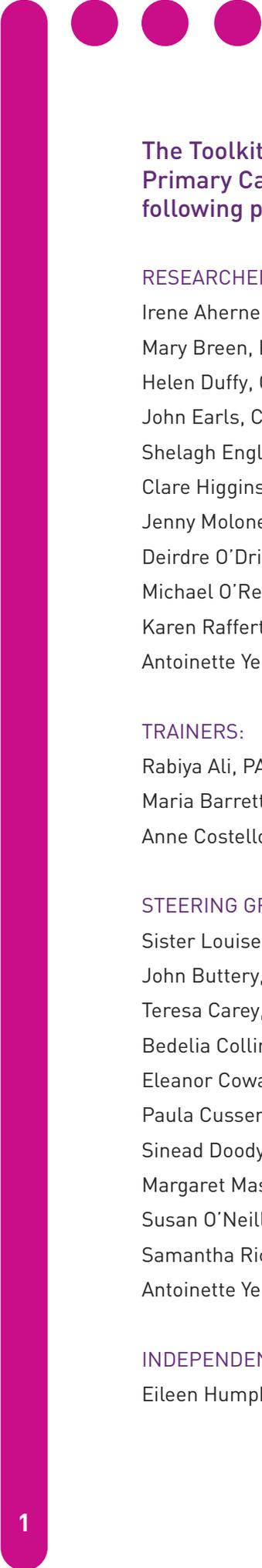# Sustainable Community Participation in Primary Care:

A Toolkit for Community Involvement in Primary Care Areas

**The Toolkit was developed by the Community Participation in
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I. Introduction

The following is a step-by-step guide to facilitating sustainable and meaningful community participation in Primary Care Teams. It is based on the learning from a project developed and implemented in the Northside of Limerick City in 2009. While the project in this area was deemed a success, one of the key learnings from the project was that any approach must be flexible and responsive to local needs and circumstances. The following represents, therefore, one potential approach to supporting community participation on Primary Care Teams.

II. What is Primary Care?

Primary Care is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being.

Traditionally, in Ireland there has been a dependence on the hospital system to undertake patient care ranging from the most complex surgeries to basic diagnostic procedures. However, all the research and analysis in recent years has suggested that most patient care does not need to take place in a hospital setting but is more suited to local, community locations which feature multi disciplinary teams of healthcare professionals working together in Primary Care Teams. Agencies ranging from the Irish College of General Practitioners to the World Health Organisation have recognised Primary Care as being the most effective and cost efficient way to treat patients.

Primary Care includes the range of services that are currently provided by general practitioners (GPs), public health nurses, social workers, practice nurses, midwives, community mental health nurses, dieticians, dentists, community welfare officers, physiotherapists, occupational therapists, home helps, health care assistants, speech and language therapists, chiropodists, community pharmacists, psychologists and others (Department of Health and Children, 2001a). It was within this context that the national strategy for Primary Care, *Primary Care-A New Direction* was published in 2001. The strategy outlined a major modernisation programme which aimed to reorganise the way people received their healthcare by bringing GPs, nurses, therapists and other healthcare providers together into specific teams to cover populations of up to 8,000.

Since the inception of this strategy significant progress has been made, and Primary Care Teams are now being rolled out across the country.

III. What is the Community Participation in Primary Care Project?

The Community Participation in Primary Care Project in the Northside of Limerick City (Ballynanty/Moyross Primary Care Team) was one of nineteen projects around the country. The Project was established as a collaborative effort between PAUL Partnership, the HSE (the Primary Community and Continuing Care section of the HSE in Limerick, health professionals in the Primary Care Team from nursing, occupational therapy, physiotherapy, GPs and Health Promotion), RAPID, Limerick Regeneration Agencies and the communities of Moyross, Ballynanty, Kileely and Thomondgate. It was funded by the Combat Poverty Agency and the HSE.

The overall purpose of the Project was to ensure that there is meaningful and sustainable community participation on the Primary Care Team within the area. Community participation in Primary Care is regarded as essential to ensuring that Primary Care Teams work with the community to meet their health needs. Community participation can also inform the way health services are delivered in the community and improve the health and well-being of people who live there.

