Formative Evaluation of the **Joint Community Participation in Primary Care Initiative**

EXECUTIVE SUMMARY

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Dr. Jane Pillinger, May 2010

Glossary of Terms

Primary Health Care

Primary health care includes a range of services designed to keep people well. It incorporates the promotion of health and screening for disease, assessment, diagnosis, treatment and rehabilitation, as well as personal social services. People can access primary health care by self-referral. Primary health care has a strong emphasis on working with communities and individuals to improve their health and social well-being. Disadvantaged communities and groups, who are more likely to have poorer health status than others, frequently have a greater need for primary care services.

Primary Care Teams

Primary Care Teams or PCTS are teams that delivery a range of primary care services that keep people well in their own communities. Teams can include, GPs, Nurses, Health Care Assistants, Home Helps, Physiotherapists, Occupational Therapists, Social Workers and Speech and Language Therapists. The Health Service Executive is current developing 530 teams which should cover 95% of the population. The Transformation Development Officer (TDO) supports the formation of these teams.

Local Implementation Group

A Local Implementation Group is a local management structure for primary care teams in each local health office area. There are 32 local health offices in Ireland.

Community Participation

The participation of communities and groups who experience poverty and social exclusion is essential to the development of primary health care services in order to shape these services and make them relevant to those with the greatest need.

Learning from the Joint Community Participation in Primary Care Initiative

The Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs and the Health Service Executive (HSE) developed a Joint Initiative to support the involvement of disadvantaged communities and groups in the development of primary health care services at local level. The Joint Initiative aimed to support and test models of community participation in primary care with a view to informing national policy and practice. Nineteen projects were funded. They were located in community development projects, local development companies, family resource centres and community and voluntary fora and worked with a range of health service staff and primary care practitioners.

Summary of project learning

This Joint Initiative, with relatively small resources, has acted as a catalyst for engagement and provides valuable learning for new community participation in primary care projects. A key to the success of the Initiative is the multiplicity of approaches that have been developed; these have allowed flexibility to respond to local needs and the different stages of project development. This suggests that a ‘one size fits all’ approach is not appropriate, since levels of community development and infrastructure and Primary Care Team (PCT) development vary from area to area.

Key learning from the Initiative is that:

- Community participation is a process that takes time and requires resources, particularly in building mutual learning and respect, promoting dialogue and creating realistic goals, expectations and actions.
- Different starting points require different methods of community participation on a continuum from information sharing to full representation on a PCT.
- Dedicated resources are needed for technical assistance, external facilitation, training and support; for example, external facilitation can be very helpful as it brings objectivity and independence to meetings, while the technical support and regional training provided by the Community Action Network (CAN) has been crucial to developing participative methodologies and partnership working.
- Utilising HSE support and expertise, for example, from community workers, social inclusion officers, social workers and health promotion officers can give real added-value and expertise to projects.
- Local community involvement has enhanced the understanding of the broader determinants of health and has uncovered and identified new community health needs. The focus on the broader context of health can be both enabling and challenging. However, this has assisted in meeting broader HSE objectives for the social inclusion of marginalised communities and a means for addressing inequalities in health.
- Multi-sectoral approaches are essential if community participation in primary care is to achieve long-term outcomes; for this reason community participation must be seen to have a broad impact cutting across the remit of many government departments and agencies.
- The need for a strategic policy direction to embed community participation as a core principle underpinning the development of primary care and in this context for policy to reflect a greater focus on poverty and inequalities in health.

1. Background to the Joint Community Participation in Primary Care Initiative

Public policy recognises that communities should be centrally involved in shaping health services, including primary care services. More recently, the *National Strategy for Service User Involvement in the Irish Health Service* has reflected these commitments and prioritised the participation of 'socially excluded groups and those whose voices are seldom heard'.

