the community to support in this regard. Their fluency in Tamil and English combined with a good understanding about the cultural context of the Tamil community, was a big help in the translation process.

In addition to this, Mrs Balasingam joined the CEI team. She supported the team by communicating the benefits of the project to the participants. As a retired teacher she has a good understanding of the community, how to develop a rapport with people and the ability to convince unwilling participants to participate in our research. She also was involved in the forum discussions. Informal communication channels and an empathetic explanation regarding the purpose, enhanced the community participation in our forum discussions. Mrs Balasingam made it possible for the voices of highly oppressed people in the community to be heard. The couple is very active and are always ready to render their services. Their continuous support has been crucial for the success of this research.



Photo : Involvement of Mr & Mrs Balasingam

2. Community involvement - case study 2

Successful implementation of community engagement and involvement plan was made possible with active participation of many volunteers and community workers. Mr Varmilan is a prominent Social Activist, who put in an enormous amount of time and effort for the success of this project. We came across Mr Varmilan during a community forum for the Nallur DS division. He is a farmer and has been involved in social activities for more than a decade. In the forum, food habits was inquired and what could be the future state of the food habits. People discussed different opinions and Mr Varmilan expressed his belief in organic agriculture and traditional food consumption. He was already aware about the ill effects of high calorie, low nutrient food. He played an important role in the pilot implementation of the project in Kondavil. He himself started an organic home garden to demonstrate to other villagers. He conducted small group discussions in the village and recruited interested participants. With his help we coordinated the home gardening and healthy eating project and we supported them by providing traditional seeds. He got support from local youth volunteers, mothers club, school principal, agriculture department staff and organic activists from the organic movement. He supported regular field visits even in the midst of the COVID 19 pandemic. Through all these efforts, we were able to actively engage and involve the participants in our project. The interaction was helpful to keep our research participants connected with the research team. Mr Varmilan was also instrumental in replicating similar models in other areas. His initiative would be a great contribution for us to develop longstanding relationship for our future research activities and community empowerments.



Photo : Distribution of Seeds

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Annexure

Annexure:1

Table No 1 : Details of the mapped out stakeholders in the community by sectors

Private Sector Stakeholders	Public Sector Stakeholders	Civil Society & Non-profit sector stakeholders
<p>1. Private Health Institutions</p> <p>a. Private Hospitals: Northern Central, Yarl, Venus</p> <p>b. Private Clinics: Suharni, Thayakam</p> <p>c. Medical Labs: Asiri, Durdans</p> <p>d. Private Pharmacy: City, Ratnam</p>	<p>1. Public Administration</p> <p>a. Central government: Governor, District secretary, Divisional secretary, Grama Niladhari, Samurdhi officers</p> <p>b. Provincial government: Chief Secretary,</p> <p>c. Local Government Municipal Council, Pradesha saba</p>	<p>1. Citizen's organisations</p> <p>Activist groups – Nature Trails, Green Shadows, Organic Movement of North & East</p>
<p>2. Individual business</p> <p>Vegetable & fruit venders in the village</p>	<p>2. Political parties</p> <p>Elected politicians</p>	<p>2. Community based organisations: Sports clubs, Elders club, Community centres, mothers clubs, youth volunteer groups, young men religious associations (YMHA & YMCA)</p> <p>Religious organizations: Temple trusts and societies</p> <p>Family & Neighbours</p> <p>Participants & their family members</p>