IV. What do we mean by Community Participation?

One of the first tasks for the members of the Project Steering Group was to ascertain what, in reality, we meant by community participation. The group was clear that we needed to go far beyond just consulting with the community. Members of the community needed to be actively involved in decision-making at every stage of the project, brainstorming stages of how to develop the process to the nomination of community members to the Primary Care Team. From the earliest stages, the project worked from the principle that all members of the project, both the members of the community and the Primary Care Team, had meaningful contributions to make to the process and that all would be treated with equality and respect. The group also agreed that community participation was not only valuable to the successful development of the Primary Care Team in meeting the health needs of the community, but that it was essential. The process that we developed to facilitate community participation, therefore, needed to become deeply embedded within the working practices of the Primary Care Team.

This led to the selection of Participatory Appraisal (PA) Methods as the foundation of the training programme developed to facilitate community participation. PA works from the principle that local people are experts on their own lives and that their views and priorities should be the starting point for any local planning and action. Local people should be actively involved in decision-making. The PA methods chosen for this project were user-friendly, and they could be delivered by and to local people. This allowed a greater degree of local ownership of the project.

The objectives of the Project were:
1. To design a training resource, using Participatory Appraisal Methods, to support community engagement in the Primary Care Team

2. To recruit community representatives and Primary Care Team staff to participate in the training

3. To support community representatives and Primary Care Team staff to engage with the local community in relation to their health needs

4. To gather and analyse data on local health needs and develop an action plan to address those needs

5. To develop and establish a Local Health Forum that will ensure sustainable and meaningful community representation on the Primary Care Team.

The outcomes of the Project were:

1. Improved capacity for community engagement

2. The development and delivery of a training resource for community representatives based on Participatory Appraisal Methods to support this (see appendix 1 on PA methods.)

3. Analysis and dissemination of data on health needs generated by the Project

4. The establishment of a structure to sustain community engagement

5. Meaningful and sustainable community participation on the Primary Care Team.

At the conclusion of the first phase of the project, the members of the Steering Group and the community and Primary Care Team members who participated in the project agreed that the project had been very worthwhile and that it needed to continue. The group also agreed that there was a great deal of learning from the project and that other projects trying to achieve similar objectives might find the experience from this project useful. As a result of this, it was agreed to compile this Toolkit based on the ongoing learning from the project and the learning from the formal evaluation. One of the key conclusions of the evaluation was that,

> A process centred on community participation (in health) needs to recognise that disadvantaged communities are not all the same, and there are internal differences in communities. The processes of community engagement need to be embedded in the way different communities work to organise themselves (presence of community organisations, informal clubs, meeting places, role of leaders / lack of leaders, sense of stigma, exclusion, past experiences). The methods need to be adapted to suit different communities and, as such, some flexibility is required. The thinking behind PA methods is that they work with such differences to bring out views that capture the distinctiveness of different communities. It is important to keep in mind that it is not appropriate to take a specific model (like this one that worked well in Ballynanty, Moyross, Kileely and Thomondgate) or particular parts of it (the way people were recruited, the same training programme), implant it elsewhere and expect it to work in the same way and with similar results. (Humphreys 2009)

The toolkit, therefore, is intended as a guide only and should be adapted to suit local circumstances. It is one approach, which proved successful in meeting the objectives of the project in the area in which it was piloted.

V. Toolkit

STEP 1: Project Pre-Development and Communication

What needs to be done?
- Develop the overall aims and objectives of the Project

- Develop and agree the project outcomes

- Develop a draft budget and other resource requirement

- Identify who should be involved in the process

- Engage with stakeholders (both within the HSE and the community) around the project and ask for relevant nominations to the Steering Group.

Who needs to be involved?
- The Lead Community Organisation

- HSE (such as Primary Care Transformation Development Officer (TDO), Health Promotion, Community Development)

When should it be done?
- The pre-development should be done prior to the first meeting of the Steering Group.

Issues to Consider:
- At this stage, the plan needs to be very flexible and allow for the input of all future partners. It should outline the overall aims and objectives and provide a map of the how the project might develop.

- The resources required should be agreed from the beginning. The project requires significant time resources from all partners.

Step 2: Convening the Steering Group

What needs to be done?
- Develop an agenda and format for the meeting
- Convene the first Steering Group Meeting
- Agree a clear terms of reference
- Engage in a fluid and open process to build trust and develop a shared understanding of the project aims and objectives.

Who needs to be involved?
- All members of the Steering Group (drawn from the HSE and Community Organisations)

When should it be done?
- This aspect of the process should be given sufficient time to ensure that all partners develop a shared understanding of the project and the agreed project plan.
- It may require a number of meetings.