In this context, the Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs (DCEGA)[1], and the HSE Office of Consumer Affairs jointly developed and funded the Community Participation in Primary Care Initiative (the Initiative), which was designed to support disadvantaged communities and local health service providers to work together and plan for the participation of excluded communities and groups in local Primary Care Teams (PCTs) and networks, and in the implementation of the *Primary Care Strategy: A New Direction*. The Initiative supported nineteen demonstration projects in rural and urban locations across Ireland.

A Formative Evaluation of the Initiative took place between September 2009 and April 2010 with a view to drawing out the learning from the nineteen projects and to make policy recommendations for the further development of community participation in primary care.[2]

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[1] The project was initiated by the former Combat Poverty Agency, which integrated with the Office for Social Inclusion to form the Social Inclusion Division, now part of the Department of Community, Equality and Gaeltacht Affairs .

[2] The full evaluation including summaries of the nineteen demonstration projects can be accessed on **www.hse.ie/eng/services/ysys/SUI/Library/participation**

In addition to funding for the nineteen demonstration projects several supporting mechanisms were also put in place:

- Four national networking events brought together community and HSE project partners to share and exchange project developments and link projects to national developments.
- Technical support and regional training was provided by the Community Action Network (CAN) to increase capacity of community and HSE representatives in areas such as participatory methodologies, establishing representative structures and the provision of support and facilitation to individual projects.
- An online forum was established through HSE Land (**www.hseland.ie**). This additional on-line resource enabled all projects to share resources and provided a space for exchanging ideas, perspectives and approaches.
- Monthly *Community Participation Bulletins* were widely disseminated across the HSE and to community projects[3] to communicate learning and ongoing developments within the nineteen projects.
- A National Working Group was established as a sub-group of the HSE's Oversight Implementation Group of the *National Strategy for Service User Involvement*, with representation from Consumer Affairs (HSE), the Social Inclusion Division (DCEGA), HSE representatives from primary care, population health and social inclusion, the Department of Health and Children, Royal College of Surgeons, Irish College of General Practitioners, the Institute of Public Health and representatives from community organisations. Two sub-groups were also formed, one to map HSE community work and social inclusion staffing resources, and the other to provide a framework for the Formative Evaluation.

[3] The Bulletins can be accessed from: **http://www.hse.ie/eng/services/ysys/SUI/Library/participation/**

2. Policy framework on community participation in primary care

The Initiative builds on a commitment to develop community participation in primary care established under the National Partnership Agreement *Towards 2016*[4] and under the *National Action Plan for Social Inclusion 2007-2016*[5].

Community participation in primary care is a key objective of the HSE's *National Strategy for Service User Involvement in Irish Health Services 2008-2013*[6], which contains a number of goals to progress the involvement of disadvantaged groups and communities in PCTs.

The *Primary Care Strategy - A New Direction*[7] provides the framework for community participation in primary care services across the country through PCTs and more recently primary care has become integral to the HSE's Transformation Programme and the development of Integrated Service Areas. The HSE has planned for 530 PCTs to be in operation by the end of 2011 and is on target to have 394 PCTs in full operation and a further 136 in development by the end of 2010.

Community participation in primary care has been introduced as a Key Result Area and a Performance Indicator in the HSE's 2010 Service Plan.

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[4] Government of Ireland (2006) *Towards 2016 Ten Year Framework Social Partnership Agreement 2006- 2015.* Government Publications: Dublin.

[5] Government of Ireland (2007) *National Action Plan for Social Inclusion 2007 -2016.* Government Publications: Dublin

[6] Department of Health and Children (2001a) *Primary Care Strategy: A New Direction.* Stationary Office: Dublin

[7] Department of Health and Children & Health Services Executive (2008) *National Strategy for Service User Involvement in the Irish Health Service,* DOHC & HSE: Dublin.

3. Background to community participation

Community participation is essential to enable service users to participate in decisions about their health and to ensure that services are responsive to identified needs. It has gained in momentum nationally and internationally, not least because participation can positively contribute to health outcomes, to the building of trust between users and service providers, and to identifying the needs of the most marginalised communities.