<p>3. Financial Institutions & banks:</p> <p>HNB, Commercial, LB finance</p>	<p>3. Health</p> <p>a. Department of Provincial Director of Health Services office Northern province: Provincial director of health services (PDHS), Provincial Consultant Community Physician (CCP), Medical officers (MO), Provincial Public Health Inspector, Chief pharmacist at Regional Medical Supplies Division (RMSD)</p> <p>b. Regional directors of health services (RDHS): RDHS and key staff</p> <p>c. Medical Officer of Health (MOH) office: MOH and staff</p> <p>d. Primary Health Care Institutions: Divisional hospital, Primary Medical Care Units (PMCU)</p> <p>e. Secondary and tertiary care hospitals</p> <p>f. Traditional Hospitals + Healers</p>	<p>3. Non-governmental organisation:</p> <p>a. National NGOs- TRRO, JSAC SANASA, Sarvodayam,</p> <p>b. International- World Vision, UNICEF, IOM</p> <p>c. Rehabilitation centres- AROD (Association for Rehabilitation of the Disabled)</p> <p>d. Professional associations Lawyers association, Bankers association, Jaffna Medical Association (JMA), Chamber of Commerce</p>
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<p>4. Education:</p> <p>Private tuition centres: Edison, Royal,</p>	<p>4. Education:</p> <p>Provincial, zonal and division</p> <p>Schools</p> <p>Higher education institutions: University and Technical colleges</p>	<p>4. Education:</p> <p>a. Preschools</p> <p>b. Tuition ventures</p> <p>c. Value education centres</p> <p>d. Private technical institutions</p> <p>e. Private vocational training institutes and campuses</p>
<p>5. Media</p> <p>a. Local News papers: Uthayan, Valampuri, Thinakural</p> <p>b. TV channels: DAN, IBC, Capital</p> <p>c. News website: IBC, Tamilwin, Lanka sri</p>	<p>5. Social services:</p> <p>Department of social services, elders home, rahabiliattion centres (alcohol and mental health)</p>	<p>5. Social Organisations -</p> <p>Performing arts groups – Social action theatre group</p>
	<p>6. Food & farming:</p> <p>Department of Agriculture</p> <p>Department of Agrarian</p>	<p>6. Food and farming:</p> <p>Farmers societies</p> <p>Young farmers club</p> <p>Farmers club</p> <p>Farm women societies</p>
	<p>7. Justice, Law & order:</p> <p>Courts, police, humanrights commision</p>	<p>7. Other organizations:</p> <p>Diaspora organisations</p> <p>Media – Journalists, social media,</p>

