

Formative Evaluation of the Joint Community Participation in Primary Care Initiative

Final report

Dr Jane Pillinger, Independent Researcher and Policy Advisor

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Feidhmeannacht na Seirbhíse Sláinte
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The views expressed in this evaluation are the author's own and not necessarily those of the Social Inclusion Division or the Health Service Executive

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Glossary

AND	Assistant National Director
CAN	Community Action Network
CDHN	Community Development Health Network
CDP	Community Development Project
CHF	Community Health Forum
CIC	Citizens Information Centre
CPAG	Community Participation Action Group
CPWG	Community Participation Working Group
DCEGA	Department of Community, Equality and Gaeltacht Affairs
DFSA	Department of Social and Family Affairs
DoHC	Department of Health and Children
FRC	Family Resource Centre
GP	General Practitioner
HEBE	Health Boards Executive
HSE	Health Services Executive
KRA	Key Results Area
LCDP	Local Community Development Programme
LGBT	Lesbian, Gay, Bisexual and Transgender
LHAG	Local Health Action Group
LHO	Local Health Office
LIG	Local Implementation Group (local management structure for PCTs at the LHO level)
LIT	Local Implementation Team
NAPS	National Anti-Poverty Strategy
PA	Participatory Appraisal
PCT	Primary Care Team
PHN	Public Health Nurse
RAPID	Revitalising Areas by Planning, Investment and Development
RDO	Regional Director of Operations
TDO	Transformation Development Officer
WHO	World Health Organisation

Definition of terminology used in the report

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.

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.

Executive Summary

Community Participation in Primary Care Joint 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 few 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 the 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. This work 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

- There is a 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). This 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 making policy recommendations for the further development of community participation in primary care.²

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 to link projects to national developments.
- Technical support and regional training was provided by the Community Action Network (CAN) to increase the 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.

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

- Monthly *Community Participation Bulletins* were widely disseminated across the HSE and to community projects³ 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: HSE Office of Consumer Affairs, the Social Inclusion Division (DCEGA), HSE representatives from primary care, population health and social inclusion, the Department of Health and Children, the Royal College of Surgeons, the 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.

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 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.

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.

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

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*. Stationery Office: Dublin

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

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).

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. This 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 service 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 Health 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 Health 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 in ensuring that there was no duplication of local representative structures.

Several projects produced publications on 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 Health 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 were 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 of providing 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 which 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 Health 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
- Changes in culture and practice to ensure that community participation becomes core to the PCT work, including a stronger focus on 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.

Alongside this community participation will only be successful if there are appropriate anti poverty/social inclusion representative structures for the HSE to link with.

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.

Section 1: Introduction

Structure of the Report

The report is structured into six sections:

- Section 1 gives an overview of the aims and objectives of the Joint Community Participation in Primary Care Initiative (the “Initiative”) and of the aims, objectives and methodologies of the Formative Evaluation.
- Section 2 provides a background to the policy and service delivery strategies that impact on community participation in primary care and sets the policy and service delivery context for the work of the Initiative.
- Section 3 provides an overview of conceptual frameworks and methodologies on community participation in primary care.
- Section 4 is the main body of the report and provides a detailed overview of the outcomes and findings of the nineteen projects that were funded under the Initiative.
- Section 5 gives an overview of how the Initiative has been developed and implemented nationally and includes an overview of findings from interviews with key stakeholders who are in a position to progress community participation in primary care.
- Section 6 concludes the report and sets out the recommendations from the Evaluation.

A more detailed overview of the nineteen projects can be found in Appendix 2, which sets out, project-by-project, the objectives, backgrounds, project actions and project learning.

1.1 The Joint Community Participation in Primary Care Funding Initiative

The Joint Community Participation In Primary Care Funding Initiative was established as a partnership between the Combat Poverty Agency (now Social Inclusion Division, Department of Community, Equality and Gaeltacht Affairs, DCEGA)⁸ and HSE Office of Consumer Affairs, in collaboration with Primary Care HSE, from 2008-2010. This partnership brings together three distinct areas of expertise and policy development:

- The work of the Combat Poverty Agency in its project *Building Healthy Communities* and in establishing a national framework for community development and health and in highlighting the role that local communities can play in addressing inequalities in health

⁸ The Initiative originated in the Combat Poverty Agency, which was integrated into the Social Inclusion Division of the DFSA in 2009. In 2010 the Social Inclusion Division was moved into the new DCEGA. Throughout the report reference is made to the Social Inclusion Division (DCEGA).

- The development of service user involvement in health through the HSE's *Strategy for Service User Involvement in Irish Health Services 2008-2013* (DoHC & HSE 2008) and, as part of this an ambition to give practical effect to the objective of implementing community participation in health.
- The ongoing development and roll-out of Primary Care Teams (PCTs) under the national primary care strategy: *Primary Care Strategy - A New Direction, 2001* (DoHC 2001a) and the objective to build community participation as a core activity in primary care. More recently this has become a core element of the HSE's Transformation Programme and the newly formed integrated national and regional structure of Integrated Service Areas.

The project was funded jointly by the Social Inclusion Division (DCEGA) and Community Affairs HSE. Project funding of between €10,000 and €15,000 was provided for nineteen local demonstration projects that were developed and run jointly between community organisations and the HSE. The projects were funded from January 2009 for between twelve and fifteen months.

The Initiative had three broad aims:

- To support and enable disadvantaged communities and groups to participate in local PCTs and networks
- To test and develop models of community participation in primary care
- To inform the ongoing development, policy and practice of primary care.

The ongoing work of the Initiative has been to:

- Develop and support community representative structures to feed into PCTs and Networks
- Develop joint plans between the HSE and community groups to support community participation in PCTs and Networks using participative methodologies
- Training and support for community groups and PCTs on community participation.

1.2 Aims, objectives and methodology of the formative evaluation

The formative evaluation of the Initiative commenced in September 2009 and was completed in April 2010.

1.2.1 Aims of the formative evaluation

The aim of the formative evaluation was to develop and progress community participation in primary care by focussing on:

- The building of community infrastructure in the Initiative
- The project work plans, delivery and project outcomes
- The development of participatory methods and strategies
- The learning from the nineteen projects that are funded through the Initiative
- The potential for the mainstreaming of learning for policy and service delivery.

1.2.2 Objectives of the formative evaluation

The objectives of the formative evaluation are:

- To assess the degree to which the objectives of the Initiative are being met and whether the resources committed to their achievement are appropriate and realistic
- To identify the strengths and weaknesses of the Initiative, enabling factors and barriers
- To capture the main learning for policy and practice
- To identify models of community participation in primary care and to suggest approaches and guidelines for consideration at national level
- To analyse and provide evidence of the contribution of the Initiative, and the approaches adopted, to tackling poverty and health inequalities
- To identify and elaborate on key policy issues arising from the work
- To make specific policy recommendations on tackling poverty and health inequalities and on the participation of disadvantaged communities in primary health care.

Whilst the primary focus was on the Initiative overall, the evaluation drew on the work and experience of all the groups funded under the Initiative.

1.2.3 Evaluation methods and approaches

The evaluation used a variety of evaluation methods and tools. The methodology sought to provide for ongoing assessment and reflection, methods for building learning into the process and the provision of regular feedback. This included:

- A system for benchmarking milestones and progress in achieving the aims and objectives of the Initiative
- A monitoring and evaluation framework for measuring and progressing actions
- The development of a set of principles and benchmarks for good practice, against which the project's objectives, actions, outcomes and processes were monitored
- A method for regular communications and feedback to the individual projects, the Steering Group, established for the Initiative, and the Evaluation Sub-Group, established by the Steering Group.

This was carried out by:

- Documenting and informing the ongoing development of the Community Participation in Primary Care Initiative
- Analysing developments, with reference to national and international literature and current policy
- Engaging with national and local stakeholders, including participants in the Initiative
- Disseminating learning from the evaluation in order to contribute to the ongoing development of projects to enhance community participation and service provision in primary care
- Interviews and focus groups with each of the nineteen projects, including two visits to each project, to draw out the learning from community participation; and to identify ways of overcoming barriers and obstacles,
- Highlighting success stories and the role that can be played in PCTs. This also involved supporting projects to develop self-evaluation processes and to document learning in project diaries

- Two evaluation questionnaires, one at the start of the Formative Evaluation and one at the end of the Initiative
- Drawing out policy and practice issues and relating these to relevant national policy commitments and strategies, and making recommendations for national policy.

A number of ongoing information activities were carried out during the formative evaluation, including:

- Participation in national networking events and regional training seminars
- Presentations to the National Working Group and the Evaluation Sub-Group
- Production of monthly *Community Participation in Primary Care Bulletins*. These were widely disseminated amongst community organisations and HSE staff via email and the HSE's Internet site⁹.

⁹ The Bulletins can be accessed from: <http://www.hse.ie/eng/services/ysys/SUI/Library/participation/>

Section 2: Community participation and primary care: policy and service delivery context and background

2.1 Introduction

“Enabling people to live healthier and more fulfilled lives is the core purpose of the HSE. Our vision is that everybody will have easy access to high quality care and services that they have confidence in and staff are proud to provide”. HSE Mission Statement

Community participation is a long standing objective of Irish health care policy and was identified as a priority in the National Health Strategy *Quality and Fairness* (DoHC 2001a). Community participation is set out in the Primary Care Strategy, *Primary Care: A New Direction* (DoHC 2001a). This is in line with the commitments to enhance service user involvement in health care under the *National Strategy for Service User Involvement in the Irish Health Service* (DoHC & HSE 2008), which provides the focus for involving services users in the design, planning, development and delivery of health services in Ireland.

Community participation in health care is defined as:

‘A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (HEBE 2002: 3)

Community participation in primary care is now a core policy objective and represents a new direction and focus for primary care services. This is being driven by two key developments in health service delivery, notably the integration between hospital and primary care services and the involvement of service users and communities in decision-making about health services. Alongside this is a more strategic direction being given to integrated delivery of health services and to social inclusion, inequalities in health and health promotion.

The HSE Change Process (HSE 2008a) highlights how service users and the local community are integral to HSE service quality through:

“A partnership approach that engages all parts of the system, including service users, their families and local communities, voluntary and community-based organisations, other statutory bodies, staff, trade unions and representative bodies” (HSE 2008a:4).

Community participation is also a commitment under the White Paper on Supporting Voluntary Activity on the basis that:

“There is a shared commitment by both the State and the voluntary sector to ensure the involvement of consumers and people who avail of services in the planning, delivery, management and evaluation of policy and programmes. This applies at all levels: national, regional and local” (Government of Ireland 2000: 16).

Ireland also has a long tradition of community development and a wealth of expertise on the ground in local communities. It is under the Initiative that a concerted national focus has been given to community participation in primary care.

Core policy strategies relating to community participation in primary care

Primary care

- The development of PCTs is a strategic goal under the National Partnership Agreement *Towards 2016* (Government of Ireland 2006) and under the National Action Plan for Social Inclusion 2007-2016 (Government of Ireland 2007).
- The *Primary Care Strategy - A New Direction, 2001* (DoHC 2001a) has provided the direction for the development of primary care services across the country through PCTs.
- Primary care is integral to the HSE's Transformation Programme and the development of Integrated Service Areas.

Community participation

- The *National Strategy for Service User Involvement in Irish Health Services 2008-2013* has a number of goals to progress the involvement of disadvantaged groups and communities in PCTs (DoHC & HSE 2008).
- The involvement and participation of citizens is a core objective of the *White Paper on Supporting Voluntary Activity* (Government of Ireland 2000). The White Paper highlights the importance of creating "a more participatory democracy where active citizenship is fostered" (2000:63). It refers to the fundamental role played by the Community and Voluntary sector in Ireland to "provide channels for the active involvement and participation of citizens" (2000:63).
- The Local Community Development Programme (LCDP) is the main programme of statutory funding for social inclusion and local development, funded by the DCEGA and administered by Pobal. It replaced the Local Development Social Inclusion Programme and Community Development Programmes (CDP) in December 2009. The new programme has led to the integration of CDPs into Local Development Companies/Partnerships. Goal 4 of the LCDP is relevant to community participation: "To promote engagement with policy, practice and decision making processes on matters affecting local communities".
- Three main outcomes are established under Goal 4. First, effective structures and processes in place for dialogue between policy makers, providers and local communities. Second, greater engagement in policy and decision making processes by the community. Third, improved understanding of local community concerns and priorities by policy makers and service providers (Centre for Effective Services 2010).

2.2 Policy documents and service delivery strategies with relevance to community participation in primary care

The Department of Health and Children (DoHC) has the overall responsibility for the Primary Care Strategy and its implementation and evaluation; as well as for the oversight of the Primary Care Capital Programme; and policy regarding GP services and general practice policy issues. The practical implementation of primary care rests with the HSE, the targets of which are set out in the HSE Service Plan 2010.

2.2.1 Quality and Fairness: A Health System for You (DoHC 2001b)

The Health Strategy sets out the government's health strategy, vision, principles, national goals and framework for change. This includes the strengthening of primary care; reform of the acute hospital system; funding; developing human resources;

organisational reform; and information. Action 52 of the Strategy sets out a commitment to community participation:

“Provision will be made for the participation of the community in decisions about the delivery of health and personal social services. While there are some community participation initiatives already operating in discrete areas of activity at national and regional level, a more structured approach to community participation is required. Such participation has a number of important advantages”. (DoHC 2001:81)

The Strategy contains specific actions on social inclusion, including anti-poverty targets to implement the (then) National Anti-Poverty Strategy (NAPS) health targets and the identification of five specific target groups: Travellers, asylum seekers, homeless people, substance misusers and prisoners. The Strategy is based on the principles of equity, people-centredness, quality and accountability.

Specific guidelines on a health service approach to community participation were produced by HEBE (2002) in response to this commitment in the Strategy. The guidelines were developed to enable health service providers to ensure that the principle of ‘people-centredness’ was integrated into the way that services are planned and delivered.

2.2.2 Primary Care: A New Direction (DoHC 2001a) and recent developments in primary care

The *Primary Care Strategy* aims to strengthen the primary care system, to develop integrated, inter-disciplinary, team-based, quality and user-friendly services, and to enhance the capacity of primary care in disease prevention, rehabilitation and personal social services. It refers to the need for community participation:

“Mechanisms for active community involvement in Primary Care Teams will be established. Community participation in primary care will be strengthened by encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services”. (DoHC 2001a: 39)

The Strategy outlines how the development of an integrated primary care service can lead to better outcomes, better health status and better cost effectiveness. The plan places an emphasis on a comprehensive model of primary care that meets clients’ needs in more integrated ways, including co-ordination between primary care and hospital services. The Strategy also focuses on the integration and delivery of social inclusion in services such as intellectual disability services, Traveller health, palliative care, acute hospitals, community paediatrics, physical/sensory disability services, childcare and specialist services for the elderly and mental health.

According to the HSE “Primary care services aim to support and promote the health and well-being of the population by providing locally based accessible services” (HSE Service Plan 2010: 14). It is envisaged that, in the future, there will not only be better integration between hospital and community based services, but that more services will be provided in the community setting, resulting in expanded community based services and fewer services in a hospital context. Primary care is a key priority of the HSE’s Transformation Programme and for the development of the HSE’s Integrated Services Programme. On this basis:

“The establishment of PCTs creates a supportive environment to facilitate structured approaches to chronic disease management, enhanced multi-

disciplinary working and integration between primary, secondary and tertiary services". (HSE Service Plan 2010: 14)

A consistent and standardised approach has been put in place that allows for local flexibility to enable PCTs to develop programmes that respond to identified needs in their local areas. Key areas of PCT activity include chronic disease management programmes; linkages to mental health services and mental health promotion programmes in the community; hospital avoidance initiatives; services integrated to hospital services, following discharge; and health promotion initiatives.

PCTs are typically made up of General Practitioners, nurses / midwives, home helps, physiotherapists, occupational therapists and administrative staff. In the longer term it is anticipated that all PCTs will include a wider health and social care network of other primary care professionals such as speech and language therapists, social workers, community pharmacists, dieticians, community welfare officers, mental health services, disability services, dentists, chiropodists and psychologists. While some PCTs already include some or all of these professionals, this tends to be the exception rather than the rule.

The establishment of PCTs

The establishment of targets for PCTs was made under *Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015*, which states that:

"This will entail ongoing investment to ensure integrated, accessible services for people within their own community with a target of 300 primary care Teams by 2008, 400 by 2009 and 500 by 2011. A review of these targets will be undertaken in 2008". (Government of Ireland 2006: 52)

This is reiterated under Goal 11 of the National Action Plan for Social Inclusion which sets out the commitment to:

"Develop 500 primary care Teams by 2011 which will improve access to services in the community, with particular emphasis on meeting the needs of holders of medical cards". (Government of Ireland 2007: 15)

The HSE has planned for 530 PCTs, across 134 Primary Care Networks, to be in operation by the end of 2011. This is on the basis that people will access up to 95% of the care they need within their local community. The roll-out of the PCTs commenced in 2003/2004 through pilot sites across the country. The roll-out of the remaining Teams began in 2006. A target has been set to have 394 Teams holding clinical Team meetings and a further 136 Teams in development by the end of 2010.