Community participation is one element along the spectrum of service user involvement and empowerment in health. It exists along a continuum of participation from information, consultation, partnership, to full delegation and control. Core to successful community participation initiatives is the active participation of local people through processes of community development, which result in the empowerment of local communities to address health within a broader framework of the social determinants of health.

4. Activities carried out by the nineteen community participation demonstration projects

The Initiative funded nineteen demonstration projects in local, urban and rural, disadvantaged areas. Community partners included Community Development Projects, Community and Voluntary Forums, Local Development Companies, a Family Resource Centre and a Local Regeneration Agency. In many cases the projects took a multi-sectoral approach by involving a wider network of statutory and non-statutory organisations and agencies that are tasked with tackling social exclusion and local regeneration. Seventeen projects were based in rural or urban areas of disadvantage across the country, while two projects focussed on specific target groups (Travellers and the minority ethnic community).

Table 1 summarises the different project activities that were undertaken by the nineteen projects and the various levels and types of participation that took place.

The ten main methods used to promote and sustain community participation in primary care are summarised as follows:

i) Joint project planning through a Community Participation Steering Group

All projects established a joint Community Participation Steering Group and in some cases this was made up of a wide network of local agencies. The Steering Groups managed and developed the strategic goals of the projects locally. The Steering Groups provided a basis for partnership working, joint problem-solving, project planning and the development of joint actions. This led to a shared ownership of the projects locally and a space for exchanging ideas, perspectives and approaches.

ii) Key person(s) to coordinate and manage the project

All projects benefited from having a key person(s) to oversee and manage the project locally. This was particularly beneficial to coordinating the actions of partners, carrying out day-to-day activities and organising consultations.

iii) Mapping of community and PCT resources in the project area

A number of projects carried out a mapping of local community and PCT resources in the project area and was considered by all projects to be an essential first step in project activities. Mapping these local resources enabled project partners to identify where groups and services were located and formed the basis for information sharing and for making contact with groups locally in advance of community consultations.

iv) Information sharing

Information sharing activities were carried out jointly by all projects and proved to be a valuable tool for breaking down barriers between community and PCT representatives, promoting a dialogue, connecting local people with local services and services providers with community groups and facilities. Information sharing activities ranged from informal meetings between PCT members and community representatives to structured information sharing workshops, information fairs and seminars.

v) Recruitment of local community volunteers

Community participation requires time and commitment from volunteers in the community. The projects that recruited community volunteers, for example, to sit on a Community Health Forum or to carry out participatory research to identify local health needs, put in place processes of capacity building to build engagement, knowledge and the confidence to participate. In some cases volunteers were recruited through local community development networks, while in others volunteers came forward as part of a community consultation event. Some key issues were raised by projects about ensuring that community volunteers were representative of their local community and of key target groups. This was particularly important in developing structures for community representation on PCTs.

vi) Training and capacity building of community and PCT representatives

A significant number of projects carried out training and capacity building of community and PCT representatives. Having project funding enabled them to source experienced external trainers and facilitators for this purpose. This was approached in three main ways:

- Joint training for community representatives and PCT representatives: to develop skills for participatory research and community needs assessments or for establishing structures and terms of reference for community representation on PCTs.

- Training for community representatives: to build the capacity, knowledge and skills of local volunteers, to raise awareness of PCT services and to identify appropriate community participation methods and structures.
- Training for PCT members: to raise awareness of community participation processes and methods and the social determinants of health.

vii) Community consultations

All projects engaged in some form of community consultation through public meetings, workshops or focus groups. The community consultations were either jointly planned or run by community and PCT representatives or by the community partners. Community consultations took three main forms:

- *Consultations to assess community health needs as a basis for establishing an evidence base to be presented to and discussed with PCTs.* Some very innovative approaches were put in place, including participatory research involving and empowering local community representatives and community needs assessments grounded in local realities. These consultations often tapped into local knowledge and identified health care gaps and needs faced by the most disadvantaged communities.
- *Community consultations for information sharing:* several projects decided that it was appropriate to develop information sharing workshops as a basis for community consultations. These have enabled community and PCT representatives to come together in a neutral space to share information and knowledge about their respective roles and services as a first step to engagement. These workshops also gave participants an opportunity to identify local health needs.
- *Consultations with local groups and agencies about the most appropriate representative structure for community participation on a local PCT or primary care network*. These consultations were particularly important to ensuring that there was no duplication of local representative structures.