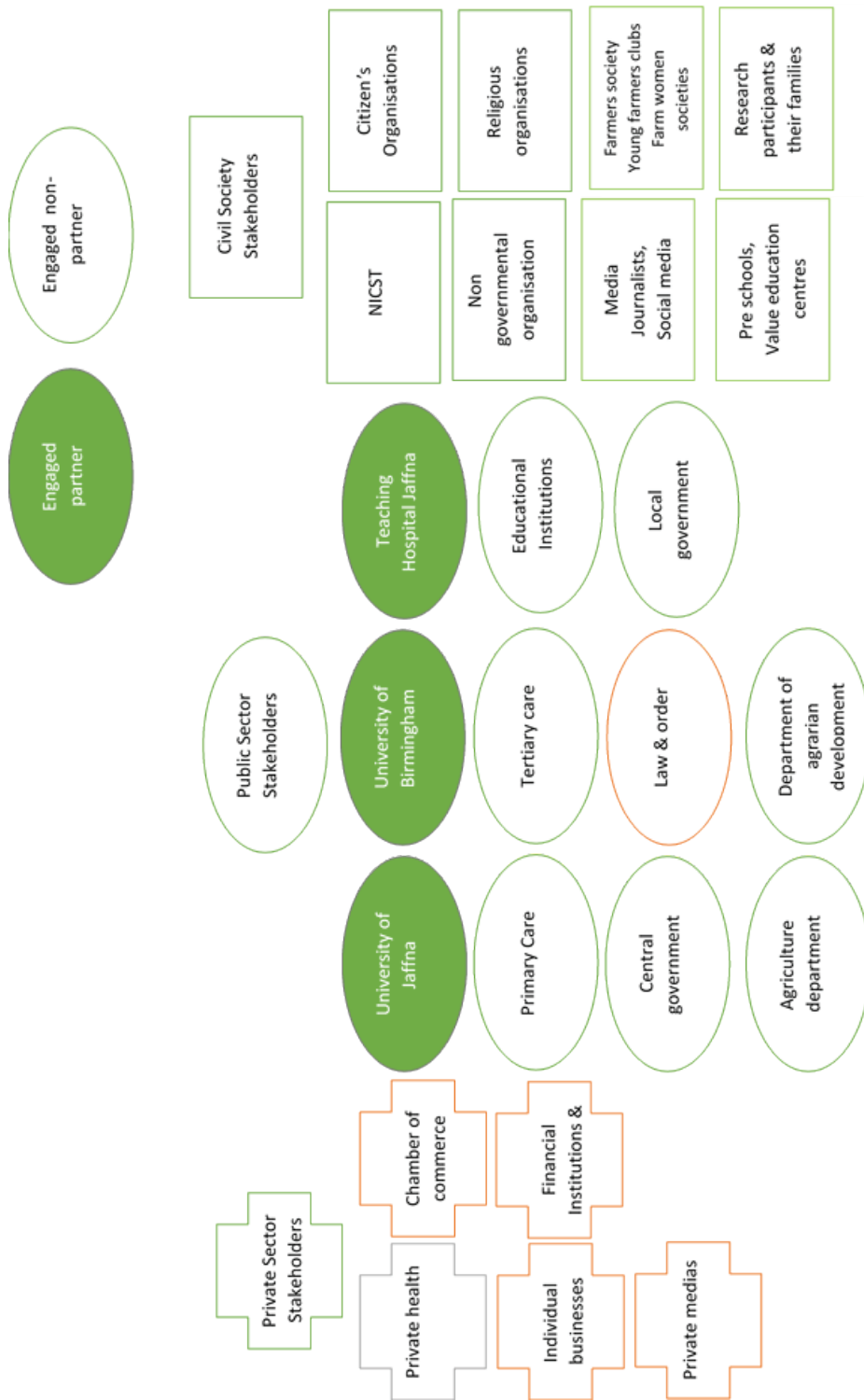


Figure Mapping chart of the community stakeholders

Annexure: 2

Template 1

1. Title/ Headline

Community representatives who are requested for the forum discussion.

2. Key questions

You are requested to represent the community and involve in the development of the research. You will be asked to answer certain questions and tell your perceptions and suggestions on particular aspects. You should be able express your ideas clearly and without any hesitation.

- Will you come alone or with caretaker/ family member?
- Do you need transport facilities?

3. Background of the study

Atrial fibrillation (AF) is the most common heart rhythm disorder globally, and it is also severely affecting the low middle income countries like Sri Lanka. This leads to stroke which cause an increased burden in health care system and patient's families. Patient number and it's effects are not properly recorded in Srl Lanka. So University of Jaffna planning a research with University of Birmingham to measure the number of patients and its effects. Through this research we can prevent the worse complication – stroke and help the community and health system.

4. What would this mean for people getting involved?

Participants can join the development of a research which is very useful for the community and health system. they will get an understanding about their health condition and undergo some investigations free of charge. The results of the clinical and laboratory evaluation will be informed to the participants by the medical officer supervising the evaluation process. Necessary medical action will be taken if any follow up care is needed.

Template 2

1. Title/ Headline

AF patients who are requested for a visit to cardiologist.

2. Key questions

Personal details-name, age and NIC number from the patient (for conformation)

- Will this coming Wednesday convenience for you to meet the consultant at 8am in the Echo room? If is not convenience to you, let's know to arrange it in another Wednesday.
- Will you come alone or with caretaker/ family member?
- Do you need transport facilities?

3. Background of the study

The patient's information regarding heart disease and ECG reports were already collected by the data collectors. The ECG has examined by Dr.Guruparan, Consultant Cardiologist and some abnormalities have found. As a part of the research a time has allocated for direct interview with the consultant at the Echo room in the Teaching Hospital, Jaffna on Wednesday at 8am. Test for blood glucose and cholesterol will be done. Therefore, the patient will be asked to keep fasting after 9pm in the previous night. Patient will be clearly instructed clearly to have the dinner before 9pm on previous night and not to have tea or breakfast on the day morning. The patient will undergo ECG and Echo test, So the patient will be asked to bring their clinic records.

4. What would this mean for people getting involved?

The patient will be confirmed with the diagnosis for AF or cardiac risk in future. It will help to prevent the early onset of the complications by starting an effective disease management. These patients will get an opportunity to work as partner with the research team. They will get an understanding about their health condition clearly. Also they can express their perception towards the research. If the patient wants further information, they can contact through telephone.

Template 3

1. Title/ Headline

Request for administrative officers (DS & GN) and volunteers join for the successful conduct of the research.

2. Key questions

For administrator

We are requesting your support to conduct the research successfully. You can connect the relevant officers and suggest a volunteer who can help us in this data collection task.