At the end of January 2010, 252 PCTs were either fully operational or in development (HSE 2010a):

- 228 PCTs in full operation (holding clinical Team meetings and involving GPs and HSE staff), with 1,605 staff members and 840 GPs providing services to over 1.8 million people
- A number of Teams currently in development, with 69 of these Teams having held introductory Team meetings
- A further 24 Teams holding multi-disciplinary clinical meetings without the participation of GPs.

Community participation and PCTs

Primary care plays a central role in improving access to a wider range of services in the community. A core element of this is the participation of the local community in the planning and provision of services. This was first signalled in the Primary Care Strategy (DoHC 2001a) where reference was made to the need to establish active community involvement in PCTs and to facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services.

A number of resources have been produced to raise awareness on the need for community participation, for example, *Guidelines for Community Involvement in Health* produced by the National Primary Care Steering Group (DoHC 2004) and *Community Participation Guidelines* (HEBE 2002). However, it has been necessary to develop a strategic policy direction to community participation in health and to make this a requirement of all PCTs. As a result, community participation in primary care has been created as a Key Result Area of the HSE 2010 Service Plan. The Key Result Area states that community participation will be a deliverable in 2010 through:

“Opportunities for engagement with local communities provided through PCTs in a systematic way in accordance with the principles and guidelines endorsed in the *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*”. (HSE 2010b: 15)

In addition, a performance indicator (PI) is established based on “the number and % of PCTs with engagement with the local community” (HSE 2010b:12).

As part of the process of providing a model for community participation in primary care, the national Working Group of the *Community Participation in Primary Care Initiative* developed a set of guidelines setting out a *Process for Community Participation in Primary Care*. These were widely circulated across the nineteen projects and PCTs, to all Transformation Development Officers and Local Health Offices, and published on the HSE’s Internet site (see Appendix 3).

2.2.3 National Strategy for Service User Involvement in the Irish Health Service 2008-2013

The *National Strategy for Service User Involvement in the Irish Health Service* (DoHC & HSE) is based on the principle that “the service user should be central to their own care and to the design and delivery of health and personal social services” (2008: 7). The objective is that this will result in the provision of more appropriate and higher quality services and increased satisfaction and compliance with services. A wide and transformative definition is given to service user involvement:

“A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change”. (DoHC & HSE 2008: 2)

Specific reference is made under Goal 2 to the development of service user involvement in PCTs, including the provision of guidance to local services and PCTs on best approaches to user involvement. This, alongside Goal 5 of the Strategy, where “all involvement work will prioritise the participation of socially excluded groups and those whose voices are seldom heard” (DoHC & HSE 2008: 16) provided the

framework for the partnership with the Combat Poverty Agency / Social Inclusion Division (DCEGA) for the *Joint Community Participation in Primary Care Initiative*.

The goals and actions of the Strategy are monitored by an Oversight Implementation Group through the HSE Office of Consumer Affairs. A sub-group of the Oversight Implementation Group has been established in relation to the Initiative, in partnership with the Social Inclusion Division (DCEGA)

2.2.4 HSE Transformation Programme

The HSE Transformation Programme (HSE 2006) has highlighted key challenges in providing needs-based, integrated health and personal social care services. The Transformation Programme addresses the importance of adopting a population health approach in delivering health and social-care services.

2.2.5 Integrated Services Programme and improving linkages across the HSE

A recent development in HSE service delivery is the new framework for integrating services between hospital and community-based care through the Integrated Service Programme. A single national Integrated Services Directorate, delivered through four new regional structures (HSE Dublin Mid Leinster, HSE Dublin North East, HSE South and HSE West) has been created. The Regional Directors of Operations (RDOs) now have the responsibility for delivering and managing services at a regional level, based on national priorities and regional budgets. This integration also extends to the newly established Care Group Leads, led by Assistant National Directors (AND) covering:

- Children and Families
- Mental Health
- Disability
- Older People
- Social Inclusion
- Palliative Care.

This integration across Care Groups, through mainstream services, along with the Integrated Services Programme, has the potential to create a more strategic approach to coordinating the design, planning and delivery of PCT services than has existed in the past. A strategic mechanism has been introduced to improve the integration between primary care and Care Groups, nationally and within the RDO structure. The Performance Contracts drawn up for RDOs integrate the HSE's 2010 Service Plan actions and the work plans for each Care Group.

Interviews carried out for the evaluation with the Assistant National Director for Social Inclusion and the National Primary Care Services Manager highlighted the benefits of this structure for a more joined up way of working in the HSE, which is considered to be of particular benefit to the development and operation of PCTs.

2.2.6 Health promotion

A new strategy for Health Promotion is due for publication in 2010. This builds on the existing *National Health Promotion Strategy* (DoHC 2004b), which has focused on the link between health promotion and the determinants of health and the importance of inter-sectoral and multi-disciplinary approaches. Like the *National Health Strategy Quality and Fairness* (DoHC 2001b), it refers to the (then) *National Anti-Poverty Strategy* (NAPS) and poverty as key determinants of health, and the importance of

poverty proofing. In so doing the *National Health Promotion Strategy* identifies the specific health needs of men, women, children, older people, and the impact of socio-economic status on health. It recommends health proofing as a key mechanism to ensure healthier public policy development. It advocates the role of multi-sectoral partnerships in contributing to health promotion actions, advocating community action in health promotion and collaborative work with statutory bodies, local development agencies and the mainstream NGO sector as well as community capacity building to ensure the participation of the most marginalised groups.

2.2.7 Population health

The HSE *Population Health Strategy* aims to “Maintain and improve the health of the entire population and to reduce inequalities in health status between population groups” (HSE, 2008b:2). HSE Health Inequalities Framework is due to be published in 2010 and integrates with and builds on the Population Health Strategy. The *National Health Inequalities Framework (2009-2012)* will aim to improve and promote a population approach to reducing inequalities in health. As well as working to address key health issues it will address the broader determinants of health. The framework is timely in that it will highlight how primary care can address the health and well-being of the most marginalised communities. This will be important to raising awareness and policy responses to the social, economic, cultural and political factors that impact on health status and access to health services. It will be a lens on the how poverty, disadvantage and socio-economic status can be addressed as determinants of health. The Strategy provides a unique opportunity for the HSE to work in partnership with local agencies and local communities to address health inequalities and to engage PCTs in this process.

2.2.8 Social inclusion

In the area of social inclusion there are now greater possibilities for synergy between social inclusion target groups¹⁰ and PCTs. As a result there is an increasingly important role to be played by Social Inclusion Specialists (one located in each of the four RDOs) in promoting community participation, particularly of the most marginalised communities and groups. The work carried out with disadvantaged target groups is now being disseminated to TDOs and PCTs. For example, methodologies on comprehensive needs assessments for homeless people and information from the ethnic identifier pilot projects carried out under the National Intercultural Strategy in Health. There is also a key role to be played by the Social Inclusion Care Group in the future on the promotion of community participation and through the development of and links to community infrastructure on the ground, for example, through existing networks such as Traveller health projects, Drugs Task Forces and the roles of local Social Inclusion Managers. A core objective of the Social Inclusion Care Group is to develop and promote a mainstreaming approach, rather than a targeted approach that can reinforce stigmatisation, to the delivery of services for groups such as asylum seekers and homeless people. This has the potential to enable mainstream service providers and PCTs to be better equipped to provide services to marginalised groups.

The *National Traveller Health Strategy 2002-2005* has highlighted the central role that primary care has in the provision of improved services to the Traveller community. In particular, Traveller Primary Care Projects have become an innovative

¹⁰ The Social Inclusion Care Group provides the following services: drug and alcohol services, homeless services, services for minority ethnic communities, Traveller health services, community development, HSE RAPID and CLAR programmes, HIV / STI services, services for LGBT communities, and Community Welfare Services.

and appropriate way to engage Travellers in improving access to health services, with a focus on the broader determinants of health, and in carrying out local needs assessments.

The National Intercultural Strategy in Health 2007-2012 (HSE 2007) provides a framework for the provision of intercultural health services and highlights the key role of primary care in meeting the needs of minority ethnic groups. It states that the “provision of active support around community participation and development are regarded as critical to the attainment of enhanced health outcomes” (HSE 2007:12).

Section 3: Community participation in primary care: conceptual frameworks and methodologies

3.1 Introduction

Community participation in primary care is a central element of a thriving civil society and a responsive health service. In recent years the role of civil society and volunteering have become an essential part of contemporary forms of democracy, often defined as 'participatory' democracy. Stronger government-citizen relationships are increasingly seen as vital to building trust, accountability and legitimacy with government, and improved policy outcomes (OECD 2001), while a strong civil society can meet human needs and provide the conditions for a healthy and inclusive society (Carnegie Trust 2010).

In this respect the concept of civil society has become a unique way in which marginalised groups and individuals can articulate their common concerns and engage actively with contemporary democracy (McInerney & Adshead 2010).

3.2 Defining community participation in primary care

Community participation in primary care is a powerful and dynamic tool for change and is one element of service user involvement and empowerment. It can be defined as a process that gives a voice to the community and enables local communities and health professionals to develop joint approaches, shared perspectives and appropriate solutions to the health and well-being of people in the community (Combat Poverty Agency 2005 and 2009). In turn, building sustainable integrated communities is crucial to generating social capital and to improving well-being (NESC 2009), while building healthy communities provides a unique way to empower local people and communities to address inequalities in health (Burke 2009).

As a result, community participation is a process which promotes the active involvement of people in shaping and implementing changes in services at a local level. It provides a method for assessing local needs, identifying priorities and empowering local people to be active agents of change. Community participation can have a dual benefit: empowered communities with better health outcomes and more responsive health service providers, who are better tasked to meet these needs.

Wilcox's (1994) framework of community participation suggests that community participation has to be rooted in processes that develop trust, shared values and partnership to enable joint working, while HEBE's (2002) guidelines on community participation emphasise the importance of mechanisms to "actively seek to listen to the diverse voice of service users" (2002: 3).

<p>According to the World Health Organisation (WHO) the goal of primary care is to improve 'health for all' in five core areas: reducing exclusion and social disparities in health; organising health services around people's needs and expectations; integrating health into all sectors; collaborative models of policy dialogue and increasing stakeholder participation. This requires reforms to provide universal coverage to improve health care; service delivery reforms to make health care systems more people-centred; leadership reforms to make health authorities more reliable and public policy reforms to promote and protect the health of communities (WHO 2008a) to locate health within a framework of the social determinants of health (WHO 2008b).</p>

Communities can be defined by locality, based on 'space and geography', or by interest, based on membership of a particular social group such as women, Travellers, minority ethnic groups, disabled people, the LGBT community etc. They can also be defined as connections between individuals and groups that result in shared values of solidarity and loyalty to a collective group, which, in turn, connects people to their sense of their 'self' and through this to their social world (Butcher et al 1993).

3.3 Service user and consumer empowerment and participation

In building accountability and trust, the HSE has also responded to the need for a framework of 'participation'. The HSE's *National Strategy on Service User Involvement* builds on a momentum to provide a multiplicity of ways in which service users can participate in decisions about their health care, particularly in addressing inequalities in health and in ensuring that services respond to the needs of the community. While participation in health care is a relatively new concept, the Strategy represents an important milestone for service user participation.

The empowerment and participation of service users has become an increasingly important objective of service quality improvements, nationally and internationally. Different levels of user empowerment, participation and involvement exist on a continuum of participation including information, consultation, partnership, delegation and control. There are many different dimensions of user involvement, including direct user influence and campaigning led by social movements; user participation through consumer panels, surveys, quality groups and forums; user involvement in the assessment of needs; users as volunteers; user advocacy schemes; and user information services. The basis for many user involvement strategies is an objective to create client or consumer orientated services, so that service providers can be more responsive to the needs and interests of services users.

Two particular types of user involvement exist, first, management-led user involvement systems which incorporate user perspectives and user feedback into service quality initiatives (for example, through surveys, consumer panels and focus groups); and second, user participation or dialogue-oriented forms of user involvement, which directly involve users in influencing policy and service outcomes (Pillinger 2001). The shared values of user orientation and empowerment have been central to the participation of users in service design and planning. Whilst the former is now a universally accepted value underpinning government policies and local service strategies, the latter has been more difficult to implement in practice.

User involvement strategies also acknowledge that power differentials and dynamics between service users and professionals are relevant to understanding processes of service user involvement (McEvoy, Keenaghan and Murray 2008). As a result this means taking account of the extent to which the voice of the user is seriously taken into account in service delivery and planning, since professional ethics and interests may take a priority over user needs and in so doing do not fully integrate user perspectives into quality discourses. There is a danger, therefore, that user empowerment can "become a panacea that does not fully take into account the different meanings of empowerment for different groups of users, which can have the effect of accommodating rather than empowering users" (Pillinger 2001:84).

A literature review of service user involvement in the Irish health service (McEvoy, Keenaghan and Murray 2008) found that service user involvement has gained significant momentum, nationally and internationally and has been integrated into

health care strategies in many countries, including the UK, Australia, New Zealand, Switzerland, Norway and Canada. Service user involvement has the benefits of improving individual, organisational and community responses to multi-faceted health needs and changing the culture of health service delivery. In so doing, this opens up spaces for community perspectives on equity, social inclusion and measures to address health inequalities to the planning and monitoring of services. The report concludes that service user involvement strategy needs to incorporate:

- Leadership to promote service user involvement and new ways of working
- Readiness and commitment for effective service user involvement so that participation is planned for and developed as a long term commitment
- Common goals and clearly articulated results to be achieved
Participants, particularly those whose voices are seldom heard, are given an opportunity to participate in inclusive and diverse ways.
- Fair process that utilises appropriate methods for involvement
- Appropriate supports such as information and knowledge sharing, training, tools, time and resources to build capacity
- Evaluation and dissemination to build evidence and methodologies.

3.4 The potential for community participation to improve health outcomes

A significant finding from health research is that community support through social networks is protective of people's health and well-being (Berkman and Syme 1979). Community participation can have a powerful impact on the outcomes of family and the intergenerational cycles, which have a cumulative effect of disadvantage across the life-course on the social patterning of disease (Marmot 2010).

Building high levels of trust and group participation have been shown to be critical to reducing mortality (Kawachi and Kennedy 1997), while a lack of participation, control or self-esteem, along with poor social support structures, directly contributes to increased morbidity (Berkman 1995).

Participatory processes can positively enhance community involvement and health outcomes (Combat Poverty Agency 2005, Burke 2009). For example, in identifying health needs, communities can be empowered by a process of building the capacity and skills for effective participation. For example, participatory research methodologies have been shown to have a positive benefit for the community since the knowledge, expertise resources of community representatives can positively enhance research outcomes (Macaulay et al 1999, Combat Poverty Agency 2009b, Fatima Regeneration Board 2009). This is also in line with contemporary social research ethics that recognise the importance of active community participation in research processes.

Community participation is essential to enable communities to participate in decisions about their health and to ensure that services are responsive to identified needs. Community participation takes substantial amounts of time to realise in practice, and resources and supports are essential to provide time for preparation and training for participation. Effective methods of participation, therefore, need to incorporate capacity building and training as part of this process.

This is particularly important, as community participation in primary care needs to target those people who are the most marginalised and excluded, so that decisions

that affect their health are not missed. Local communities, individual service users and carers may also have different perspectives on services and different needs and requirements. These may also differ significantly from beliefs and understandings held by HSE staff.

3.5 Models of community participation

3.4.1 Community development approaches

Community development is a process to enable local people to be involved in identifying local needs, influence decision making and evaluate their local services. This can result in mainstream services being more effectively tailored to meet the needs of the most disadvantaged groups. Community development plays a central role in tackling poverty and in reducing ill health (Crowley 2003, Combat Poverty Agency 2000 and 2009a).

While many community development initiatives are broad ranging and have a focus on poverty and disadvantage, there are some that have a specific focus on health. Many community projects have employed Community Health Workers to bring health issues into the community development setting, with a focus on the social determinants of health. They play a key role in empowering, supporting and building the capacity of local communities, so that they can effectively set priorities and desired outcomes (Combat Poverty Agency 2009a and 2009b).

Community development approaches to health are distinctly different from service user involvement strategies because they aim to empower and build the capacity, skills and resources of local communities to have lasting impacts on health. They provide a valuable method for involving local people around health in local communities (Crowley 2003). There are many good examples across the country of how community development principles have been integrated into health, resulting in measures to strengthen and bring about change in local communities through consultations, advocacy and working in partnership with local groups (Burke 2009, Combat Poverty Agency 2009b).