Several projects produced publications of their consultations. These provided an evidence base and a record of the consultations, which were then used as a basis for a launch in the community to engage a wider range of agencies and local groups, or in some cases the launch of the PCT itself. In many cases community needs assessments were wide ranging and focussed on the broader determinants of health. These proved important for PCT awareness and for establishing the basis for engagement with other agencies in addressing health related issues that were out of the scope of PCT services.

viii) Development of Community Health Forums

The majority of projects have established Community Health Forums, with the remaining projects planning to do so in the near future. In some cases several local Community Health Forums came together in a primary care network to coordinate their representation at the Local Implementation Group (LIG) level. In other cases community representation was facilitated through a sub-group of the PCT or LIG, or as a separate Community Participation Working Group, made up of community and PCT representatives. Community Health Forums have nominated a minimum of two representatives to attend PCT meetings.

The projects presented various different models of how to establish a Forum. In several projects the Forum has been established as part of the process of community consultations, while in others nominations have been sought from groups representing specific target groups in the local community. In most cases criteria was established from the outset in terms of representation from local geographic communities and target groups, with terms of reference setting out the role, scope and purpose of their local Community Health Forums.

Community Health Forums have the objective to provide a representative group of people from the community who can provide a community voice on PCTs and through which PCTs can feed information about services back to the community. They form the basis to build the capacity, knowledge and expertise of community representatives to become 'community experts' in health. Community Health Forums have carried out various activities including the collection of information about issues affecting the health and well-being of local people, a forum for prioritising issues for PCTs to address and information sharing in the wider community about local services.

ix) Partnership with a broad range of relevant agencies to tackle identified needs

An important outcome of many projects is that a renewed focus has been given to the broader determinants of health. This has led some projects to develop partnerships with local agencies to ensure that PCT services link into agencies that can impact on health outcomes, for example, local authorities, local development agencies and regeneration bodies.

x) Strategy to sustain community participation

All projects have put in place a strategy to sustain community participation in the light of the ending of the funding from the Initiative. This has included action plans and facilitated discussions between community and PCT representatives to identify priorities and future actions. The projects have a real commitment to sustain this work in the longer-term. However, some community projects are concerned about how community participation in primary health care can be sustained in the new Local Community Development Programme. This is particularly important to the roll-out of PCTs across the country and has led many project partners to suggest that community organisations need to be supported through a national strategic framework that focuses on the participation of disadvantaged communities in the roll out of primary care teams

5. Summary of project outcomes

The Initiative has led to some very promising outcomes that have relevance to the roll out of community participation in primary care, including:

- A better understanding and huge learning for community and PCT representatives of the role and impact of community participation in primary care and of the different models of community participation that can be effectively implemented.
- Development of new models of community participation and new working relationships between the HSE and community organisations, and in some cases a wider network of agencies and organisations.
- Improved capacity, motivation and commitment from the community to participate in primary care and for PCTs to understand the value of community participation, particularly with regard to the broader context of the social determinants of health.
- A wealth of innovative and creative approaches and outcomes to promote processes of community participation, for example, in carrying out information sharing, community needs assessments and in creating representative community structures. This has resulted in an improved capacity to identify and address the health needs of the most marginalised communities.
- Enhanced knowledge of PCT and community-led services to the mutual benefit of PCTs and local communities.
- A significant value from the sharing of roles, perspectives and understandings, and a potential for a greater sharing of decision-making, problem-solving and joint approaches between community organisations and PCTs, resulting in mutual understandings and the realistic managing of expectations.
- Positive outcomes from the Initiative and substantial buy-in from key policy makers and practitioners in the HSE, resulting in a network of community participation 'champions' advocating for community participation both nationally and on the ground.