For volunteer

- Do you know well about this place and people?
- Do you know any additional information about index participant?
- Do you know about the located areas?
- Is there any problem in that area?
- Are you available in the recruitment day?
- Can you go along with the data collectors for the selected houses?

You can tell additional information you know about the participant and you also can suggest any improvement in the data collection process.

3. Background of the study

Faculty of Medicine, University of Jaffna conducting a research about heart disease among people aged 50 years and above in the Northern Province, Sri Lanka. The University of Jaffna entered into a Memorandum of Understanding (MOU) with the University of Birmingham, UK and funded by NIHR. This project has implemented through the University of Jaffna under the Ministry of Higher Education Atrial fibrillation (AF) is the condition which commonly diagnosed among the people aged more than 50 years. AF can lead to stroke. This affects the person's family as well as the community. Therefore, screening in the early stage will help to prevent or reduce the occurrence of stroke.

According to the information collected from the Divisional Secretary (DS) office regarding the residents in each Grama Niladari (GN) division, households will be selected by multistage cluster sampling techniques. Person aged 50 years or above will be selected for the data collection.

First, we will visit to those 20 selected home and give all the explanations and information sheet regarding the research. Next, the data collectors will go for data collection. Another day we will go an collect the blood samples and analysis for blood pressure, cholesterol, glucose, liver function and renal function.

4. What would this mean for people getting involved?

They would be working in partnership with other administrative officers, public and researchers to support the research development process. They will provide the required information and also give their suggestions to improve the research process. They do not need any previous experience, just a willingness to participate is enough. The position is voluntary. For further information they can contact over the phone.

Annexure: 3

Role description of the templates

Role name

Patient representatives for the AF research development forum

Summary

Expected outcomes of the study are to determine the prevalence and associated risk factors of AF, model cost effectiveness and assess acceptability of smart phone-based case finding strategies in Northern Province, Sri Lanka.

Background

Atrial fibrillation (AF) is the most common heart rhythm disorder globally, conferring a major burden of morbidity and mortality. However, AF burden is not addressed properly in Sri Lanka especially in the Northern Province, mainly due to the inadequate health care resources. Health care resource allocation towards managing AF, needs estimation of AF disease burden. Prevalence of AF is a key element in estimating the disease burden. Determining the prevalence of AF in the Northern Province of Sri Lanka will be possible through a community-based case finding method. At the same time, such case finding method could be incorporated into the routine health care delivery if it is cost effective and acceptable by the key stakeholders.

The success of this study depends on the active involvement and engagement of participants and relevant stakeholders. However, it is not a straightforward task. Hence it is crucial to implement an appropriate method to understand the community, formulate culturally appropriate trust-building activities to obtain active engagement and involvement of participants and stakeholders. It will not only help to conduct the current study effectively but also will open a way forward for a potential cohort study in future.

The forums we conduct will consist community representatives, patient representatives, health staffs, local government officers, researchers and other interested local organisation's representatives.

Consideration of representatives

Conflict interest: As a representative you will be required to disclose any involvement you may have with other organisations, government bodies or corporate/commercial interests which could result in a conflict of interest with the work of representing the patients and giving suggestions to improve the research development process.

Confidential of data: As a representative of the patients you are asked not to share confidential information you may have received as a result of your position. This should be discussed with the project group and / or contact person.

Annexure: 4

Roles and responsibilities of user representative

1. Duties

Representatives are expected to contribute their maximum active participation as per the instruction given and to attend all the discussions through the study period. (available to contact, attend the discussions in person, represent the population and actively involve with the research team for their betterment) and they need to undergo the following phases and at the end of the each phases they need to express their perception about these procedures and give suggestions to improve the process further.

Data collection will be conducted in two phases. The first phase will be a survey and data will be collected by through an interviewer-administered questionnaire, clinical evaluation, evaluation using a smart phone based single lead (Lead I) ECG electrode called AliveCor.

The questionnaire will document the participant's demographic data, life style pattern, well-being, disease status (if any) and health care facilities utilisation.

Participant will be invited for a laboratory evaluation at the nearest selected primary care institution. Transport and refreshments will be provided free of charge to the participant.

The results of the clinical and laboratory evaluation will be informed to the participants by the medical officer supervising the evaluation process. Necessary medical action will be taken if any follow up care is needed.