In particular, the Combat Poverty Agency's *Building Healthy Communities* programme, provided support for the formation and sustainability of community groups to respond to identified health needs. Supporting local groups and using approaches such as consultation and advocacy, the programme enabled people to develop their own skills and knowledge, and through this to be empowered to work in partnership with voluntary and statutory agencies. A fundamental principle underpinning the programme is that complex issues such as poverty and social inclusion require a multi-sectoral approach (Combat Poverty Agency 2009a and 2009b).

Community development processes build skills, capacities and empowerment of local people. This can enable PCTs to:

- Develop structures for user involvement and participation as a basis for improving access to health services and improved health outcomes
- Support the process of planning and developing services by identifying health needs
- Highlight the importance of the social, economic and environmental causes of ill health and put a lens on inequalities in health in the community.

3.4.2 Models of participation

There are a number of well-established models of community participation that have informed a range of approaches to community participation in Ireland (McEvoy, Keenaghan and Murray 2008) and the *National Strategy for Service User Involvement* (DoHC & HSE 2008). They include:

- The *Ladder of Citizen Participation* (Arnstein 1969) which is perhaps the most commonly cited methodology, showing a typology of different developmental stages of citizen participation as outcomes, ranging from manipulation, therapy, informing, consultation, placation, partnership, delegated power to full citizen control. Each step of the ladder represents a different level of community participation, ranging from non-participation, tokenism to full citizen power.
- *Health Canada's Public Involvement Continuum* which provides a continuum of five outcomes of public involvement and influence, and which presents participation as a cumulative process. Early stages of participation include communications and listening. As this progresses community participation includes consultations and engagement and partnership.
- *Tresseder's Model of Participation* which has become a much cited model that relates to children's and young people's participation. It identifies five types or degrees of participation that can be applied to different activities and situations, and focuses specifically on the nature of relationships in the participation process.

The models can provide useful conceptual frameworks and a basis for assessing community involvement (Allsop and Taket 2003) and can be assessed at an individual and organisational level (Pillinger 2005) as seen in Figure 1 below.

3.4.3 Community participation and the social determinants of health

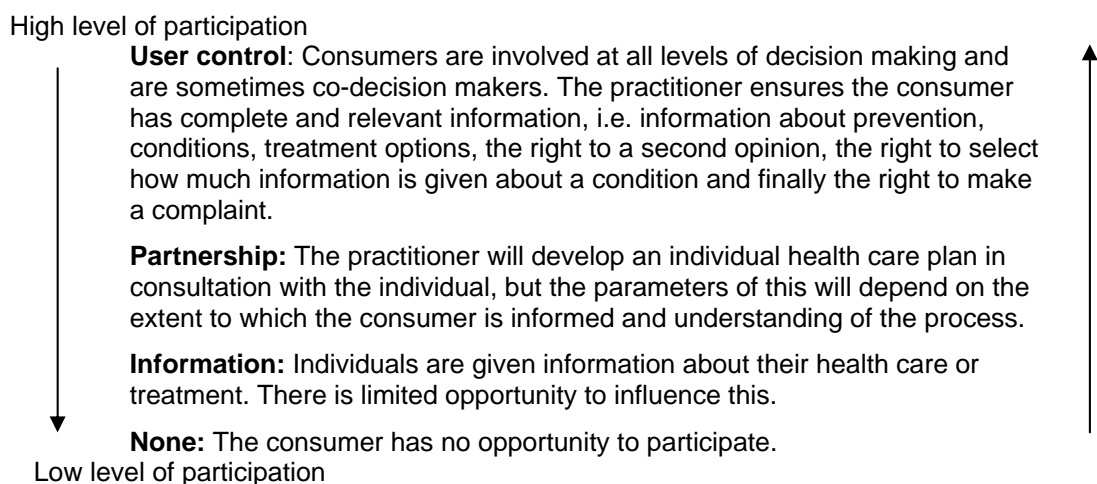
The causes of poverty and inequality are multi-faceted and result from unequal social, economic, cultural and political contexts. Addressing these inequalities requires an understanding of the complexities of the risks and opportunities that individuals or groups experience in relation to poverty and social exclusion, and importantly an understanding of how flexible and creative policy initiatives can also be developed to respond to these. It is evident today that there is a better understanding of the connections between inequality, based on identity or status and poverty and exclusion (Institute of Public Health 2008, Pillinger 2005).

It is estimated that around 80% of factors impacting on health take place outside of the formal health services in areas such as education, working conditions, housing, food safety, the physical environment and transport. This means that it is important to see the solutions to ill health to be broader than health services themselves and for a range of agencies to work together in the planning and development of solutions in local communities. This is particularly relevant because socio-economic status directly impacts on disease causation and inequalities in health (Dahlgren & Whitehead 1991, Institute of Public Health 2008).

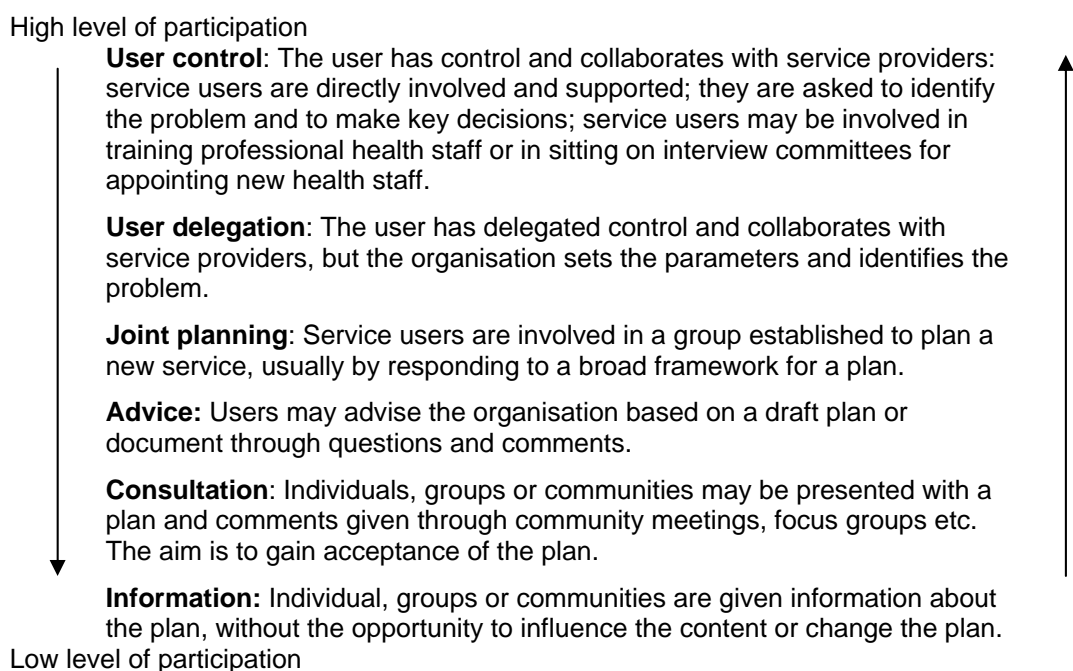
The work of the former Combat Poverty Agency has shown that "people who live on low incomes are more likely to suffer poorer health, experience more psychological distress and generally lead shorter lives than those who are affluent" (Combat Poverty Agency 2005a:2).

Figure 1: An assessment of community involvement: individual and organisational

Individual level: ladder of participation



Organisational level: ladder of participation



Source: Pillinger (2005)

This work has shown the importance of tackling health inequalities through a social determinants of health approach (Farrell et al 2009) and building community participation of into primary care (Combat Poverty Agency 2005b, Crowley 2005).

Evidence of the causes of inequalities of health from a social determinants of health perspective include the impact of:

- Income inequalities, whereby health inequalities are smaller in societies where income differentials are narrower (Wilkinson and Pickett 2009);
- Poverty which results in ill-health and disease across the lifecourse (Layte et al 2007, Burke et al 2004, McEvoy et al 2006);
- The social environment, including family and other relationships, friendship, wider social networks, community involvement and social relationships (Wilkinson 2005);
- Socially unequal positions, based on education, occupation or income, which in turn impact on opportunities for full social engagement and participation (Graham 2004);
- Social position which determines the amount of control a person has over their lives and opportunities for full social engagement and participation, which are considered to play a crucial role for health and wellbeing (Marmot 2004).

Judge et al's (2006) review of government action to address social determinants of health inequalities shows that most countries have adopted equity principles as espoused by the WHO. Some countries have emphasised these health equity objectives in their broader health strategies (Sweden, Denmark and Poland), whereas others have specific quantitative health inequality goals (Finland and Netherlands), with Ireland, England, Scotland, Wales and Northern Ireland being the only countries with detailed qualitative targets. Whilst those countries with qualitative targets have tended to express targets in terms of reducing inequalities between the poorest and most affluent groups, in Scotland and Wales these are expressed in term of improving the position of the poorest groups. No countries had explicit targets related to the gradient across the whole of the population regarding social-economic status and health status.

Addressing inequalities in population health and building health strategies to address these has been part of the ongoing work of the World Health Organisation (WHO). WHO health targets in *Health For All Strategy* (WHO 1999) include addressing inequalities in health by tackling poverty and the particular risks faced by women, children, older people and people with a mental health difficulty. Priority is given to equity and the social determinants of health. More specifically its Health21 targets underline the importance of measures to reduce inequalities between social groups, with specific policy targets for promoting health and reducing inequalities in health by 2020. Whitehead has interpreted equity of access to health care from WHO Health for All Targets to include "equal access to available care for equal need, equal utilisation for equal need and equal quality of care for all" (Balander & Wilde 2001: 30).

This requires an understanding of who is poor and excluded, how the risks of poverty are distributed amongst certain social groups, whether new forms of inequality and discrimination are emerging, and what national/local or urban/rural variations exist. These social relations are relevant as they can show how socio-economic status interacts with health status.

Community participation can result in a better understanding of the determinants in health and how they impact on access to health services, health status and health outcomes. By focussing on these determinants it can be possible to identify and act on multi-dimensional social factors.

These include low income, social isolation, poor access to social networks and inadequate access to services such as transport and health. Therefore multi-dimensional solutions in policy and service delivery require coordinated and integrated responses so that health services are part of a broader integrated solution to addressing poverty and disadvantage. Key to this is enhancing the participation and involvement of socially excluded groups and local communities in the planning, delivery, monitoring and evaluation of health services and putting in place community development approaches that promote engagement with local communities.

Section 4: Overview of the findings from the evaluation of nineteen demonstration projects

4.1 Introduction

This section provides an overview of the main findings from the evaluation of the processes, structures and outcomes of nineteen community participation in primary care demonstration projects by:

- Drawing out the learning of the different models and approaches adopted by projects to community participation in primary care
- Showing what works and what are the critical success factors that can progress community participation outcomes
- Highlighting difficulties encountered and ways to overcome them as well as achievements and outcomes of community participation
- Providing examples of good practices and areas for development.

All projects carried out a range of different activities to promote the engagement of local communities with the services provided by PCTs. In some projects community participation was a new concept.

4.2 Background to the nineteen projects and summary of project activities

The nineteen projects were developed as joint projects between community organisations and HSE personnel (Community Workers or TDOs / Primary Care Managers). Both project partners had joint ownership and management of the projects.

The lead community partners represented community organisations from the following organisational groupings:

- Community Development Projects (9 projects and 1 co-project)
- Community and Voluntary Forums (2 projects)
- Local Development Companies / Partnerships (3 projects)
- Family Resource Centre (1 co-project)
- Other community organisations with a focus on health and/or representing specific target groups (Travellers and minority ethnic groups) (2 projects)
- Local Regeneration Agency (1 project)
- Local community health project (1 project)

The breakdown of the projects and their organisational location can be found in Table 1 (Appendix 1).

All projects established Steering Groups and project activities that engaged a wide range of organisations and agencies, including:

- PCT members (14 projects)
- TDO / Primary Care Manager (18 projects)
- HSE Community Worker / Social Inclusion Officer (12 projects)
- HSE Health Promotion Officer (10 projects)
- Community Development Projects (12 projects)
- Community & Voluntary Forums (2 projects)
- Local Development Company / Partnership (4 projects)
- Family Resource Centres (5 projects)
- RAPID Coordinators (5 projects)
- Regeneration Agency (2 projects)
- Other local community / statutory organisations (9 projects)

The breakdown of the agencies participating in each project Steering Group and project activities can be found in Table 2 (Appendix 1).

There were a variety of different project activities carried out in the Initiative. These are summarised as follows:

- Community Participation Steering Groups (19 projects)
- Community consultations (19 projects)
- Community Health Needs Assessments (7 projects; 4 projects had carried out previous Community Health Needs Assessments)
- Joint training for PCT and community representatives (7 projects)
- Community participation training for PCT members (3 projects)
- Community participation training for community representatives (14 projects)
- Community Health Forum (11 projects)
- Sustainability built into the project activities (19 projects)
- Specific focus on Travellers and minority ethnic groups (2 projects)

The breakdown of these activities can be found in Table 3 (Appendix 1).

The level and type of participation between community groups and PCTs varied from project to project. During the funding phase sixteen PCTs were operational to varying degrees, while in three cases PCTs were not fully operating. All nineteen projects carried out some form of information sharing process at an informal level, while nine projects had established a formal process for community representation on the PCT or Local Implementation Group (LIG). Nine projects established procedures and terms of reference for the joint or community structures, for example, for a Community Health Forum or joint Community Participation Working Group.

The breakdown of this information project-by-project can be found in Table 4 (Appendix 1).

Appendix 2 provides a summary of each of the nineteen projects. These summaries cover project objectives, project backgrounds, project actions and project learning.

The projects have developed a range of under-pinning principles that are shaping the focus and direction of community participation in primary care. These principles can be summarised as follows:

- Joint ownership of project planning and decision-making
- Commitment to share experiences and perspectives in a respectful and equal way
- Time and commitment to build mutual learning and relationships based on mutual respect
- Flexibility to respond to local needs
- Focus on the participation and inclusion of the most marginalised communities
- A lens on how the broader determinants of health and inequalities in health can shape new approaches to primary care
- Joint evaluation of project learning and outcomes
- Importance of measuring success by 'distance travelled' on the basis that projects have different starting points
- Human rights in health and equality.

4.3 Towards a model of community participation in primary care: evaluation of the findings from projects

The nineteen demonstration projects have shown that there are a variety of different methods for progressing community participation. Many of the methods used have been the basis for creating an informal or formal engagement and connection between the community and the PCT members. Because community participation in primary care is new and because many projects are at an early stage of community participation, these emerging models of participation will continue to evolve.

The Initiative has shown that there are a variety of methods of community participation that work and that are relevant for projects that are at different stages of development. These are dependent on four critical success factors, which are discussed in more detail in Section 4.6 below. These critical success factors relate to:

- The readiness of the community to participate
- The extent to which the PCT is ready, prepared and willing to engage
- The availability of support structures and resources in the community
- The extent to which there are existing structures and forums for participation.

There are some common methods that have emerged that provide a direction for successful community participation activities and initiatives. In the initial stages many projects took important first steps to community participation through informal activities of dialogue, information sharing, relationship and trust building. This created a working environment and culture that reflected an openness and confidence to engage jointly. Once these informal measures had been put into effect successfully, possibilities then emerged for more formal methods of engagement, resulting in representative structures for participation on PCTs and structured activities.

Even in those projects that have carried out significant and successful community participation initiatives in the past, for example, through Building Healthy Communities projects a step back was required in order to develop effective methods of community participation in primary care. The projects in Rialto and Offaly did

precisely this and engaged in locally based community consultations that aimed to promote information sharing and build a joint approach between local communities and PCTs.

Of the nineteen projects, five specific approaches have shaped how community participation projects have evolved. However, these are not mutually exclusive and in many cases projects have spanned one or more of these approaches:

- Representative structure for community participation
- Community capacity building and engagement
- Community Health Needs Assessments
- Community and PCT information sharing
- Traveller and minority ethnic cross cutting representation.

Throughout the formative evaluation project partners have stressed the importance of recognising that community participation is time-consuming and requires a commitment and energy from both the community and the PCT. For this reason projects have shown that it is important for developmental work to evolve so that it responds to the particular economic and social contexts of PCTs and the populations that they cover.