6. Critical success factors

The Formative Evaluation has highlighted four critical success factors for effective outcomes. These are:

i) The readiness of the community to participate

- It is necessary for there to be a vibrant and effective community infrastructure with which PCTs can engage. PCTs should be able to link with existing organisations on the ground as a basis for developing community participation on their teams.
- All of the projects in the Initiative had the active participation of community organisations that were functioning in the community and this was deemed to be key to the success of the projects.
- In the context of a changing environment in the funding and management of local community development projects it will be important to ensure that there is a solid community infrastructure with which PCTs can engage. This can be usefully progressed under the new Local Community Development Programme.

ii) The extent to which the PCT is ready, prepared and willing to engage

- This is affected by the level of PCT development and the extent to which performance management and team development have incorporated community participation, as well as levels of awareness of the benefits and opportunities of community participation and preparedness to engage in community participation.
- A critical role is played by active participation of the TDOs / Primary Care Development Officers in each network area. For this reason it is essential that TDOs / Primary Care Development Officers are provided with the incentives, training and tools to be ‘champions’ of community participation.

- Community participation needs to be built into the learning and development of PCTs to ensure that they are ready and equipped with the capacity and knowledge to play an active role in shaping and developing community participation in primary care.
- Community participation in primary care needs to be able to develop in constructive ways so that local communities can see a value to participation. If PCTs are poorly developed or if they are unable to respond to community needs, this can have implications for engagement.
- PCTs have a critical role to play in the future in identifying and assessing community health needs, reducing inequalities in health, listening to and responding to the views of the community and working in partnership with local agencies. These are new skills that many PCTs do not currently hold.

iii) The availability of support structures and resources in the community

- Having resources in the community to support and build capacity for community participation requires expertise from community development workers to build capacity, motivation and interest.
- In some cases these resources and expertise can be found in the HSE from community workers, social inclusion officers, health promotion officers and social workers.
- In the future this expertise will need to be more strategically targeted to community participation in primary care and through a national framework of supports.

iv) The extent to which there are existing structures and forums for participation

- If community participation projects are to be successful in the long-term, having the appropriate structures in place for participation is crucial. In some cases there are existing structures and forums for participation, while in others these need to be established.
- The process of engagement was significantly strengthened in those projects that established joint terms of reference for participation on PCTs.

7. Sustainability of community participation in primary care

The Formative Evaluation suggests that if community participation in primary care is to be sustained and rolled out across all PCTs there will be a need for:

- A strengthened national framework, including robust guidelines and indicators so that actions are implemented and reported upon.
- Dissemination of the learning from the Initiative, including easy to use guidance on models of community participation.
- Ongoing resources to enable community organisations to participate effectively and articulate their interests and needs, to build the capacity, skills and awareness of community participation of both HSE and community representatives, and to bring in specialist external supports and technical assistance.
- Alongside this community participation will only be successful if there are appropriate anti poverty/social inclusion representative structures for the HSE to link with.

- Changes in culture and practice to ensure that community participation becomes core to the PCT work, including a stronger focus given to community participation methodologies and the benefits of community participation in PCT learning and development.
- More attention to the measurement of the impacts and outcomes of community participation in primary care and a method for measuring qualitative and quantitative impacts of community participation, from a community and a PCT perspective.

8. Recommendations

The following recommendations provide a framework for building this sustainability, learning and strategic direction for community participation in primary care in the future.