Issues to Consider:
- At the first meeting, information on Primary Care and the Primary Care Team and the overall aims and objectives of the project should be presented.
- This is an intensive and critical stage of the process, and sufficient time should be devoted to it. Meetings may be frequent and long, but it is essential that all stakeholders have the opportunity to feed into this process and that a shared understanding is developed.
- The lead organisations will play an important role here in terms of ensuring that there is open communication and that the overall plan stays on track.

"Some meetings were tough and we were concerned at times about whether we could actually do it ... almost after every single meeting, we had to change or tweak things to try to get them to work better ... such a flexible way of working together is good and not really the ways things are done in statutory agencies."

Step 3: Development of an Action Plan

What needs to be done?
- The Action Plan for the Project should be developed. It should address the following elements:
- Establishment of clear structures and processes for communication.
- Development of training programme in PA Methods, including identification of qualified trainers
- Recruitment of participants (from the Community and the Primary Care Team)
- Delivery of training programme
- Community engagements
- Analysis and presentation of data
- Feedback to the community
- Project evaluation
- Ongoing participation in the process and in the Primary Care Team.

Who needs to be involved?
- All members of the Steering Group.

When should it be done?
- This should be started after the aims and objectives have been agreed by the Project.

Issues to Consider:
- Clear but flexible timeframes should be established from the outset.
- Responsibility for each action should be assigned to individuals and/or agencies.
- The timeframes and responsibilities should be clearly recorded and circulated to all members of the Steering Group.

"We struggled a bit in the beginning ...
but then something snapped into place
.. having a plan kept it in shape."

Step 4: The Process to Develop and Establish a Local Health Forum

The following specific tasks are crucial to reaching the overall objective of establishing a Community Health Forum. Each step needs to be given sufficient time in its own right, but the steps are closely interrelated.

Task 1: Identify a Suitable Training Programme on PA Methods

What needs to be done?

- The Steering Group should review the objectives of the training programme and establish clear terms of reference for the Training Sub-group.
- A Training Sub-group should be established. The Group should develop a training programme in PA (Participatory Appraisal) methods that is semi-structured but flexible and responsive to the needs of the participants.
- The training group will be responsible for identifying appropriate facilitators and resources for the programme and ensuring the training meets the objectives of the programme and the needs of the participants.

Who needs to be involved?

- The identified members of the Steering Group and external partners with relevant expertise.

When should it be done?

- As above, the training programme should be finalised after the Steering Group has developed a shared understanding of the aims and objectives and developed an action plan.

Issues to Consider:

- The training programme needs to reflect the overall project objectives, and these need to be reinforced throughout the training.
- The training programme needs to be flexible and responsive to the needs of the participants. The amount of time devoted to training and the level of support given to participants will vary, and the trainers will need to be able to respond quickly and effectively to this.
- Clear channels of communication between the Training Group and the Steering Group should be established.

"I thought it was a great idea and the first time the public were seriously consulted by the HSE about health and their services .... people working in the HSE learnt as much if not more than we did about health in the communities."

"I love working in the community but there are gaps in many areas and a barrier between people and health professionals ... especially in disadvantaged communities. I saw it as an opportunity to go out and find out more about the wider community".

"In the training itself, we gelled very well. It was a bonding experience. It was well-focused and we wanted to learn.. but I hated all that sitting on the floor talking to people."

"Only for the connections within the community, there is no way we could have gone out and done that research."

Task 2: Recruitment of Participants from the Community and the Primary Care Team to participate in the training, the initial community engagements and the Health Forum

What needs to be done?

- Criteria should be established and agreed as to who should be targeted for participation.
- Flyers, posters and promotional materials should be developed.
- The Primary Care Representatives on the Steering Group provide information on the project to the Primary Care Team and take responsibility for recruiting representatives from the team to participate in the project.
- The Community Representatives take the lead role in recruiting participants from the community. There should be a multi-stranded recruitment plan including informal, open coffee mornings, targeted information sessions with groups and organisations in the community, posters and flyers, and word of mouth.

Who needs to be involved?

- All members of the Steering Group.

When should it be done?

- The Recruitment Process should begin once the Steering Group has developed a shared understanding of the aims and objectives and developed an action plan.
- The process should be done simultaneously with the review of the Training Programme.

Issues to Consider:

- Sufficient time should be given to this process, and there should be a window of time between the conclusion of the recruitment process and the beginning of the training.
- The approach needs to be flexible and responsive to both the needs and the strengths of the participants. Information should be given personally and informally as much as possible.