4.4 Summary of the ten main methods used to promote, develop and sustain community participation

The following ten methods were used by projects to promote, develop and sustain community participation:

- 1. Joint project planning through a Community Participation Steering Group**
- 2. Key person(s) to coordinate and manage the project**
- 3. Mapping of community and PCT resources in the project area**
- 4. Information sharing**
- 5. Recruitment of local community volunteers**
- 6. Training and capacity building of community and PCT representatives**
- 7. Community consultations to identify needs assessments and representative structures**
- 8. Development of Community Health Forums**
- 9. Partnership with a broad range of relevant agencies to tackle identified needs**
- 10. Strategy to sustain community participation**

4.4.1 Joint planning through a Community Participation Steering Group

Community Participation Steering Group

All projects created a joint project Steering Group from the outset to oversee the project's strategic development and build partnership working methods. The benefits of establishing a joint Project Steering Group were highlighted by Project Coordinators as being critical to:

- A shared ownership of the project structures and processes and a basis for partnership building
- Providing a space for exchanging ideas, perspectives and approaches
- Setting down the procedures for an equal sharing of roles and responsibilities
- A joint approach for the development of project planning, implementation of actions and monitoring of progress.

There were variations in the membership of the Steering Groups, with some limited to membership of the project partners, while others had a broader community and inter-agency membership. Some projects established sub-groups to carry out specific tasks, for example, to recruit community volunteers, to carry out community consultations or to plan training programmes.

In a number of projects the Steering Groups introduced new and separate joint structures for community participation, for example, through joint Community Participation Working Groups. This structure was established in three different ways as:

- A sub-group of the PCT or an autonomous structure to provide a forum for joint discussion and planning between PCT members and community representatives
- A strategic group to provide a focus for community participation across a PCT network, with representation from Community Health Forums established at PCT level and PCT representatives
- An interim measure to plan for full community participation on an individual PCT.

Examples of Community Participation Steering Groups

Paul Partnership

The Community Participation Steering Group brought together a wide range of agencies, including four representatives from the PCT, the HSE Health Promotion Department, the Paul Partnership, RAPID Limerick Regeneration Agencies, and two community representatives from the disadvantaged target communities. Although the Local Authority was not on board from the start of the project, the project recognised the importance of embedding the Local Authority in the process. Two sub-groups on community recruitment and training were established to carry out the detailed planning for the project's main activities, to recruit community representatives and to carry out joint training. These sub-groups were later incorporated into a Community Participation Task Force. A joint project plan was put in place and this was seen to be crucial to ensuring that all partners participated in this process and at a pace that was appropriate to the community. As a result the initial stages of the project required regular meetings to share information and to build trust between HSE and community representatives. This ground work was seen as crucial to establishing a joint approach to the ownership of the project, to learning from each other's perspectives and to finding the common ground between the community and the PCT.

Roscommon Community Development Project

A Community Participation Steering Group was established at the start of the project, with representatives from the HSE and community partners. The Steering Group provided the direction, planning for and monitoring of the project, and planned the community consultations. It was through the Steering Group that awareness was raised and models for community participation explored.

Follain Community Health Project

A Community Participation Steering Group was established by the Follain Community Health Project, Waterford Partnership and the HSE's Senior Community Officer to oversee the project and its development. The initial objective had been to establish a Working Group, with representatives of the community partners, local CDPs and members of the PCT, in order to design a workable model of participation for Waterford. However, it was not possible to create this structure as the PCT was at an early stage of development. As a result the project developed informal ways of engaging with PCT members.

Joint project planning

Many projects put in place a project planning process, which has enabled them to successfully keep to or amend project goals as the projects progressed. This also formed an excellent basis for project Steering Group members to identify priorities, build relationships, share information and develop joint actions. As one representative stated, the process of project planning was very time-consuming and required several meetings:

“We struggled a bit at the beginning...but then something snapped into place...having a plan kept it in shape”(Participant in the Paul Partnership, Limerick, Steering Group).

Where Community Health Forums have been developed (discussed below), a process of planning has also been put in place, often provided through support from external trainers/facilitators or the Project Coordinator. This has helped to enable Community Health Forums to identify priorities and build capacity to address identified needs.

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

All projects highlighted the importance of having a key person/people to drive, coordinate and manage the project. While Steering Groups provided the overall strategic direction of the projects, having someone who provided the day-to-day management and implementation of project actions was seen as crucial to ensuring that projects were coordinated and implemented in practice. This includes having someone to organise activities and events, support community representatives, liaise with multiple partners and bring people together. For example, in the West Cork Islands Project community representatives were clear that it would have been very difficult to sustain the project without support, particularly because the project was linking with seven rurally dispersed island communities.

The role of the HSE community worker at the interface of the project has been critically important to the success and long term sustainability of the project - particularly in organising meetings and delivering goals.

All nineteen projects were coordinated and project managed by one or two people. Different approaches were taken to this. Twelve projects were managed by the community project partner and six projects were managed by the HSE lead partner, while two projects were managed jointly between the community and HSE lead partners.

In addition to this many projects spoke about the importance of having community participation champions who could 'move people out of their comfort zones' and make the case for community participation. Whether they are based in the community or the HSE, community participation champions can be critical to getting buy-in for community participation and for sustaining the momentum and motivation for projects.

The critical role of community participation champions

"Having the HSE champions has been really important to getting the buy-in on the project and particularly to selling the concept of community participation to PCT members. This meant that we didn't have to sell it to them" (Community Development Worker, Iorras Le Chéile CDP).

"It has been crucial to have the active support from the Social Inclusion Manager. We would be lost on the Local Implementation Group without this, particularly as she provides us with a source of information and a strategic vision of the HSE" (Coordinator Lifford-Clonleigh Resource Centre).

4.4.3 Mapping community and PCT resources in the project area

Mapping local community and PCT resources, groups and services was carried out in two ways: at the start of the project; or as a process of and tool for engagement as a core project activity.

The first activity carried out in several projects was to map community groups and HSE services in the geographic area covered by the PCT. This revealed that in many cases the geographic area of the PCT did not match that of community structures, which has meant engaging with a wide range of groups and organisations that either fully or part-cover the PCT area. However, this enabled project partners to identify where groups and services were located.

The following are two examples of different approaches taken:

In the **South Leitrim** project an important and valuable first step was to provide a review and map of all of the groups that fell within the geographic area of the PCT. A total of 73 groups were identified in the area including older people, childcare, youth, women, men, Travellers, lone parents, asylum seekers, disabled people, residents and community development groups. This provided a solid base upon which the project was then able to embark on community consultations with key target groups and geographic communities. Without this the project's community consultations would have been significantly impeded.

In the **Rialto** project the objective of the community consultations and information workshops was to develop shared understanding and approaches and to map community and HSE services. This resulted in a publication: *What's out there? A profile of health and wellbeing groups and services in the Dublin South Inner City Area.*

On reflection, those projects that had not carried out initial mapping exercises identified this as an important first step, particularly as a basis for ensuring that specific target groups were identified and enabling community consultations to be as inclusive as possible.

4.4.4 Information sharing

Information sharing was identified by individual projects as one of the most important tools for initial and ongoing community participation. This has represented an important first step for engagement, either as part of the ongoing project development through Steering Groups or through specific activities held between local community groups and PCTs. Information sharing has been successfully carried out in all projects. This has proved to be a valuable tool for breaking down barriers between community and PCT representatives, promoting a dialogue, connecting local people with services and connecting service providers with community groups and facilities. This approach is summed up by one Project Coordinator:

“The work has highlighted the need to ‘listen’ to the community and answer particular needs instead of deciding what services the Team will provide i.e. the need for a cancer support group based in the community from a social perspective that the community can take ownership over rather than a clinical perspective which may already be provided in the hospital or clinical setting. This ‘listening’ and ‘talking’ and exchange of information will ensure that the needs of both are addressed”. (Project Coordinator, Equal Access CDP)

Examples of how information sharing has been carried out include:

- Informal meetings between PCT members and community representatives
- Structured information sharing workshops and/or facilitated training sessions
- Steering Group or Working Group discussions
- Community-led meetings on specific identified themes, such as domestic violence in the community, mental health or services for older people
- Information fairs and seminars.

Examples of joint information events

The Corduff/Mulhuddart project identified information sharing as a core project activity. Two health information fairs '*Respect your health and wellness fair*', have been held in community centres in Corduff and Mulhuddart, and were jointly organised by PCT and community representatives. These provided free blood and cholesterol checks and information about different HSE and primary care services as well as information about community groups and agencies. Over 25 different agencies were represented at each event and this has provided good evidence of the HSE and community working together.

It is anticipated that owing to the significant interest from local groups and service providers, the events will be held annually. An up-to-date mapping of the structures, organisations and services has been carried out as part of this process and a Directory of local HSE services circulated in local communities.

The **West Cork Islands Project Group** identified information sharing as one of their first major activities. A health information day / seminar was attended by HSE services and community organisations (including the partners projects, the Citizens Information Centre, rural transport, education providers, West Cork carers etc.). This enabled the project to be introduced to community organisations and other agencies, and PCT staff to give presentations to the community about the role of the PCT and the community to provide information about its roles and services. This was a very positive experience for community and HSE representatives and it was viewed as important not only for providing information but also in managing expectations. Public meetings have been held on three islands (hosted by the three CDPs) and an external facilitator was employed to facilitate and report on the meetings.

4.4.5 The recruitment of local community volunteers

Community participation requires time and commitment from volunteers in the community. Recruiting volunteers, particularly from disadvantaged communities where there has been limited community engagement, can be very challenging and time consuming. Moreover, many community volunteers need to be trained so that they can have the capacity to participate and to enable them to have the motivation and confidence to champion community participation in primary care. As a result the recruitment and training of volunteers requires resources, encouragement and support from community development workers.

- In several projects the recruitment of community volunteers took place through 'word of mouth', through contact with local community organisations and through leaflets and flyers. In practice, 'word of mouth' contact has proved the most effective, particularly if the volunteer was approached directly by a project participant who was familiar with and able to explain the anticipated role of volunteers.
- A number of projects recruited community volunteers on foot of open evenings, information workshops and community consultations. In these cases people were informed of the role of primary care services and given an opportunity to feed their views into a consultation process. It was often at the end of a workshop or feedback session that invitations were given for people to put their names forward to join a local health group. For example, in the Limerick project informal community consultations took place through local coffee mornings and this proved a good basis upon which to recruit volunteers. In the Erris project in Co Mayo, community representatives were asked to put their names forward for the Community Health Forum at community consultation events.

- Four projects developed a training programme as a basis for recruiting community volunteers. Starting with a training programme to build community capacity was highlighted as valuable for harnessing capacity to recruit community volunteers. These initiatives are discussed in Section 4.4.6.

A key issue raised by several projects related to how community representatives can be fully representative in their roles, particularly in providing feedback to local groups. This is a particularly important issue in relation to the establishment of Community Health Forums and in putting community representation in place on the PCTs.

Examples of different approaches to recruiting volunteers

In the **Paul Partnership** local community representatives who undertook training and local Community Health Needs Assessments were selected on the basis that they had some experience of adult education, community work and activities, and therefore a capacity to participate at an early stage. The group of community volunteers were also very knowledgeable of their local communities. The majority were contacted by 'word of mouth' on the basis of their local community experience. While the group were of a very high capacity, it was considered that if such a high calibre group had not been recruited more time for training and capacity building would have been needed.

In Offaly, the project was a partnership between the Offaly Local Development Company and the South Offaly PCTs. The Project Coordinators carefully selected community volunteers to participate in their Community Health Forum. The objective was to work with existing groups on the ground and through consultations events carried out with community groups, and to identify potential volunteers. At a community meeting, held to give feedback to the community about the outcomes of the community consultations, volunteers were asked to put their names forward. In addition, community development workers approached people in the community to encourage them to participate, and also to ensure that all target groups and communities were represented. The only group that they had difficulty gaining representation from were carers and the project identified a need to carry out more work with carers to ensure that their views were represented.

In the **Roscommon** project a lot of work had to be carried out in the early stages of the project to recruit volunteers and develop and deliver a training programme to volunteers. Local community groups, representing men, women, disabled people, mental health service users, carers, Travellers, older people, asylum seekers, ethnic minority groups and young people, were contacted with information about the project and an invitation to attend a meeting. Two representatives from each group were invited to attend the meeting, which provided an introduction to the role of primary care services and an explanation of community participation. This process proved very effective in engaging local people in the process and in recruiting local people to join the community participation in health training programme. People from the Travelling community, young parents and young people did not attend the meeting and the project is continuing to find ways to represent these groups.

The **Westmeath Community Development Project** carried out a lot of work on the ground to identify community volunteers. Through consultations with individuals and community groups on the ground, and with the Athlone Community and Voluntary Forum, a core group of sixteen people was identified and supported to participate in a Community Health Forum. This was supported by a programme of in-depth training to enhance the capacity and knowledge of volunteers, many of whom came from disadvantaged backgrounds with no experience of community involvement. The Community Development Worker recognised the need to discuss the issue of representation with as wide a network of people as possible and to identify and meet potential Forum members. This development work paid off and the face-to-face contact with people and groups in the local community was deemed necessary for providing information, managing expectations, building confidence and trust and in persuading representatives from the community to join the training programme for representation on the Forum. There have been some notable successes in involving people from marginalised communities and representatives from different target groups.

4.4.6 Training and capacity building for community and PCT representatives

“The training has been a real advantage in moving us forward. We are now ready to communicate with the outside world...From this we can be a help to the PCT, raise issues and give feedback”. (Community Representative, Ballina Migrant Health Forum)

Projects engaged in a wide range of training activities, which was made possible because project funding enabled the hiring of experienced external trainers. Fourteen projects carried out training for community representatives, while seven projects carried out joint training for community and PCT representatives. Training has been important to providing information and awareness about community health issues, the organisation and delivery of health services, models of community consultation and decision-making skills.

Training carried out for community representatives has helped to build capacity and knowledge for community representatives prior to their engagement with the PCT.

“The Team building for the PCT has been really important as there was not a good understanding of community participation. Now we are embracing the Community Health Forum and see its value...We can see what’s happening out there and the problems people face, particularly the marginalised groups. This broader sense of health is now part of my agenda” (Public Health Nurse, Erris PCT).

“Community participation has to be ingrained from the beginning of a PCT being established” (Public Health Nurse, Erris PCT).

Training and development carried out for PCT representatives has been important to raising awareness of community participation and engaging PCT representatives in the process.

Examples of joint training

Paul Partnership: training for community consultations

The Paul Partnership, working with other community and statutory organisations, developed a training model that enabled community and PCT representatives to carry out community consultations to identify local health needs. The project Steering Group decided to commence this at an early stage. A long process of discussion and development took place to ensure an appropriate structure and that all participants bought into the objectives of the training. The planning took place in two sub-groups of the project’s inter-agency Steering Group. One took responsibility for the recruitment of community and PCT representatives and the other focussed on the content and organisation of the training. Seven community representatives and four PCT representatives were recruited to participate in the training, which was carried out by external trainers with experience of community development and training methods. The training focussed on tools for community research, community consultations and feedback, team building and awareness of community health issues. The feedback from the training showed that the training led to new skills, capacities and confidence, to team building, community engagement and participatory research skills.

South Tipperary: joint training for community participation and Community Health Needs Assessment

A joint training programme was organised for community groups and representatives from the Cashel PCT. This was a pilot project. The learning from it is intended to be rolled-out to other PCTs in South Tipperary. An interagency forum was established in Cashel, facilitated by the Social Work Department, to develop training to promote understanding of the social determinants in health and to carry out a needs assessment. Participants include representatives from the Tipperary Community and Voluntary Forum and community representatives in the Cashel area. PCT representatives from Cashel and the social worker from the Clonmel PCT also attended the training. The training provided the skills and capacity

for representatives to conduct local consultations, training and focus groups within their own local communities and groups. The social workers from Clonmel PCT were actively involved in the process and the training was cascaded to members the Clonmel PCT. Once the consultations were completed these were then brought back to the group in a final training session. This spin-off training was delivered in Slieveardagh, Carrick-on-Suir and in Clonmel. It is anticipated that the training and consultations will be the basis upon which a Community Health Forum is created in Cashel and will provide a model for community engagement that will be cascaded to other PCT areas.

Examples of community training

North West Roscommon: training for community participation

In North Roscommon, a six-week training programme was organised and an external facilitator and trainer appointed to work with the group. From the start the group established its own objectives based on a framework of the social determinants of health and community development. Fifteen local people have attended the training and this has enabled them to gain knowledge of community health issues and a better understanding and capacity to act as community representatives. As one participant said 'it was a real confidence booster'. The training was a critical factor in engaging a group of community representatives to form a Community Health Forum. This led to some joint training with the PCT and the community representatives, and joint work to discuss structures for community representation.