They also will be requested to attend the forum discussions where they express their opinions about the process and perceptions about the data collection tool and suggestions to improve further.

2. Qualities

Patient and public who are representing the population are not expected to have previous experience to involve in the research project. Participant should be able to maintain the confidentiality as the important information about the research will be shared. Participant should be able to have the time to attend meetings preferably face-to-face or answer questions via telephone.

Essential criteria

Tamil speaking resident of age 50 years and above in the Northern Province. Representatives should be able to understand the main issues/ topic of the research and its importance as well as be confident to participate in the study.

Desirable criteria

Have access to a mobile phone and should be able to respond immediately. Their experience with the disease is important to participate.

3. Remuneration

Participants will be provided with travel expenditures and refreshment also will be provided on the discussion days.

4. Support:

All investigations with the participants will be done free of charge. Upon completion of data collection, each participant will be provided with the outcome of AF screening and their clinical evaluations. AF screening positive individuals will be referred to the Teaching Hospital Jaffna (or their area hospitals) for further follow up.

5. Further information:

You are free to not to participate or withdraw from the study at any time of the study without any loss of or compromise in medical care/ other service otherwise you are entitled. If you have any questions/doubts about the research, you may contact the following investigators.

Contact details:

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Senior lecturer

Mobile: 0773777446.

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Glossary

Atrial fibrillation

a problem in which the heart beats faster than normal and in a way that is not regular, resulting in the atria (= the top spaces) of the heart not emptying properly:

Prevalence

Proportion of a population who have a specific characteristic in a given time period

Questionnaire

a list of questions that several people are asked so that information can be collected about something:

ECG

It is a test that measures the electrical activity of the heartbeat.

Stroke

a sudden change in the blood supply to a part of the brain, sometimes causing a loss of the ability to move particular parts of the body

Annexure: 5 Tamil translation of the templates

வார்ப்புரு 1

தலைப்பு -

குழகலந்துரையாடலுக்காக சமுதாயத்தைப் பிரதிநித்துவம் செய்யப்போகும் நபர்களைத் தெரிவுசெய்தல்

பிரதான வினாக்கள்

நீங்கள் உங்கள் சமுதாயத்தைப் பிரதிநித்துவம் செய்யும் முகமாக இந்த ஆய்வில் கலந்து கொள்ள அழைக்கப்படுகிறீர்கள். உங்களிடம் இவ் ஆய்வு தொடர்பான சில வினாக்களும் ஆலோசனைகளும் கேட்கப்படும். உங்கள் கருத்துக்களை விரிவாகவும் தெளிவாகவும் பதிவு செய்யுமாறு கேட்கப்படுகிறீர்கள்.

- நீங்கள் அழைக்கப்படும் இடத்திற்கு எவ்வாறு வருவீர்கள்? (தனியாக அல்லது குடும்பத்தினரோடு/ பராமரிப்பாளருடன்)
- உங்களுக்கு போக்குவரத்து உதவி தேவையா?

3. ஆய்வு பற்றிய சிறுகுறிப்பு

யாழ்ப்பாணம் பல்கலைக்கழக மருத்துவ பீடம் Birmingham பல்கலைக்கழகத்துடன் சேர்ந்து வடக்கு மாகாணம் முழுவதும் இதயநோய் (Atrial Fibrillation - AF) தொடர்பான ஆய்வொன்றை மேற்கொள்கின்றோம். அது தொடர்பாகக் கதைக்க வந்துள்ளோம். பொதுவாக 50 வயதிற்கு மேற்பட்டவர்களுக்கு பாரிசுவாத நோய் ஏற்படுகின்றது. ஒருவருக்கு ஏற்படும் இந்நிலை அவரின் குடும்பம் மற்றும் சமூகத்தினைப் பாதிக்கின்றது. பாரிசுவாதம் ஏற்பட இதயத்தில் ஏற்படும் AF எனும் நோய் நிலைமை காரணமாக அமைகின்றது. எனவே இந்நோய் நிலைமையை ஆரம்பத்தில் கண்டறிவதன் ஊடாக பாரிசுவாத நோய் ஏற்படுவதைத் தடுக்க / குறைக்க முடியும்.