Step 4 Cont'd

Task 3: Deliver the Training Programme

What needs to be done?
- The Training should involve a pre-training information session to introduce the participants to the concept of Primary Care and the project. This session should provide the participants with an understanding of what the project requires them to do and the time involved. It should also give them a taste of PA Methods. A clear timetable for the training should be given to the participants.
- The core element of the training should provide the participants with the skills to use PA methods to engage with the community. The training should provide sufficient time for the participants to practice their skills and to plan the fieldwork engagements.
- The training should also provide an opportunity for the participants to build relationships and to gain a better understanding of Primary Care and community issues.
- Support for the participants should be available throughout the process and should include interim and final reflective support sessions.

Who needs to be involved?
- The trainers and the participants, with the support of the Steering Group.

When should it happen?
- The training should begin upon completion of the recruitment process and the finalisation of the training programme.
- The pre-training session and the core training should be held as closely together as possible. Sufficient time (at least one month) should be allowed for the completion of the engagements, and an interim support session and the final session should be scheduled accordingly.

Issues to Consider:
- It is essential that sufficient time is given to the planning of the engagements. Participants need time to contact groups and to make arrangements to meet them. There also needs to be coordination of engagements so that there is no duplication.
- Lists of the meetings of community groups might be circulated to support the planning of the engagements.

"The first day, I was very sceptical. I sat back and took it all in. 'T was a good learning situation."

"We learnt new skills and techniques. We are now looking within our department. We need to evaluate our services and maybe PA techniques could be helpful here."

"It is important to go in knowing what Primary Care is and what services are out there when people start asking you questions … some people we talked to didn't know where the health centre was."

"Some people were shy, some thought we were selling something and we got a negative response before we could even say what we were doing, some were too busy."

Step 4 Cont'd

Task 4: Community Engagements

What needs to be done?
- Ensure that there is a trial run with members of the public as part of the training. This will allow participants to practice their skills in a supportive environment.
- Select the research teams. There should be three members on each team, with at least one representative from the Primary Care Team on each team. There should be a minimum of three teams.
- Plan engagements with the relevant groups in the community. Select the relevant methods for the engagement and allow the teams time to plan.
- If the engagement is with an existing group, ensure that the group has plenty of notice and is informed of what is going to happen. If the engagement is with members of the general public, ensure that the researchers have clear identification and materials with information on the project.
- Support should be available during the first engagement for those teams that want it. Allow for regular feedback on the process and make adjustments as necessary.

Who needs to be involved?
- The representatives from the community and the Primary Care Team with the support of the Steering Group.

When should it be done?
- The community engagements should be undertaken after the core training is delivered and the engagements are planned.
- The participants should be given at least one month to complete the engagements. After the first engagement, an interim support session should be conducted.

Issues to Consider:
- The research teams should be a mix of representatives from the Primary Care Team and the community. This allows for the teams to draw on different strengths and areas of expertise and is useful in building relationships.
- In selecting the groups from the community, consideration should be given to making them representative of the community i.e. age, gender, different locations etc.
- Engaging with the public can be intimidating for many people, and this should be taken into consideration. The capacity of participants to do this will vary, and it is essential that effective support and guidance is available to participants who may feel anxiety about doing this.

Step 4 Cont'd

Task 5: Analysis of Data

What needs to be done?
- The data should be analysed in two ways. First, the participants in the data collection should "tell the story" of the engagements, including where they went, who they engaged with and a summary of what they found. This will serve as an introduction to and an explanation of the "raw" data.
- An external person (or someone within the group if the capacity is available) should be identified to collate and analyse the data. A summary of this should be done in a user-friendly format.
- The use of PA Methods should be considered for summarising data for feedback to the communities. The original H-diagrams, Area Maps and Body Maps, along with summaries of the data, should be presented in a user-friendly format.

Who needs to be involved?
- The participants on the training programme, with the support of the Members of the Steering Group and the Training Group, should complete the first element.

When should it happen?
- The analysis should be done as soon as possible after the completion of the community engagements. It is important the findings are presented back to the community as quickly as possible.

Issues to Consider:
- Sufficient time will need to be devoted to this process, but, as noted above, it is important that it is fed back to the community as soon as possible. It is important to establish clear timeframes for doing so.

"Many people had come before doing research and they never heard anything about it again … well, we promised we would come back."