Iorras le Cheile: training for participation in the Community Health Forum

A sub-group of the project Steering Group was established with representation from the community and the PCT and an external facilitator to clarify the roles and objectives of the Forum. A training needs assessment was carried out to identify training needs of potential Community Health Forum members, and this was followed up by training in Team building. Terms of reference and Operating Rules for the Forum were subsequently agreed by the Forum. The time devoted to this was considered to be very important in ensuring that community representatives have ownership of the process. Since then Team building sessions have been held, focussing on officer roles and responsibilities and an introduction to community development. Forum members have participated in ASIST suicide awareness training. The creation of the Community Health Forum, with thirty-two members is considered to be a significant achievement, particularly because of the dispersed rural community from which membership has been drawn.

Wolfe Tone CDP: training for community participation and participatory action research

The Wolfe Tone project in Wexford devoted a great deal of time to the training and capacity building of community representatives to enhance their skills. This included two accredited FETAC modules on health and community participation, delivered to twelve people living in disadvantaged communities. The training has focussed on community health issues and skills building and introduced participants to the structure and policies of the HSE, medical terminology, primary care services, as well as leadership, speaking, research and advocacy skills. The training has resulted in an empowered group of local people who are motivated and enthusiastic to participate in primary care in the future. It has enabled participants to build their capacity and confidence to discuss health issues that affect the whole community. As one of the participants on the training said:

"We met up in a group and we stayed meeting. Catherine our tutor broke the ice with everyone. We most of all found friendship in the group and I personally found it brilliant. The training gave us a lot of awareness of what's going on out there. I left school early and the training gave me the confidence to go out and get the information and participate" (Community representative, Wolfe Tone)

Nine of the trainees are still very active in the project and are engaging in direct community health work. The Project Coordinator considers that the skills and competencies achieved in the training were vital to giving local communities a voice in health policy. A particularly valuable element of the training was that community representatives were skilled up to participate in the design of the research, including the drafting of questionnaires and in assisting with interviewing. This was particularly important in enabling people to acquire

research and writing skills. A report of the research *Growing Healthy Communities: Community Needs Analysis*, has been produced. The research provides a rich resource of data on health and well-being that includes the impact of housing, employment, unemployment, poverty, education, neighbourhood and the local environment, and lifestyle issues on the health of people living in Wexford Town. The needs assessment provides a wealth of baseline quantitative and qualitative data that will be fed into the PCTs in Wexford.

Westmeath community capacity building and training for community volunteers

In Athlone, the training and capacity building of community representatives in the Westmeath Community Development project was designed to build the capacity of sixteen community representatives from disadvantaged communities to enable them to engage with health issues in their local communities. The training began with an introductory information workshop and monthly two hour training sessions over a period of six months. The training was provided in a flexible way that was responsive to the needs and backgrounds of participants. The training focussed on health and well-being, establishing Team roles and responsibilities and setting a vision for the Community Health Forum. Information packs were prepared for community representatives containing information about the role and purpose of a Community Health Forum, HSE structures and primary health care services, contact and referral information about local services, community development principles and information about the social determinants of health. As one participant in the training said:

“I had never heard of primary health care. I didn’t have a notion at the beginning. The training was a lot of fun and we learnt how to work together as a Team...Now we are doing it and it is amazing...it is really important to have health on the agenda as everything feeds into it” (Athlone Community Health Forum Representative).

Mayo Intercultural Action: training for the Ballina Migrant Health Forum

At an early stage in the project a programme of training was organised for the members of the newly formed Community Health Forum. A four-day training course, run by the HSE Health Promotion Officer, covered community development principles, health promotion and mental health, community participation in primary care, the role of the health forum, decision-making skills and Team building skills. The training was highly successful and there were very positive outcomes in the evaluation of the training, particularly in giving participants the confidence to act as community representatives. A core group of seven Forum members have completed the training programme and are actively involved in the project.

Blakestown/Mountview: training for local people from disadvantaged communities

Training has been carried out to build the capacity of local people and to enable them to engage in consultations. The emphasis was on building the involvement of local people who had no experience of community activism. Local groups and local organisations in the area participated in a six-week training programme run by the CAN. Bringing in external trainers with experience of community development and of working with marginalised communities was considered to be critical to the project as community participation in health was a very new issue for project partners. Workshops were organised for different local groups and organisations to build up a picture of the issues impacting on health. This has been very successful and has engaged a group of local people and representatives of local community organisations and agencies. The emphasis of the training has been on developing awareness of the broad social and economic determinants of health and building the capacity and involvement of local people on health related issues in their community. Representatives of the two community organisations and the TDO participated in the training. The training was interactive, creative and participatory, and had very positive outcomes. The training formed the basis of community consultations and local people received training on how to facilitate focus groups and identify health needs. A key objective of the approach taken was to “staying grounded with the overall aim of the project” (CDP Coordinator) and working closely with community workers in the area.

Examples of PCT training

Pave Point: training for PCTs on Traveller health issues

Pavee Point’s project has focussed on a programme of training and awareness raising for PCTs to highlight the importance of engaging and participating with the Travelling community

on primary health care. In particular the project training activities have highlighted the possibilities for engagement between PCTs and Traveller Primary Care projects across the country. The project has developed and draws on a set of resources to promote awareness of Traveller health issues in a primary care context, which have been designed in partnership with Travellers. This includes a leaflet setting out how PCTs can address Traveller health in a primary care context and a number of training modules relevant to Traveller health, covering suicide awareness, cardiovascular health and cancer prevention and will form the basis of training for Community Health Workers. A pilot training project has been established with Wicklow and Bray Traveller health projects to train members of three PCTs in Wicklow. The training programme will be delivered by Traveller Community Health Workers and will form the basis for relationship building and engagement between Traveller health projects and PCTs. It is anticipated that the training in Traveller awareness for PCT members will promote a model for other PCTs across the country.

Offaly: training for PCT members on community participation

PCT development training has been carried out by the HSE Midlands Performance and Development Unit (four half days), which has set out the roles and visions for the PCTs, as well as sessions on the determinants of health, community needs, participation and consultation. The training has helped to enhance the engagement of the PCT with the community and facilitate community representation at the monthly development meetings.

The development of the skills of both community and HSE representatives has been achieved in many projects through participation in project Steering Groups. For example, in the West Cork Island Project the Project Management Group has been important in building the capacity of HSE and community representatives to work together. For the community representatives their capacity to participate and engage has grown during the nine months resulting in an informed representation on the Local Implementation Team (LIT). According to one community representative “We got capacity from being on the group and this made it easier to participate on the LIT”.

From the projects there appears to be some markers that point to the effective organisation and delivery of training and particularly at what point it is viewed to be appropriate to engage in training:

- Joint training initiatives tended to take place at a later stage in the project. For example, the West Cork Islands project group carried out a joint training day for community and HSE representatives towards the end of the project. The aim was to develop and formalise the terms of reference for engagement with the LIT and to discuss how island community issues can be represented on the PCTs.
- In other cases training to build community capacity and skills took place at a much earlier stage, since this was seen to be essential to building the base for community participation in primary care.
- At whatever stage the training takes place it can build skills in areas such as presentation skills, speaking skills and knowledge of HSE structures and primary health care services.
- Feedback from community representatives is that it is important for training to be flexible and able to adapt to the needs of the group as it progresses.

4.4.7 Community consultations to assess community health needs and representative structures

All projects have engaged in some form of community consultation, through public meetings, workshops or focus groups. Some community consultations have identified the most appropriate and representative structure with which to engage with PCTs, while others have focussed on identifying community needs. As mentioned above, information sharing has been a critically important first step in a number of

community consultations, and this has provided a basis for local people to identify health needs or highlight concerns about services.

A number of community consultations have been held to identify local health needs, where the focus has been on the broader social and economic determinants of health. Social isolation of older people and lone parents; an absence of social networks; anti-social behaviour; the impact of poverty on inequalities in health, mental health and well-being; and the environment in which people live are some of the issues raised in these consultations. In Erris, Co Mayo, a rural location with a highly dispersed population, social isolation from living in a rural location, and access to services and transport were key issues raised by local people. In the case of the project with Mayo Intercultural Action, access to health services and information for migrant and minority ethnic groups were highlighted.

Many of the projects view the consultations and needs assessments as being very important to establishing an evidence base, which can be presented to or discussed with PCTs. In the case of the Rialto project, the outcome of a series of workshops was that local people identified the need for access to more information about local health services and local community groups. The result was that the project drew up the directory of local health and community services.

There have also been different approaches to community consultations. In some cases the consultations have been jointly organised by community and HSE primary care staff, while in others they have been organised solely by the community. All approaches have worked extremely well.

There are a number of different methods developed for consulting with local communities. These include:

- Community consultations that focus on information sharing
- Community consultations that identify health needs / Community Health Needs Assessments
- Community consultations to discuss and develop representative structures.

Community consultations: information sharing

An important focus of many community consultations has been the development of information sharing activities which have enabled community and PCT representatives to have a neutral space to share information and knowledge about the respective roles, services and structures. These have often been a first step to building engagement and to identifying health needs and other more structured activities.

Examples of community consultations that have focused on information sharing exercises

In **Monaghan**, the Community Participation Working Group designed an information sharing exercise, followed by opportunities for people to raise issues about what influences their health. The information largely focussed on the location and services provided by the PCTs and this was supported by an information leaflet and a display stand about local services. Consultations were held with ten groups representing older people, new communities, Travellers, young people, parents with disabled children and other advocacy groups. Consultations were organised at times and in venues that were accessible to the groups consulted. The PCT were briefed about the consultations and this helped to gain buy-in to the process and a connection with the project. Each consultation had a representative of the Steering Group and at least one member of the PCT to answer questions. This was a very new experience and there were positive outcomes from the process.

An objective of the project was to ensure that local people are kept in the information loop and are given regular feedback from the consultations. Some of the issues raised in the consultations concerned waiting lists for services, scheduling of appointments for people with multiple needs and the need for clearer information about the development of primary care services and changes in the HSE. Suggestions to improve services included the introduction of an advocacy system to enable vulnerable and hard to reach groups to access services.

Rialto Community Health Project carried out six lunchtime workshops, which were held monthly. The project decided that sharing information between PCT members, local people and local community groups was a good way to build a shared understanding of the services provided in the community. By focussing on information sharing, the workshops provided a neutral and safe space for community health workers and community representatives to meet and share information with PCT members. This enabled the project to do two things. It provided a map of local health services and the support services provided by local community and voluntary groups. It also formed a step to relationship building as a basis for more formal representation on the PCT. The workshops proved very popular, with 35-40 representatives from the PCT and the community participating in each workshop. A balance of speakers from community and HSE backgrounds attended around the themes of mental health supports, supports for older people, supports for people affected by addiction, promoting healthy lifestyles and presentation of the Rialto health research, family supports and early intervention. As well as presentations from the community and HSE, the workshops also provided an opportunity for facilitated small group work to encourage relationship building, to identify local health service needs and information about services in the community. As a result of this a local directory of community and statutory organisations, *What's out there? A profile of health and well-being groups and services in the Dublin South Inner City Area*, was launched at a community event. The outcome is that PCT staff are more aware of the supports from local community groups and local people are more aware of where they can access PCT services. This approach helped to build a process of mutual learning and has resulted in the development of cross sectoral relationships and joint working. For example, the Social Worker on the Community Mental Health Team now refers clients to community run groups for support and social contact. This process has also been important in keeping the focus on the social determinants of health and has added a richness to the engagement process. As the project's community health worker stated:

"We believe the workshops space allowed those who work across the community to meet with each other, find out about each other's work and to develop working relationships on an equal basis recognising the perspective, talent and particular expertise of all those who work and live in the community" (Community Health Worker, Rialto).

Community consultations to identify health needs / Community Health Needs Assessments

Another way in which community participation has resulted in an engagement between PCT members and the community is through Community Health Needs Assessments. These have been important to building awareness of community health needs and bringing community and PCT representatives together to discuss local health needs.

All projects have carried out or have planned some form of consultation to identify local health needs, either as part of information sharing workshops or through specifically developed needs assessments. In many cases Community Health Needs Assessments have been jointly planned and carried out by community organisations and PCT representatives working together.

"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" (Community Representative, Limerick consultation).

Some projects have highlighted difficulties in prioritising core health issues for the PCT to address, since Community Health Needs Assessments are often wide ranging. Related to this is the need to ensure that there is ownership of the issues by the community representatives who are tasked to take the issues forward onto a PCT. In some cases it has been important to hold a facilitated meeting with community representatives to identify priorities and actions to take forward. In some cases, where the broader determinants of health have been identified, it has been important to discuss what issues are relevant for the HSE to act upon and what issues can be referred to other agencies, for example, local authorities.

Examples of different approaches to community consultations

Mayo Intercultural Action: community consultations to identify health needs and Forum members

The Mayo Intercultural Action project carried out substantial development work in Ballina with local agencies and community organisations. Information was circulated to members of the PCT and community groups, with a view to holding community consultations to identify health needs and recruit members of the migrant community to join the Community Health Forum. Publicity was generated through the local media and flyers and posters circulated in the town. Consultations included an open evening for migrants, attended by 25 people, and focus groups were held to identify the health needs of migrants.

South Leitrim: Community Health Needs Assessment

The South Leitrim project carried out a Community Health Needs Assessment over a four month period in the three geographic areas of the PCT. A lot of work went into the planning of the consultations including public awareness raising, advertising and publicising of the consultations, liaison with community groups and media involvement. A number of methods were used to identify needs. First, twelve focus groups were held with groups representing older people, disabled people, lone parents, Travellers, asylum seekers, young people and people with mental health difficulties. The information collated from each focus group was summarised and given back to each group to ensure that there was ownership and accuracy in what had been said. Second, written submissions were received from eight groups and individuals who were unable to attend focus groups or public meetings. Third, consultations were held with local agencies in the PCT area. The findings from the focus groups and consultations were written up into a report, which highlights the needs identified and the strategies proposed to resolve them. Specific issues of concern highlighted included transport; support for independent living; integration of existing services; health promotion and prevention programmes; out of hours and localised services; anti-social behaviour; crime and drugs; local clinics and waiting times; housing; dental services; safety; community facilities; and support and services for parents and children.

Additional resources were provided to consult with some of the hardest to reach groups and organisations representing mental health service users and people with an intellectual disability, older people living alone, people with difficult family circumstances and gay and lesbian people. Consultations were attended by community representatives and an HSE primary care worker. The Facilitator attended a PCT meeting to update the Team on the consultation process. Three public meetings were held in each of the three towns in the PCT area in October 2009 to provide feedback on the outcomes of the consultations and to inform local people about the role of the PCT. The meetings were widely advertised in local newspapers and local radio and enabled those who had not participated in the focus groups to participate in the consultation process.

Offaly Local Development Company: Community Health Needs Assessment

In Offaly, the project focussed specifically on identifying community health needs. Prior to organising focus groups a community open evening was held, attended by 50 local people, as well as Offaly Local Development Company and PCT representatives. The aim was to inform the community of PCT services and also to signal to the community that community consultations would be taking place in the coming months. Community consultations took the form of sixteen focus group sessions with target groups in the area. The consultations were

organised and facilitated by the community development worker in Offaly Local Development Company and the social worker in Birr PCT. In most cases the consultations took place through existing groups and where this was not possible groups were organised for this purpose. A wealth of information has been collected on community health needs including the needs of young people, parents, unemployed people, lone parents, older people, disabled people, Travellers, non-Irish nationals and small holders. Specific issues highlighted were mental health, domestic violence, play and recreation, and social isolation. Significant gaps were identified in services for carers, physical and sensory disability, intellectual disability, addiction and homelessness. There is some very useful learning from this exercise, particularly with regard to the significant amount of time that is required to organise successful community consultations. In particular, the project attributes the success to the significant input of time devoted to the pre-development phase in working with groups on the ground, meeting with groups and informing them of events, encouraging participation through word-of-mouth, circulating flyers and leaflets. It was also a great benefit to the project that the social worker in the Team was able to devote a significant amount of time to supporting the community consultations. Another element of the success of the consultations was the feedback session given to the community, held jointly by Offaly Local Development Company and the PCT. This enabled local groups to have an overview of the findings of the Community Health Needs Assessment, gaps in services and plans in the project to address them.

Blakestown and Mountview: consultations to engage local people in assessing health needs

The project developed a creative approach to community participation on the ground by asking local people what they think impacts on their health and well-being. Following a successful training programme with local community representatives a series of consultations were held with local people, facilitated by the CDP and FRC project partners and community representatives. This has been hugely successful and has engaged local people in a way that had not been achieved in the past. Over 120 people, including older people and young people, have participated in workshops, which have identified a diversity of issues ranging from the need for access to local health services to issues such as social isolation, community safety and anti-social behaviour. By working with local groups and taking the consultations out to local people, there was significant engagement and interest on the ground. Some of these consultations have taken place with existing target groups in the CDP and FRC. Health and well-being are issues that have really interested and engaged local people who have not been engaged in local groups. A great deal of effort was put into providing information for local people and with local groups in order to encourage participation. A critical success factor was finding the language with which to engage with people. For example, a consultation with older people was organised as part of one of the weekly Bingo groups held at the community centre. The consultations started by asking people 'how are you', which led to a conversation about everyday health experiences. This led to a very positive engagement and discussion with older people that would not have been achieved in a more structured workshop. The learning from the project is that it is important to build a local focus and awareness of health in the community, and to use this as a basis for building capacity to participate in primary care. An example of a positive and concrete outcome of the consultations is that responses have been developed to social isolation and anti-social behaviour. Working with local youth groups, the project has established an inter-generational initiative whereby young people have invited older people to a breakfast meeting as a basis for discussing how they can have better connections with each other.