- Recommendation 1: Implement a strengthened national policy framework for community participation in primary care.
- Recommendation 2: Create a senior commitment in the HSE to community participation.
- Recommendation 3: Enhance the visibility of socio-economic equality and inequalities in health.
- Recommendation 4: Disseminate the learning on community participation from the Initiative.
- Recommendation 5: Sustain and provide resources for community participation in primary care.
- Recommendation 6: Provide resources for training, technical support, external facilitation and other networking supports.
- Recommendation 7: Build community participation in primary care through a wider network of organisations and agencies.
- Recommendation 8: Build the capacity of PCTs to engage more effectively in community participation.

Table 1: Summary of project activities

Lead community partner	Community Participation Steering Group	Community consultations	Community needs analysis
HSE West			
NW Roscommon CDP, Ballaghaderreen	✓	✓	
Mayo Intercultural Action, Castlebar	✓	✓	✓
Leitrim Development Company, Co Leitrim	✓	✓	✓
Iorras le Cheile, Belmullet, Co Mayo	✓	✓	
Paul Partnership, Limerick City	✓	✓	✓
Lifford-Clonleigh Resource Centre, Donegal	✓	✓	✓*
HSE South			
West Cork Island Projects Group, Bantry	✓	✓	✓**
Wolfe Tone CDP, Wexford	✓	✓	
Follain Community Health Project, Waterford	✓	✓	
South Tipperary Community Forum, Clonmel	✓	✓	✓
HSE Dublin Mid-Leinster			
Westmeath Community Development Ltd, Athlone	✓	✓	
Equal Access CDP, Tallaght, Co Dublin	✓	✓	✓
Fatima Regeneration Board, Dublin	✓	✓	✓*
Offaly Local Development Company, Banagher	✓	✓	✓
HSE Dublin North-East			
Blakestown CDP/Mountview FRC, Blanchardstown	✓	✓	✓
Corduff CDP / Blanchardstown CDP, Blanchardstown	✓	✓	✓*
Monaghan Community Forum, Monaghan	✓	✓	
Finglas South CDP, Finglas, Dublin	✓	✓	
Pavee Point, Dublin	✓	✓	

* Community needs analysis carried out prior to the project

** Community Health Needs Assessment was carried out in 2004; this is to be updated in 2010

Joint training	Community participation training for PCT members	Training for community reps	Community Health Forum	Sustainability built into project
✓		✓	✓	✓
		✓	✓	✓
✓		✓	✓	✓
		✓	✓	✓
✓		✓	✓	✓
✓	✓	✓	✓	✓
✓		✓		✓
		✓		✓
		✓		✓
✓			✓	✓
✓		✓	✓	✓
	✓			✓
		✓	✓	✓
	✓		✓	✓
		✓		✓
✓			✓	✓
				✓
		✓		✓
		✓		✓

Joint Community Participation in Primary Care Initiative:
Summary of project objectives, actions and learning

Corduff CDP / Mulhuddart, Co Fingal

Blakestown CDP / Mountview FRC

Finglas South CDP

Pavee Point

Fatima Regeneration Board

West Tallaght

- Community Participation Steering Group
- Community consultations
- Community needs analysis
- Joint training
- Community participation training for PCT members
- Training for community reps
- Community Health Forum
- Sustainability built into project

4 km
4000 yds

Joint Community Participation in Primary Care Initiative:
Summary of project objectives, actions and learning

HSE Dublin/North East

HSE Dublin Mid-Leinster

HSE West

HSE South

Lifford-Clonleigh Resource Centre

Monaghan Community Forum

Leitrim Development Company

Westmeath Community Development Ltd

Offaly Local Development Company

South Tipperary Community Forum

Wolfe Tone CDP

Fallain Community Health Project

Mayo Intercultural Action, Castlebar

North West Roscommon CDP

Iorras le Chéile

Paul Partnership, Limerick City

West Cork Island Projects Group

Hare Island

Sherkin Island

Cape Clear Island

Long Island

Whiddy Island

Bere Island

Dursey Island

- Community Participation Steering Group
- Community consultations
- Community needs analysis
- Joint training
- Community participation training for PCT members
- Training for community reps
- Community Health Forum
- Sustainability built into project

70 km
40 mls