Step 4 Cont'd

Task 6: Community Feedback

What needs to be done?

- The information gathered through the engagements should be fed back to the community as soon as possible. The groups that were engaged with should be personally invited to view the findings.
- The feedback should be organised as a "roadshow" and presented in as many areas in the community as possible. The summaries, along with the raw data (H-Diagrams, Area Maps, Body Maps, etc.) should be displayed in areas that are accessible to the community. Community centres, schools and local libraries should be considered.
- If possible, the display should be timed to coincide with other events that will bring significant numbers of people to the centre. Flyers should also be produced and displayed throughout the community to inform people of the feedback.
- A number of people involved in the project, including members of the Steering Group and participants on the training programme, should be present to explain the process to those who attend.

Who needs to be involved?

- All of those who have been involved in the project, the Steering Group, the trainers and the participants, should support this phase of the Project.

When should it be done?

- As noted above, the feedback to the community should be done as soon as possible after the community engagements are complete. The feedback should also be planned around community events that will ensure that as many people as possible are able to see the feedback.

Issues to Consider:

- The importance of establishing a "loop" (regular feedback between the Primary Care Team, the Project Participants and the wider community) should be emphasised. This "loop" should be continued on an ongoing basis and should provide regular feedback to the Primary Care Team and others involved in providing health services.
- There needs to be someone present to explain the project and the data to members of the community. One possibility might be to produce a video, which provides this information and to run this on a loop wherever the data is displayed.

Step 4 Cont'd

Task 7: Establishment of the Community Health Forum

What needs to be done?
- The Project Steering Group and the representatives from the community and the Primary Care Team should begin to plan the role and structure of the Community Health Forum following the community engagements.
- Terms of reference for the Forum should be developed.
- The Forum should develop and finalise the action plan based on the findings from the community engagements
- The Forum should nominate representatives to the Primary Care Team and engage regularly with the community. The Forum will be responsible for maintaining the "loop" of communication and participation.
- The forum is an evolving and fluid structure, and it needs to review its membership on an ongoing basis i.e. who needs to be involved and how best to integrate and include new members.

Who needs to be involved?
- The Steering Group, the participants on the Training Programme and others as identified.

When should it be done?
- The establishment of the Community Health Forum is an evolving structure from the outset of the whole process, and it should begin to take shape following the community engagements and community feedback sessions.

Issues to Consider:
- It is important that the structure of the Community Health Forum remains fluid and open to new membership.
- At the same time, there needs to be a core group committed to sustaining the Forum. Dedicated staff resources will be required to support and develop this process.
- It is vital that new members are briefed and inducted into the process before attending their first meeting.

Community Health Forum → Primary Care Team → Community → (back to Community Health Forum)

Step 5: Evaluation

What needs to be done?

If financially possible, an external evaluator should be engaged. If this is not feasible, it is imperative that a process evaluator is undertaken to ensure that the project stays on track.

- An external evaluation should be contracted early in the process.
- It is useful for the evaluator to take a "hands-on" approach to the evaluation and be included in many of the meetings and activities of the project.
- The evaluation should assess process and outcomes.
- Toward the completion of the project, interviews and/or focus groups should be conducted with all stakeholders.
- All documentation should be reviewed.

Who needs to be involved?

- The external evaluator and the Steering Group. All stakeholders will be asked to take part in an interview or focus group with the evaluation

When should it be done?

- The evaluator should be contracted as early as possible in the project.
- The final evaluation should be produced after the feedback to the community and after the Steering Group has had sufficient time to reflect on the project and to plan for its sustainability.

Issues to Consider:

- It is essential that an evaluation with experience and expertise in working both with communities and with the statutory sector is contracted for this work.
- A "hand-on" approach allows for a much deeper understanding of the complexity of the work involved in the project.

Appendix 1.

What is Participatory Appraisal?

Participatory Appraisal is a label given to a growing family of participatory research methodologies/approaches that emphasize local knowledge and enable local people to make their own appraisal, analysis and plans. Although originally developed for use in rural areas, PA has been employed successfully in a variety of settings.

PA includes a range of different methods that can be used to gather different types of information and in different settings. The PA Methods used in this project included H-Diagrams, Area Maps and Body Maps.

The methods are easy to learn and to use, but there is a need for training and support for those who are facilitating sessions using PA Methods for the first time. Facilitators will require strong interpersonal skills and the confidence to engage with people. Building these skills can be part of the training, if required.