Equal Access, Tallaght: consultations to identify community health needs

The project prioritised community consultations and engaged an experienced facilitator to conduct a consultation process with key stakeholders including community and voluntary organisations and statutory services. The consultations focussed on identifying health needs in the eight communities that fall within the four PCTs (notably West Tallaght, Killinarden, Jobstown, Belard/Springfield and Brookfield/Fettercairn). The consultations provided an opportunity for information to be given to participants and this generated discussion about the role of the PCT. The input into the consultations has been very positive and there was a lot of local networking to involve local people, the social workers on the PCT and the HSE's community workers in the area. The consultations showed that there is a lack of knowledge or understanding of primary care and the consultations can be an important vehicle for

information sharing. The consultations began with a brief presentation from the PCT about its roles and functions. This was followed by small group work to discuss what had been learnt and to identify ways in which the community could participate. The consultations were written up into a report and form the basis for discussions with the PCTs in the area.

Two projects engaged in activities to promote participatory learning and action research, on the basis of which local community volunteers and/or PCT representatives received training on how to carry out Community Health Needs Assessments and consultations. These initiatives have been particularly valuable in establishing methods of participatory research, PCT and community skills building, and community empowerment.

Examples of participation research as part of community consultations

Wolfe Tone: Community Health Needs Assessment and participatory research

The project prioritised a community development approach to consulting with the community. This was carried out through open meetings in the community to raise awareness of PCT services and to discuss the role and benefits of community participation on the PCT. The aim was to counteract potential fears and misunderstandings about changes in service resulting from the relocation of local primary care services. The project worked in partnership with three local CDPs who hosted the public meetings in the three communities in the PCT area. Fifty one people attended the meetings from the areas covered by the Larchville/Lisduggan CDP, Inner City/Rapid Areas and the Ballybeg/Traveller Project. A social care allowance was provided to participants. The meetings were organised around a question and answer session with the facilitators. A lot of issues were raised in relation to the relocation of the GP practice and services that would be provided, and a definite interest was expressed by participants about participating in the process further. Following the local community consultations a public meeting was organised, which provided an opportunity for PCT members to meet with service users. The meeting also gave local people an opportunity to gain information and awareness of community participation on the PCT. The meeting focussed on issues related to the move of services to the new location and identified issues of personnel, transport and service provision, particularly in relation to treatments available to private patients and to medical card patients.

Paul Partnership: joint approach to action research

The project used a method known as Participatory Appraisal (PA) as a tool for community engagement, although it was recognised by the project's Steering Group that it was essential to build a better understanding of this approach and its application to the area of health. The training for community representatives and PCT members provided the tools to carry out a community based research. Four research Teams were established and each Team was supported by a resource person designated to support the implementation of the research. Each of the four research Teams carried out three consultations with local community groups, and also provided local communities with information about local health services and the role of the local PCT. From this, base line information was collated about community health needs in each of the communities, with specific information about the health needs of children, young people, women, mothers, men and older people, as well as general health needs. The information, from the consultations with around 170 local people, was collated into a report and disseminated to the wider community through a newsletter. Feedback sessions and a Primary Care Open Day were also held to give feedback on the outcomes of the community consultations. The local evaluation of the project concluded that the qualitative data that was collected had been a positive exercise, with a very useful outcome for informing the PCT about local community health needs and the planning of services. This has generated a baseline against which needs and progress could be assessed over time. There have also been some positive outcomes for local services, including the dissemination of a leaflet about PCT services in the community, changes in service provision for 'taking bloods' locally, and also the provision of a new counselling service and a social worker on the PCT. An additional outcome is that the consultations provided a basis upon which broader health issues can be included in local regeneration strategies, community development, planning, housing and estate management.

Community consultations to identify representative structures

A number of consultations have had as their starting point an objective to develop a representative structure for community participation in primary care. In the community consultation in Finglas the emphasis of the project was to find the best method for community participation, while in Corduff/Mulhuddart the consultations led to discussions about a proposed model of community participation.

Finglas CDP: community consultation for the development of a model of community participation

The consultations focussed on model of community participation in primary care in the Finglas / Glasnevin catchment area of Dublin. A cascaded community consultation process was facilitated by and through the Finglas Breakfast Club, a network of community organisations in Finglas. Seventeen community development workers, linked through the Breakfast Club, were trained to carry out the consultations with local people. The training was carried out by an independent consultant with expertise in community consultations. The seventeen community development workers, representing different groups in the area, gathered the views of nearly 150 people through focus groups and a questionnaire from a cross-section of the community (including Travellers, people with disabilities, ethnic minorities, lone parents, and representatives from community networks). The community consultations aimed to identify the extent to which local people knew about the planned PCTs, to identify gaps in health services and to elicit views regarding community representative structures. The consultations were an opportunity to provide information about primary care services and a briefing document about services was circulated prior to the consultations. A Report on the proposed model of community participation has made proposals for different methods of and structures for community participation in primary care arising from the consultations. The report identifies the need for PCTs to address current service gaps; to provide locally based services and facilities, the services 24/7, to ensure that clients are treated with respect, the provision of seamless services and to provide easily accessible information on health services. A community meeting provided feedback on the findings of the consultations and a forum discussed and agreed the most appropriate structure for community participation.

Three options were presented. The first was an expansion of existing local forums/networks to include a health focus; the second was to establish an overarching Community Platform for Finglas (based on the model of Fatima United and Meitheal Forbartha na Gaeltachta/Comhar Dhuibhne); and the third was to establish two community health forums in Finglas and Glasnevin, which could act as an interim arrangement while the Community Platform is being established. The second option of a Community Platform was the preferred option of local community groups and organisations.

Corduff/Mulhuddart: community consultations for a community consultation process

The Corduff / Mulhuddart project employed an external consultant with expertise in community consultations to facilitate a consultation process with local people and service providers and to elicit feedback on the draft model of community participation. Although the consultations in Corduff were well attended it became necessary to find other ways of engaging with local people and service providers in the other two areas of the project. A detailed report of the consultations was produced, which set out the planned *Model of Community Participation in Primary Care*. The report provides an overview of the steps of the model and recommendations for the development and implementation of the model. This also identifies the main achievements and the evidence and rationale for community participation in primary care, as well as an assessment of the challenges identified from the process the supports and enablers to the process, and key lessons learnt. The consultations were also important in identifying gaps in service provision, for example, mental health services for 16-18 year olds, and the need for family planning and a well-women's centre in the area. Community groups have developed excellent working relationships with the PCTs on the ground and the process of joint working has been beneficial to community and PCT members alike. As everyone has found community participation is time consuming and requires significant resources if it is to be meaningful. There has been some important learning from working with areas where there are different levels of community development and community readiness to engage in the primary care process. The project found difficulties in getting participation in those areas where there were no active community projects. One key

area of learning according to the CDP is that 'nothing can be taken for granted but always has to be worked at'. The learning is that having local community development projects is essential for the process to progress.

The experience of holding community consultations has shown that:

- Community consultations require a significant investment of support and time. This is particularly the case with the most marginalised communities who do not necessarily have the experience or capacity to participate.
- Community consultations have worked particularly well where there have been existing good relationships between local communities and community development workers, and where there is an existing community infrastructure, such as local support groups, with which to engage.
- Experienced facilitators can provide skills in carrying out community consultations. In some cases this work incorporated learning and skills building for community representatives, for example, through the development of participatory learning and research skills, with added benefits for the community. In some cases it has been particularly beneficial to have co-facilitators who come from a community development background and a PCT / health background.
- Having a resource person to write up and provide analysis of the data collected is particularly important if the consultations to be documented as a basis for engaging with PCTs.
- Dissemination and feedback of the data and information collected from consultations needs to be carried out in an accessible way, so that local people and groups can engage with and use the local data.
- It has been particularly important to find ways of managing expectations so that community consultations have clarity about the scope of PCTs. In this regard those community consultations that provided information sessions about PCTs, with inputs from PCT members, were able to set the scope of activity and therefore manage expectations.
- It is not surprising that in a large number of community consultations many of the issues raised fall out of the scope of PCTs. This is to be expected and also highlights for PCT members the importance of understanding the broader social determinants of health and the need for inter-agency working to improve health and well-being across the community.

4.4.8 Development of Community Health Forums

All projects have an objective of creating a representative structure modelled on a Community Health Forum as a basis for community representation on PCTs.

All projects have worked towards the establishment of a Community Health Forum, with 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. In a few cases, community representation is facilitated through a sub-group of the PCT or a separate Community Participation Working Group, made up of community and PCT representatives.

The Community Health Forums have the following shared objectives to:

- Provide a 'voice' to local communities and specific disadvantaged target groups
- Build the capacity, knowledge and expertise of community representatives to become 'community experts' in health
- Identify and collect information about the needs and concerns affecting health and well-being of local people and identify actions to address identified needs

- Promote discussion about primary care issues and feed information from PCTs into the community
- Highlight issues that can be addressed by PCTs
- Share information with the wider community about community participation in primary care and raise awareness of local services
- Create structures and methods for community representation on an individual PCT or PCT networks.

In evaluating the role of the Forums this section identifies:

- Projects that have established a Community Health Forum
- Projects that are planning Community Health Forums
- Stand-alone or linked to existing structures
- Community representation on PCTs
- Joint PCT Community Health Forum.

Community Health Forums have been established in eleven of the projects supported by the Initiative, while the remainder of the projects have either begun a process to form a Community Health Forum or plan to establish one in the future. Those Community Health Forums that have already been established are made up of community representatives with a membership that is often representative of local people from specific geographic communities and/or disadvantaged target groups.

A Community Health Forum has the advantage of enabling a representative group of people from the community to be the voice of the local community on health issues. It is envisaged in most projects that a minimum of two representatives from the Community Health Forum should be invited onto the PCT to attend business meetings or periodic meetings.

There are different models emerging about how to establish a Forum. In several projects the Forum has been established as part of the process of community consultations, where nominations are invited from those participating. In others, nominations have been sought from different groups in the local community. In most cases there have been criteria established from the outset about representation, for example, from disadvantaged communities and representation from different target groups, such as older people, disabled people, women, unemployed people etc. Some have established terms of reference. This was something that the Donegal project (Lifford/Castlefinn, Ballyshannon/Bundoran, the Finn Valley and the Lagan Valley) found to be very important in setting out the role, scope and purpose of their local Community Health Forums.

Establishing procedures and structures for Community Health Forums are not only important for their operation, but can also be critical to ensure that Forum members take ownership of the Forum. As a result several projects have identified the need to develop structures of representation that ensure the involvement of socially excluded groups in the local community.

“It was very important to draw up the terms of reference ourselves as this enabled us to come together and to engage. We have decided to keep the focus on the PCT for now and we want to make an impact” (Community Representative, Ballina Migrant Health Forum).

The creation of a Forum has raised an issue about what stage to engage with the PCT; whether this should be when the Team is in its formative stage or once it is established and working. It appears there are different approaches to this depending on the level of PCT development and the capacity of community groups. While the

Community Health Forum forms the basis for representation on the PCT a number of projects have not yet developed concrete structures for representation onto the PCT, either because the PCT is not fully formed or because further community capacity building is necessary.

The voice of Forum members: Westmeath Community Health Forum

Representatives of the newly formed Community Health Forum led by the Westmeath Community Development Ltd project spoke about the huge learning curve for them. As one community representative stated:

“We didn’t know anything about this until recently and at the start it was hard to relate to it as a concept...but when it comes to your doorstep it becomes real”.

Another said that following training on community participation she felt more equipped to participate in primary care:

“It is very exciting to be part of the Forum. I am aware that we can make changes and that we have somewhere to take health issues. I am also finding that people from the community are approaching me for information about health issues and now I have information about where to refer them”.

The project has enabled Forum members to give voice to community health issues:

“The project has been really important in the community. When you talk to local people about their health problems they are isolated and have no support. For me its about having a voice on the ground” (Athlone Community Health Forum Representative).

All projects have identified the need for training and capacity building for community representatives to enable community representatives to act as joint decision-makers. Community participation training programmes have been developed for a number of Forums and these have enabled Forums to develop goals, action plans and terms of reference.

Projects that have established a Community Health Forum

The following are a selection of examples of Community Health Forums that have been established by individual projects. Many have modelled their structure and representation on the original Lifford-Castlefinn Community Health Forum, established in 2004.

Project	Community Health Forum	PCT representation
Lifford-Clonleigh Resource Centre	Four Community Health Forums have been established in each of the four PCT areas covered by the project. A Community Participation Action Group has been established, with representation from the four Community Health Forums and the four PCTs to develop a County-wide strategic focus to community participation. Each forum has developed terms of reference setting out objectives, roles and structures.	Two community representatives from each Forum are represented on each of the four PCTs.
Leitrim Development Company	A Community Health Forum has been established with representatives from disadvantaged target groups in the three geographic communities in the PCT area. Structures and methods of representation on the PCT have been agreed. The project has favoured an approach that is representative of the three geographic communities in South Leitrim, and therefore has proposed three community	The next stage is to elect the three representatives on to the PCT to attend business meetings. This has been agreed as the best forum for building relationships and establishing community

	<p>representatives on the PCT. The project's facilitator worked with the Forum to build capacity and to develop terms of reference, policies and procedures for the effective running of the Forum. A key objective is to ensure that the membership of the Forum is sustained and broadened.</p>	<p>participation as an integral part of the Team.</p>
<p>North West Roscommon CDP</p>	<p>Following training for community participation a core group of local people have formed a Community Health Forum. Representatives have been nominated from local groups, e.g. carers association, Pakistani Association, older people, mental health, rural men's group etc. There has also been attention given to ensuring that the different disadvantaged target groups and geographic areas are represented. The objective is that the Forum will provide information from and about local communities to the PCT and that information from the PCTs can be fed back to the community via the Forum.</p>	<p>At this stage there is no representation on the PCT from the Forum, although it is anticipated that this will take place in the future.</p>
<p>Rialto Community Health Project</p>	<p>The Rialto Community Health Forum was established prior to the project. However, the project helped to raise the profile and relevance of the Forum to primary care. Several Forum members have taken active roles in the project, including the facilitation of information workshops. It is planned that the Forum will have four meetings a year.</p> <p>The Community Health Forum has three representatives sitting on the Primary Care Management Team. Terms of reference for the meetings have been agreed.</p>	<p>The Forum will develop a system for electing representatives onto the Primary Care Management Team and the Rialto PCT.</p>
<p>Corduff / Mulhuddart</p>	<p>A Local Health Action Group (LHAG) has been established in Corduff and Mulhuddart and plans are in place to establish a LHAG in Tyrrelstown. The objective has been to ensure that there are representatives from different geographic areas as well as representation from women, older people, disabled people and Travellers. Terms of reference and job descriptions for representatives have been drawn up by the group. The ongoing work of the project is to ensure that the LHAGs are sustained through relevant local events and activities.</p>	<p>A Community Participation Working Group has been created (for the Local Health Office North West Dublin Network 3 Area) and from this representation is planned to take place at the LIG (through the Local Health Office in North West Dublin) and the two PCTs.</p>
<p>Westmeath Community Health Project</p>	<p>A Community Health Forum has been established with sixteen representatives from different target groups and geographic communities. Forum members have agreed terms of reference and realistic expectations. Community representatives have expressed a need for regular information from the PCTs as a basis for realising tangible outcomes. This is seen to be critical to sustaining the motivation and interest of the community representatives. A particular challenge has been to build confidence in the group and manage different levels of experience and capacity. A joint training session was organised between the community representatives and the PCT representatives to share information and build engagement.</p>	<p>A meeting is planned between the Community Health Forum and the Primary Care Network and two representatives from the Forum. Two alternate representatives, have been elected to be represented on Primary Care Network.</p>
<p>Mayo</p>	<p>A Migrant Health Forum has been formed in Ballina.</p>	<p>At this stage there is no</p>

Intercultural Action	An active group of migrants came forward at an early stage in the project and were supported by the project and through training to create a Forum. Sufficient numbers came forward to join the Forum and as the project developed new members have joined. Given the relatively short time frame for the project it was decided to create the Forum at an early stage in order to devote sufficient time to capacity building and training. The Forum meets monthly and a work plan and terms of reference have been drawn up by the group. Having a support person was deemed crucial as members of the Forum are volunteers facilitation and co-ordination are essential. The Forum is now represented on the County Mayo Liaison Forum for Immigrant Communities.	formal representation on the PCT.
Iorras le Cheile	The Erris Community Health Forum grew out of consultations in the local community and a commitment to identifying disadvantaged target groups for the Forum (carers, lesbian and gay community, men, migrants, older people, parents, people parenting alone, people who are socially isolated, people with a chronic illness, people with intellectual disabilities, people experiencing mental health difficulties, people with a physical or sensory disability, women and young people). The Forum meets monthly. The Forum aims to extend its membership to groups that are not yet represented, including lone parents, survivors of domestic violence, people with mental health difficulties, lone parents and migrants. Volunteers for the Forum undertook a training programme and since the Forum has been established further training has been provided in Team building and in drawing up the Forum's terms of reference and operating rules. The creation of the Community Health Forum, with thirty-two members is considered to be a significant achievement, particularly because of the dispersed rural community from which membership has been drawn.	Two members of the Forum will be represented on the PCT.