4. கலந்துகொள்பவர்களிற்குக் கிடைக்கும் நன்மைகள்

இவ்வாய்வில் பங்கெடுப்பதால் தனிநபர் மற்றும் சமூக சுகநல நிலமையில் தமது பங்கை பற்றி அறிந்துகொண்டு அதை மேம்படுத்த முடியும். இலவசமாக மருத்துவப் பரிசோதனைகளைச் செய்துகொள்வதோடு அதை மேம்படுத்தும் உதவிகளும் வழங்கப்படும். மேலதிக விவரங்களிற்கு தொலைபேசி இலக்கத்திற்குத் தொடர்புகொள்ளவும்

வார்ப்புரு 2

1. தலைப்பு-

இனங்காணப்பட்டோர் இருதய மருத்துவ நிபுணரைச் சந்திப்பதற்கான அழைப்பு

2. பிரதான வினாக்கள்-

- உறுதிப்படுத்துவதற்காக பெயர் வயது மற்றும் தேசிய அடையாள அட்டை இலக்கம்
- வருகின்ற புதன்கிழமை காலை 8.00 மணியளவில் Echo Room ற்கு வர முடியுமா? முடியவில்லையெனில் மற்றுமொரு புதன்கிழமையை பரிந்துரையுங்கள்
- நீங்கள் அழைக்கப்படும் இடத்திற்கு எவ்வாறு வருவீர்கள்? (தனியாக அல்லது குடும்பத்தினரோடு / பராமரிப்பாளருடன்)
- உங்களுக்கு போக்குவரத்து உதவி தேவையா?

3. ஆய்வு பற்றிய சிறுகுறிப்பு

எமது ஆய்வின் ஒரு பகுதியாக உங்களுடைய ECG ஐ யாழ்ப்பாணம் பெரிய ஆஸ்பத்திரியில் இதய வைத்திய நிபுணராக பணியாற்றும் Dr.Guruparan பார்வையிட்டார். உங்களுடைய ECG இல் சிறிய வித்தியாசம் உள்ளது எனக்கூறி, உங்களை நேரில் சந்தித்தால் நல்லது என நேரம் ஒதுக்கி தந்துள்ளார். (விளக்கம் கேட்கப்படின் (ECG மாற்றம் தொடர்பாக) AF தொடர்பான விளக்கம் கொடுக்கப்படும்). நீங்கள் வருகை தரும் அன்றைய தினம் உங்களிற்கு குருதியில் கொலஸ்ட்ரோல், குளுக்கோசின் அளவு பரிசோதனை செய்யவுள்ளோம். எனவே நீங்கள் முதல் நாள் இரவு 9 மணிக்கு முதல் உங்களுடைய இரவு உணவினை உண்டு, காலையில் Tea, சாப்பாடு உண்ணாமல் வர வேண்டும். அதனுடன் ECG மற்றும் இதய படமெடுத்தலும் (Echo) வைத்தியர் செய்யவுள்ளார். (தேவைப்படின் மேலதிக விளக்கம் இரத்தப்பரிசோதனை, Echo தொடர்பாக வழங்கப்படும்) நீங்கள் எப்போதாவது கிளினிக் போயிருந்தால் அந்த கொப்பியையும் கொண்டு வாருங்கள்.

4. கலந்துகொள்பவர்களிற்குக் கிடைக்கும் நன்மைகள்

AF உறுதி செய்யப்படுமிடத்து அதனால் எதிர்காலத்தில் எற்படக்கூடிய தாக்கங்கள் இருதயம் தொடர்பான பிரச்சினைகளிடமிருந்து முற்காப்பு உதவிகளைப் பெற்றுக்கொள்ள முடியும் இவ்வாய்வில் ஒரு பங்காளராக செயற்பட்டு அவர்கள் கருத்துக்களை முன்வைக்க முடியும். மலதிக விவரங்களிற்கு தொலைபேசி இலக்கத்திற்குத் தொடர்புகொள்ளவும்

வார்ப்புரு 3

1. தலைப்பு -

நிர்வாகம் தொடர்பான உத்தியோகத்தர்கள் மற்றும் தன்னார்வத் தொண்டரிடம் பங்களிப்புக்கோரல்

2. பிரதான வினாக்கள்

நிர்வாகிகளிடம் -

- இவ்வாய்வை மேற்கொள்ள நீங்கள் ஆதரவு வழங்க வேண்டும் என்றும் இவற்றை செய்து முடிக்க எங்கள் தரவு சேகரிப்போரிற்கு உதவி செய்யக்கூடிய தனிச்சை உதவியாளர் ஒருவரையும் தந்து உதவுமாறு கேட்டுக்கொள்கிறோம்.