Projects that are planning Community Health Forums

Community Health Forums are planned as a longer-term objective for the following projects:

- The West Cork Islands project has not yet established a Community Health Forum, although community representation takes place on the LIG group via the Project Management Group that has representation from PCTs and the seven island communities. A long-term objective will be to have a Community Health Forum for each island community.
- In Monaghan, the project has identified the objective to have a Community Health Forum in the future and to link this into a Monaghan/Cavan network of Forums.
- The Follain project in Waterford will act as a Community Health Forum and will link with groups on the ground.
- The Wolfe Tone Project in Wexford and the Blakestown/Mountview projects have put in place plans to create a Community Health Forum in each project, but recognise that further capacity building for community representatives is required before this can be realised in practice.

Stand-alone or linked to existing structures?

A number of projects have raised the question of whether Community Health Forums should be stand-alone structures or linked to existing community-based structures. In the majority of cases the Community Health Forums are stand-alone structures, while in a few cases they are linked to an existing community representative structure, for example, through the County Council Community and Voluntary Forum.

Two projects have examined how a structure can link with existing community representative structures at county level. In Offaly, the project decided to create a Community Health Forum linked to the County's Community and Voluntary Forum, while the Finglas project have used the project to develop a health 'spoke' to the proposed new Finglas Community Platform.

Examples of Community Health Forums linking into other representative structures in the community

In the **Offaly Local Development Company and Birr PCT** project community consultations with local community groups in the Birr PCT area resulted in six volunteers coming forward to join a Community Health Forum in Birr. It is planned that this will feed into a South Offaly Community Health Forum, bringing together community representatives from the South Offaly Area Community Forum (Offaly County Council), West and South Offaly Building Healthy Communities Project (which is an inter-agency group) and community representatives from the Birr and Shinrone/Moneygall PCT areas. This is a good example of how existing structures in the County are being utilised to create a specific lens on health. There is also a virtue to this in that the representation of the South Offaly Community Forum and the Building Healthy Communities project provides a focus to the work of other agencies, including the County Council. This is particularly important to the project as many of the issues raised in community consultations are relevant for action by actors outside of the PCT, including the County Council.

The **Finglas Community Health Forum** has been established following a wide ranging consultation exercise in the Finglas area. A number of options were examined for a representative structure and a decision has been made to create the Forum as a spoke of the new Community Platform in Finglas. The first meeting has taken place with twenty community representatives. Being a spoke of the Community Platform means that there will be no duplication of activity and health will be a core activity of community development organisations and local agencies in one structure in Finglas. This has strategic advantages and will be linked to the Community Platform in Dublin City Development Board. The Forum will be the mechanism for community representation in the local PCTs and the Primary Care Network in Finglas. The Community Platform has the backing of key stakeholders, including Dublin City Council, local CDPs, the HSE, the Director of Community and Enterprise of the Dublin City Development Board, Local Drugs Task Force and the Tolka Area Partnership. The Community Forum will play a strategic role and will afford a new opportunity to provide more integrated services in the area. The outcome is that "The project has enabled us to have a more strategic and longer term impact that is applicable to primary care. The community was ready for this" (Community Development Worker, Finglas). The learning from this exercise is that, with so many different agencies and groups engaged in issues at community level, it is important to find a mechanism that does not replicate existing structures and forums. The project has highlighted the importance of resources for building community participation, and particularly the training of community representatives.

Community representation on PCTs

There are different stages and levels of participation on PCTs in the nineteen projects and this has impacted on the readiness for community participation. All projects have had some form of informal or formal engagement with PCT members, and in the case of three projects community representation has not been agreed because the Teams are in an early stage of development. A formal process for engagement on either the PCT or the LIG has been developed in nine projects.

The most highly developed representation on PCTs can be found in the Donegal project coordinated by the Lifford-Clonleigh Resource Centre, where Community Health Forum members are represented on the four PCTs and through the County network established through the County Community Participation Action Group.

In most cases two community representatives are nominated or elected to be represented on the PCT. In the case of the Community Health Forum established in South Leitrim the objective of the Forum was to ensure community representation from the three geographic communities and specific disadvantaged target groups in the PCT area. In order to sustain the representation, engagement and momentum from the three geographic communities it was decided to nominate three representatives onto the Community Health Forum.

Community representation tends to take place at PCT Business and Planning meetings. For example, in the case of the PCTs in Bundoran-Ballyshannon and Lifford-Castlefinn in Donegal, community representatives chair the meetings and play an active role in setting the agenda for meetings. The two community representatives that sit on the PCTs meet with their respective Community Health Forums prior to each PCT meeting to give feedback about progress and to identify issues for discussion or action with the PCT.

The stage at which community representatives have engaged with PCTs varies from project to project. However, it does appear that community representation on a PCT can be counter-productive if a PCT is in an early stage of development and particularly if community participation has not been built into PCT development activities. As a result, in those projects that have not yet developed formal mechanisms for representation on PCTs, a range of joint information sharing activities have been carried out to build relationships with PCTs. For example:

- In South Offaly, the project decided to postpone representation on the PCTs because the Teams were at an early stage of development. However, the South Offaly Community Health Forum has been established to provide a focus to community health issues, and particularly the social determinants of health in the two PCTs in South Offaly. The overall view of the community and the PCT is that it has been important to develop and strengthen relationships between the community and the PCTs, and in the interim the Primary Care Development Manager and the social worker from the PCT will attend Community Health Forum meetings.
- In the Wolfe Tone project participation on the Wexford PCT has not been possible because the Team is still in development. However, the Community Health Forum that has been created aims to provide a voice for disadvantaged communities in the Team in the future. The launch of the project's Community Health Needs Assessment was attended by several PCT members, and represented a starting point for engagement.

Joint PCT-Community Health Forum

A number of projects have established a joint health forum structure as a method to sustain community participation in primary care. Some of these structures are based on Steering Group membership, while others have created separate structures to bring together community and PCT representatives. For example, the Paul Partnership in Limerick has established the framework for a Local Health Forum with representatives of the local community and the PCT. The Health Forum will aim to ensure that there is ongoing and sustainable community participation in the PCT. The longer term objective is to find a mechanism for community participation on the other five PCTs in Limerick. It has been agreed that two community representatives will participate in the PCT's business meetings.

Several projects have developed a structure for representation at local network or Local Implementation Group level:

- The creation of a County Network of community representative and PCTs in Donegal has facilitated representation on the LIG and this has given a strategic direction to community participation County-wide.
- In the West Cork Islands project participation on the LIG has developed as an interim measure in order to facilitate representation of the seven island communities that stretch across four PCTs. A joint training exercise has been carried out with PCT members and community representatives as a first step to developing a representative structure for participation on local PCTs.
- In the Westmeath project participation on local PCTs has not yet taken place, but a first meeting with the Community Health Forum and the Primary Care network is planned. Two representatives from the Forum will be elected to be represented on the primary care network.
- As a first step to representation a joint training session was organised between the community and PCT representatives to share information and build engagement. This was very successful. Next steps were planned and a good basis established for further discussion.

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

An important outcome of many of the projects is that community participation has brought a renewed focus on community health needs from a social determinants of health perspective. This has been particularly important in highlighting how access to economic, social and cultural resources can shape health status. One community health worker sums up the approach taken in many projects:

“Health is created and lived by people within settings of their everyday life; where they learn, play and love. Health is ensuring that the society one lives in creates the conditions that allow the attainment of health for all members” (quotation from WHO cited by Community Health Worker, at the launch of the Rialto Community Health Forum report).

In focussing on the social determinants of health several projects have created inter-agency structures to ensure that PCT services link into other local services that can impact on health, for example, through local authorities, local development agencies, regeneration initiatives, housing, environmental, sports, child care, education and

training services, to name a few. Some of this has been achieved through the development of inter-agency Steering Groups or by linking into inter-agency structures in the community.

This has become possible in some projects that are linked to local development bodies, as in the case of Paul Partnership and South Offaly Development Company, or through structures linked to City/County Development Board Community and Voluntary Forums. There is important learning in this process for PCTs to have knowledge of how and where to refer community based health issues that are outside of the remit of the services provided by PCTs.

4.4.10 Strategy to sustain community participation

All projects have developed plans for sustaining the activities commenced during the funding phase of the Initiative. These have ranged from facilitated discussions between community representatives and PCT members to identify priorities and future actions, to specific action planning processes that have been put in place to sustain community participation.

Despite the significant commitment to and positive outcomes from the projects, the concerns about sustainability are not just in relation to the ending of the funding initiative, but also in relation to perceived threats to the community and voluntary sector.

Nevertheless, a significant number of projects are able to sustain some if not all of their activities, at least in the short-term and particularly where there is support from the HSE, for example, from community workers. One of the difficulties for many community projects is how their competing priorities, commitments to other core areas work and a potential loss of resources and staff, can be reconciled with a commitment to continue working on community participation.

In some projects there is a view that community participation structures could in the future be self-sustaining. However, at this stage all projects have identified the need for ongoing support and resources for community participation:

“The group will have to stand on its own two feet at some stage in the future; many on the group have very good capacity and can easily chair meetings, but there is still a need for a support person for now” (Primary Care Officer, Leitrim).

From a community perspective there is a strong commitment to sustaining community participation. Projects have created a momentum and a high level of interest, particularly because the Initiative is regarded as having created a genuine attempt to consult with and create an engagement between the community and the HSE. This has created a sense of commitment and ownership on the part of the community to continue to sustain the work on the ground. It is interesting to note the high degree of motivation and enthusiasm of many community volunteers, and a real sense of community responsibility to improve health and well-being. In many projects the time and resources that were devoted to the process of engagement paid off in terms of commitment to sustain community participation. As one community representative in Limerick said “I have stuck with it and am in it to see it through to the end”.

However, sustaining community participation is challenging for many projects in the current environment of restructuring of community development projects, and in the

light of significant reductions in resources and public expenditure for community development. In the case of one CDP, Equal Access CDP, the project has been closed down following a review process that has deemed the project to be 'non-viable'. While the community participation project has developed a new focus for local communities in participating in primary care, without the CDP on the ground there are questions about how the community participation in primary care can be sustained. There is a commitment within other structures in the community, for example through RAPID and on the basis of a commitment from social workers in the local PCTs in Tallaght to continue to develop the project.

As a result the evaluation has found that the concerns about sustainability do not relate only to the ending of the funding initiative, but also to the impact of funding cuts in the community and voluntary sector. Nevertheless, all projects have built some form of sustainability into their projects:

- Giving a strategic commitment to building community participation into the work profiles of community development workers working in existing CDPs and local development companies. In some cases the new LCDP provides an opportunity to build community participation into the work plans of CDPs and local development companies for 2010.
- A commitment on the part of the HSE to continue to support community participation, for example, through support from HSE community development workers, social inclusion officers and health promotion officers.
- The development of a wider ownership of community participation, for example, through RAPID areas.

It is equally important for community organisations, particularly CDPs and FRCs to have a buy-in to community participation and that a national framework for community participation be established to resource and support their roles. A number of projects have highlighted the role that national programmes can play in supporting the FRCs and CDPs, for example, through the National Family Support Agency and the Local Community Development Programme (funded by Pobal). As one Community Coordinator stated:

“ there should be a national directive to say that participation in PCTs should be a core area of work, and this should be linked to national programmes of funding such as the LCDP”.

From a HSE perspective the projects helped to raise awareness of the benefit and value of community participation to the effective roll-out and implementation of primary care services. In this respect many of the PCTs now have community participation 'champions' who have seen the positive impact of community participation to their work in delivering health services.

4.5 Discussion of the learning, impact and outcomes from the community participation projects

The evaluation was completed towards the end of the funding initiative, one year after projects had commenced. For this reason it is not possible to identify measurable outcomes of community participation with regards to service improvements. However, at this early stage in the Initiative the Evaluation has captured the perceptions of community, HSE and PCT representatives about the

impacts and outcomes of community participation projects, providing some valuable qualitative evidence. Many of these outcomes relate to how processes of community participation, information sharing, relationship building and engagement can be developed and sustained. This is now discussed in relation to:

- The value of community participation
- The community participation process
- Community perspectives on working in partnership with the HSE / PCTs
- HSE / PCT perspectives on working in partnership with the community
- Reconciling HSE and community perspectives and roles
- Utilising HSE support and expertise.

4.5.1 The value of community participation

The nineteen projects have shown that by developing methods for community participation PCTs have been given:

- New opportunities to identify and address the needs of the most socially excluded groups
- A potential to focus on the health outcomes of socially excluded people and to enhance these by developing more flexible responses and better access to services.

This has raised questions about:

- How primary care can meet the multi-faceted and complex needs of the most disadvantaged groups
- Issues related to the eligibility to PCT services for medical card holders and non-medical card holders
- How PCTs can evaluate the changes that are generated through community participation
- The extent to which PCTs can put in practice changes to Team structures and services in response to community needs that have been identified
- How PCTs can respond effectively to and engage with the issues raised through community participation, for example, by enhancing the quality of services, providing an interface in the community for health services and planning for new service developments.

Overall, the evidence from the evaluation shows that there has been a significant value gained from the sharing of roles, perspectives, understandings and expectations between community representatives and PCTs. Key to this has been the building of relationships and trust between the community and PCTs. However, this has not in the majority of cases resulted in joint decision-making and planning of services or substantive new service developments.

For PCTs the value of engaging in community participation can be summarised as leading to:

- Successful and sometimes creative and inspiring outcomes
- Mutual learning about and responding to different perspectives and ways of working
- Possibilities to 'think outside of the box' and to recognise and realise the intrinsic value to them of community participation
- New ways of approaching health and an evidence base for prevention related work with specific groups in the community
- An understanding of the broader social context of health.

For community representatives the value of engaging with PCT members has led to:

- Awareness of the role of health services and their links with community-led services
- Understanding of the scope of PCT activities
- Appreciation of how the broader social context of health relates to PCTs
- An opportunity to have a genuine engagement with and potential to influence health service delivery.

4.5.2 The community participation process

There is valuable learning from the nineteen demonstration projects with regard to the community participation process. In summary this concerns the following issues:

- Community participation takes time and requires resources
- Different starting points require different methods of community participation
- The importance of building mutual learning and respect
- Breaking down barriers / promoting dialogue between the community and the HSE
- The importance of creating realisable goals and expectations
- Identifying community needs
- The establishment of Community Health Forums
- The role of external facilitation, training and support.

Community participation takes time and requires resources

Because community participation is a new concept for many community organisations and the HSE, it requires a process of time and engagement. There have been different starting points for the nineteen projects and for this reason it is important to recognise that the distanced travelled is the key to measuring success. This could be a simple level of engagement resulting from a discussion between PCT members and local community groups to sharing information, to more sophisticated methods and structures for formal engagement. In all of the projects it is clear that the process of participation is time consuming and requires taking one step at a time:

“The process has taught us that it can't be rushed and that we have to bring it along slowly, step-by-step. Training is crucial to this. It would also help if more PCT members were involved from the beginning as it is important to have the full participation of the PCT”. (Public Health Nurse, Erris PCT)

This is reiterated by a HSE Social Inclusion Officer who saw the benefits of a step-by-step approach and a neutral space for the PCT to engage with the community:

“Community participation takes time, in fact it took us four times as long to do what we set out in our original plan. It is important to take a step-by-step approach. Because the PCTs didn’t know about community participation, they needed to get ownership of it; it is good to start to create a neutral space for dialogue. The PCT was very receptive to something that was low key and would not have been receptive if we had imposed a model on them” (HSE Social Inclusion Officer, Monaghan)

For many projects the investment of time and hard work has paid off:

“It takes time and hard work and the project took quite a while to get into because the concept was hard to grasp at the beginning. It was hard to see where it fitted. Now we are making really good progress and we are developing links and networks in new areas that we have not worked with before. We are now seeing something tangible” (CDP Project Worker, Roscommon).