தன்னார்வத் தொண்டரிடம் -

- குறிப்பிட்ட பகுதி மற்றும் மக்களை உங்களிற்கு நன்கு தெரியுமா?
- மேற்கூறப்பட்டுள்ள தகவலுடன் மேலதிகமாக சுட்டலகுப பிரதிநிதித்துவரைத் தெரியுமா?
- அப்பிரிவில் வேறு ஏதும் பிரச்சனைகள் உள்ளதா?
- உதவிக்கு அழைக்கப்படும் நாளில் வேறு ஏதும் வேலைகள் உள்ளதா?
- தெரிவு செய்யும் 20 வீடுகளிற்கும் தரவு சேகரிப்போருடன் செல்ல முடியுமா?
- தரவு சேகரிக்கும் நாளில் நீங்கள் முழுநேரமும் வரத்தேவையில்லை தேவை ஏற்பட்டால் மட்டுமே அழைப்போம்.

3. ஆய்வு பற்றிய சிறுகுறிப்பு

யாழ்ப்பாண பல்கலைக்கழக மருத்துவ பீடம் வடக்கு மாகாணம் முழுவதும் இதயநோய் (AF) தொடர்பான ஆய்வொன்றை மேற்கொள்கின்றோம். அது தொடர்பாகக் கதைக்க வந்துள்ளோம். பொதுவாக 50 வயதிற்கு மேற்பட்டவர்களுக்கு பாரிசுவாத நோய் ஏற்படுகின்றது. ஒருவருக்கு ஏற்படும் இந்நிலை அவரின் குடும்பம் மற்றும் சமூகத்தினைப் பாதிக்கின்றது. பாரிசுவாதம் ஏற்பட இதயத்தில் ஏற்படும் AF எனும் நோய் நிலைமை காரணமாக அமைகின்றது. எனவே இந்நோய் நிலைமையை ஆரம்பத்தில் கண்டறிவதன் ஊடாக பாரிசுவாத நோய் ஏற்படுவதைத் தடுக்க / குறைக்க முடியும்.

நாங்கள் ஒவ்வொரு GN இலும் வசிக்கின்ற 50 வயதிற்கு மேற்பட்ட அனைவரினது தகவல்களையும் சேகரித்து (DS office இலிருந்து பெறப்படுகின்றது) அதிலிருந்து ஒருவரை எழுந்தமானமாக தெரிவு செய்வோம். அந்த வீட்டிலிருந்து வெளியில்

வரும் போது வருகின்ற வலது பக்கமாக தொடர்ச்சியாக 20 வீடுகளைத் தெரிவு செய்து அங்குள்ள 50 வயதிற்கு மேற்பட்ட ஒருவரினைப் பங்குபற்றுனராக தெரிவு செய்வோம்.

முதலில் நாங்கள் அவ் 20 வீடுகளுக்கு வருகை தந்து அங்கிருக்கும் அனைவருக்கும் ஆய்வு தொடர்பான விளக்கமளித்து தகவல் பதிவுத்தாளை வழங்குவோம். பின் அதற்கடுத்த நாட்களில் அவ்வீடுகளில் தெரிவு செய்யப்பட்ட பங்குபற்றுனரிடமிருந்து தகவல் சேகரிப்போம். பின் குறிப்பிட்ட ஒருநாளில் மீண்டும் வந்து அவர்களிடம் குருதி மாதிரிகளை சேகரித்து பரிசோதிப்போம்.

4. கலந்துகொள்பவர்களிற்குக் கிடைக்கும் நன்மைகள்

இதில் கலந்துகொள்ள முன் அனுபவம் தேவையில்லை. கலந்துகொள்வோர் பங்குதாரர்களாக செயற்பட முடியும். இது முழுவதுமான தன்னார்வலச் செயற்பாடாகும்.

மேலதிக விவரங்களிற்கு தொலைபேசி இலக்கத்திற்குத் தொடர்புகொள்ளவும்

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