Allowing the process to grow organically through support and working with groups on the ground was highlighted by a community development worker whose role has been to support community representatives in their participation in a local PCT:

“The process of community participation needs to grow organically and it needs to be supported. Initially there is a lot of knocking on doors, working with groups on the ground...but it pays off and reps now feel that they are having an impact and it is seen as worthwhile by the PCT”. (Community Development Worker, Bundoran-Ballyshannon PCT)

Different starting points require different methods of community participation

Across the nineteen projects there were significant differences in the starting point for community participation. While some projects built on an infrastructure of community consultations and participation, others started from scratch and built formative processes for community participation. In these latter projects a great deal of work took place to ‘sell’ the concept of community participation to HSE representatives and also to the community. For example, the project led by Westmeath Community Development Ltd started from a very low base of community capacity and the Development Worker spoke about the importance of working with people at the grass roots level and:

“...approaching people in their comfort zones and building from their own experiences at their levels. We approached it by asking people ‘what does health mean to you?’ and taking it to people at their levels. This made it real for people”.

The importance of building mutual learning and respect

A key element of the process of community participation is to build mutual learning and respect between the community and PCT members. For example, in the Lifford-Clonleigh Resource Centre project:

“We have built mutual respect in the process of participation and a lot of time went into this from the beginning. This laid the ground work for participation. It took time and energy and now the clinicians and GP are on board and they have seen first hand the work that the Community Health Forum have done and the benefits for them in their work” (Coordinator, Lifford-Clonleigh Resource Centre).

Breaking down barriers / promoting dialogue between the community and the HSE

Related to the building of mutual learning and respect is that barriers and fears that may exist between community and PCT representatives need to be broken down. For some community representatives the projects have enabled them to understand how the HSE works and what services are provided. The following two quotations from community representatives sum up the importance of making the concept of primary care accessible to the community:

“The HSE is a puzzle... it needs to be more joined up and coordinated. To me this is the way forward and is a way of breaking down the barriers and sharing a common goal” (Community Health Forum Representative, Westmeath project).

“A barrier has been broken between community and statutory services. A door has been opened for us to consult with the staff on the ground. Working on this project has helped us to get the bigger picture” (Blakestown CDP Coordinator).

For HSE and PCT representatives the initial stages of the projects were often fraught with concerns about how the community would respond and whether community participation would, as one PCT representative stated, “open up a can of worms and raise issues that we cannot respond to”. However, as the projects progressed and as joint working led to the establishment of common goals it became possible to manage expectations in realistic ways. Many PCT representatives were genuinely surprised at the outcomes of this engagement process and the ease at which joint approaches developed. This is not to say that all projects have taken a smooth course, rather that joint working has enabled community and PCT representatives to approach community participation in an equal way and thereby take both community and PCT representatives out of their comfort zones in ways that were not threatening or undermining.

The importance of creating realisable goals and expectations

Underpinning much of the work carried out in community participation is the importance of establishing realistic goals and expectations. Central to this is to create early ‘wins’ for both the community and PCTs to build confidence, engagement and motivation. This also means making community participation a tangible concept and goal:

“For the community primary care was initially an intangible concept. We focussed on the theme of ‘your health is your wealth’ which gave people something to engage with. It is really important to find simple ways to help people understand primary care” (Community Development Worker, Iorras Le Chéile CDP).

Identifying community needs

The evaluation has shown that PCTs have a key role to play in assessing health needs in the local community. Community participation can be intrinsic to this and can have the added element of providing a basis for community and HSE engagement. There are many different ways in which community needs can be identified and this can be carried out in creative ways in partnership with HSE and community representatives. Community participation can be critical to not only identifying and uncovering community needs that have not been picked up by health professionals, but also in identifying local solutions to local health needs.

A significant number of projects have carried out, in varying forms, community consultations on health. These have ranged from simple, yet successful open evenings with the local community to more sophisticated Community Health Needs Assessments that have been carried out with a wide range of local groups and local people. In several cases, community consultations have been the outcome of training provided for community and PCT representatives. A key, and successful angle, has been to provide information about services as part of community consultations. One of the success factors arising from some of the community consultations is that they have been planned jointly and run jointly between the community organisations and the PCT.

A number of the consultations have also raised the issue of how identified community health needs can be fed into a wider context of health care, including hospital care. This is an issue that has relevance for the establishment of the Integrated Services Areas (between PCCC and hospitals) as part of ongoing HSE reforms.

The establishment of Community Health Forums

Many projects have identified the key role that a Community Health Forum can play in representing the community on health issues. This has raised some critical issues about the full meaning of participation and the extent to which the forums can be fully representative of all sections of the community.

There are a number of different approaches taken and some issues have arisen regarding the best structures for representation and feedback to the community, as well as a mechanism to engage with PCTs. There may be more work that needs to be carried out in providing guidance and information to groups that are establishing Community Health Forums, including learning from the projects where these structures have worked well. In this regard the experiences of the Community Health Forums that have been established are particularly relevant. Specific issues identified by project participants include the need for information on:

- How to set and run up a Forum
- How to select Forum representatives
- Establishing robust and clear terms of reference, setting out roles, responsibilities etc., and for the managing of expectations
- Methods and structures for ensuring that there is effective representation of the community and accountability to the community

- Effective forms of geographic, age and gender representation, as well as the representation of Travellers, minority ethnic groups, disabled people, people from the LGBT community etc.
- The role of community development workers in providing technical support, and in supporting and developing the Forums
- Training and capacity building for Forum members
- Bringing new members onto a Forum and sustaining the structures
- The frequency of Forum meetings
- The role of the community representatives on PCTs and how the Forums engage with the PCTs, and whether there should be one Forum for each PCT or PCT networks
- Sustainability of Forums so that the motivation and interest of Forum members can be harnessed.

A number of projects have identified the need for guidance, for example, through a simple and user-friendly toolkit to be developed to provide checklists, resources and tools to help them establish representative structures for community participation.

The role of external facilitation, training and support

Projects have attached significant importance to having resources for external expertise, for example, for training in participatory methods and facilitation of community and joint meetings. Being able to resource external facilitation was seen as crucial to consulting with community representatives and groups as well as HSE primary care staff. Many projects have seen the added-value of external facilitators as this helps to ensure that consultations and reporting are independent. This has been particularly valuable in giving independence to the facilitation of meetings between community and HSE representatives.

In two projects, South Tipperary and Blakestown / Mountview, the project partners commissioned the CAN to provide training on participatory methodologies and participatory research. The model developed by CAN emphasises a starting point based on the lived experiences of participants and provided a model for partnership building and problem solving to resolve challenges. The benefit of this model is that it provides a basis for building the capacity of participants and points them to methods of engagement that are appropriate to their contexts and backgrounds. The project partners in these two projects spoke about the huge benefit of this approach in supporting engagement and finding relevant participatory strategies.

In most cases community organisations and HSE personnel would not have been in a position to engage in this work themselves given the limited staffing resources and competing priorities that they face. This raises an important lesson on the need for resources to bring expertise into the community participation process to support the development of participative processes.

4.5.3 Community perspectives on working in partnership with the PCTs

There have been very positive outcomes resulting from the working relationships developed between local communities and PCTs. For some projects finding a process for engagement has been complex, but none the less successful. However, in some cases PCTs and local community organisations cover different geographic areas. In the West Cork Islands project community representatives would like to see one PCT for the seven islands and highlighted the frustrations of many community representatives who feel “very constrained by structures; it would make more sense

to have one PCT for the islands, given the uniqueness of the situation". The project's community partners recognise the:

"huge learning process for the islands in working together with the HSE. This has been tremendous and if a forum comes out of this to provide a more efficient way of delivering services this will be hugely important" (Community Representative, West Cork Islands Project).

As another community representative stated as part of the evaluation: "the community representative can be an important go-between, acting as a bridge between the community and health practitioners". Another gave an example of a community walking scheme that had been put in place by a local community group, that was not known about by PCT members. This provided an important community asset in health to which service users could be referred. This example shows that when the PCT became aware of the scheme they became directly engaged in linking with the community on health issues.

In the case of the projects carried out by Mayo Intercultural Action and Pavee Point there is important learning for all PCTs about how the participation of Travellers and minority ethnic groups can be integrated into community participation in primary care projects in the future. This has implications for the dissemination of the learning from these projects to raise awareness of the specific health needs of Travellers and minority ethnic groups to all PCTs. In this regard the position paper and information leaflet on Traveller health and primary care produced by Pavee Point provides a set of recommendations for PCTs that can be disseminated nationally. In the case of the Ballina Migrant Health Forum there are high expectations that there is learning beyond the project of migrant health needs:

"We hope in the long run to improve the health and well-being of people who come to live in Ireland, if you have good health that helps everything fall into place...being on the Forum has given me real confidence and we are now in a position to be able to organise ourselves in the future" (Community Representative, Ballina Migrant Health Forum)

For many community projects engagement with the HSE has been a new experience. This has resulted in significant learning and awareness in the community of how local needs can be raised in the development and ongoing work of PCTs. Many projects have highlighted the important role of engagement with the HSE, for example:

"The project has opened doors to the community and the PCT has been very supportive of the project, and there have been good connections between the CDP and PCT members" (CDP Project Coordinator, Roscommon).

"Working very closely with the HSE shows what a complex structure it is and how it struggles with its own internal communications. But this project has been very good and we now have very good working relationships with the HSE...the community is not interested in complex organisational structures" (Community Project Leader, Paul Partnership)

In some cases the projects have provided legitimacy for community participation and this has opened doors for local communities to engage in a sustainable process. For example:

“The project gave legitimacy to what we had been planning and reinforced the importance of community participation. This has been a really important process and one that we want to continue and for the project to be sustainable” (Community Development Worker, Iorras Le Chéile CDP).

While in other cases the projects have mobilised an awareness of the importance of community participation to the core work of the HSE:

“I want to see the HSE seeing community participation as a central plank of their work... when we met the PCT we realised that these issues like social isolation are ordinary problems”. (Community Health Forum Representative, Westmeath).

An important outcome of the Initiative is that relationships between community and the HSE have been developed with very positive outcomes. For example:

“Primary care professionals and people in the community know each other [this is the result of] the importance of a mutual process of learning” (Community representative, Paul Partnership Project, Limerick).

This has ensured that the community has a voice in primary care that has been taken seriously by health professionals. For example:

“We have created a place for representing the views of the Islands, we now see the relevance of having a structure that enables us to find common ground...there has been huge learning for both sides and some big developments, working together has worked very well” (Community Representative, West Cork Islands Project).

Some community projects have highlighted the importance of engaging in more detailed discussions or training with PCT members on specific issues such as domestic violence, suicide and mental health.

There is also a perception in many community organisations that if PCTs are to function effectively and achieve positive health outcomes, they will need to listen to the voices of community groups and local people. This will open up spaces for participation and engagement. However, community representatives are also very clear that if PCTs do not take ownership of community participation it will be very difficult for the community to engage.

A number of community organisations highlighted the need for PCTs to effectively integrate community participation into their Team development work, for example, in developing joint approaches, working as a Team, using resources in the community and engaging with the community. There are some issues raised about how virtual Teams can work against community participation. Critical to this is having a PCT that is functioning and ready to engage with the community:

“The community can only participate if there is a functioning PCT in place i.e. where a needs assessment has been conducted, priorities identified, work plan developed and resources allocated to PCT and CHF to implement the work plan”. (Community Development Worker, Donegal)

Finally, community representatives see the value in engaging with PCT members and are now more aware of the role and scope of PCT services and the relationship between medical and social models of health.

4.5.4 HSE perspectives of working with the community

Health professionals have experienced significant learning and as one TDO stated “the learning curve has been huge and now we feel ready for community participation”. Some of this has enabled PCT representatives to understand how community participation can add value to their work and that community participation can provide a basis for joint work. As one HSE community worker stated “It’s all about give and take, and we are now in a position to share different positions and genuinely engage with the community”. In the case of another PCT representative “the PCT now sees partnership with the community as being essential”.

Some PCTs have had a real fear that they will be unable to respond to the community because of the constraints that they face, and as one representative stated ‘we will be in the firing line’, while another said ‘that we won’t be able to deliver on identified health needs’. It is interesting to note that these fears tend to diminish in importance when meetings are held with the community, and expectations and roles are discussed. The joint approach has genuinely brought people together to find a common ground and in some cases to find the basis for compromise and joint work. This has particularly been the case in those projects that have organised joint training between PCT and community representatives, and joint community consultations.

Some of these issues are particularly relevant for the leadership roles played by TDOs in building and sustaining PCTs. Several TDOs felt that they needed training in how to establish community participation, while others stated that there was a real need for a ‘mindset change’ to take place so that TDOs can be champions driving community participation. In two projects the TDOs had moved into new jobs and had not been replaced, which had a significant impact on community participation.

Nevertheless, community participation has provided an evidence base for prevention related work with disadvantaged groups in the community and has highlighted the role that the community can provide in a broader social context of health.

There is also important learning for PCTs about the importance of having a network of community organisations on the ground with whom to engage. As the HSE’s Principal Community Worker in West Cork stated:

“...we could not have done this work without the community organisations on the ground. It was crucial from the start to have representative organisations with whom to work, particularly organisations that have representatives with a mandate to provide feedback with local communities”.

There is also important learning for health professionals about how to engage with the community. For example, in one community consultation an HSE representative provided a breakdown of the internal working structures and lines of communications within the HSE. This was deemed unnecessary by community representatives as local people are not interested in internal structures rather they are interested in how they can engage with an integrated and coordinated HSE structure. This provided important learning for the HSE representative about how local communities perceive the HSE.

The importance of building good working relationships with local communities has been reiterated by many HSE workers and PCT members. For example:

“It has been a really successful and really worthwhile development, and very good working relationships and positive engagement has taken place. The PCTs and the LHO are now sold on the idea and the community organisations have managed to create a dialogue and a process that has been allowed to grow organically. Building on these good relationships will have a spin-off for the future” (Social Inclusion Officer, Monaghan).

In addition, there is also a recognition that the process of engagement is ongoing and that it needs to be built in from the start of projects:

It has been important to participate in the project from the beginning, this is key to relationship building. We have never done anything like this before and the learning has been enormous” (TDO, Blanchardstown Area).

For many PCT representatives there is significant learning about how processes of community participation take time and that effective outcomes will only take place if a process is put in place. This is important to developing joint work and to “teasing out difficulties at an early stage”:

“We have made huge process and we needed nine months to achieve what we have achieved. There are no quick fixes and the process of engagement takes time” (PCT representative).

The capacity of PCTs has been raised by both PCT representatives, TDOs and community organisations. This concerns a number of issues namely:

- The readiness of PCTs to engage in and participate with the community
- PCT formation and Team development, and the resources, training and supports that are needed for PCT members to build fruitful working relationships and in particular to resolve issues of resistance and capacity. This is particularly important as the formation of PCTs has huge implications for working relationships and working methods internally and with the community.
- A number of PCTs have highlighted the need to ensure that community participation develops in a coordinated way through the HSE, so that it connects with forums and consultation mechanisms that are in place, for example, the Older People’s Forum.
- Team development is affected by the critical role of GPs in the process. In some projects there has been active participation of GPs who are supportive of community participation and have seen the benefits of it in practice, for example, in Lifford-Castlefinn. However, in some PCTs GPs have not been active in PCTs and this has impacted on the frequency of meetings. It is very evident that if the GPs are not active on PCTs the process of community participation has been more limited and less effective.

4.5.5 Reconciling HSE and community perspectives and roles

Managing different organisational backgrounds and roles within the community and between the community and the HSE was a key challenge faced by many projects. A great deal of effort was required to create a culture and an understanding of community participation, which in some cases required changing mindsets, raising awareness and sharing organisational learning.

Many community organisations articulated the importance of the wider context of health in disadvantaged communities as being relevant for PCTs. This was not always within the understanding and perspective of PCT roles.

The role and processes of community participation were not fully understood by all partners at the start of the Initiative. However, the closer partners were to the development of projects, the greater the realisation of the benefits of community participation and of the time, resources and energy that are essential for developing capacity and representative structures.

Community partners worked from community development and community organising perspectives, which were *process driven* and flexible to community needs. Their roles are fluid and rooted in community development and empowerment. This is in contrast to the working cultures of many PCT members whose work is largely *task driven* and shaped by professional roles and ethics. Health professional roles are bound by codes of professional conduct that are determined through professional socialisation and training, often within a tight medical model. As a result, reconciling these roles can be challenging and daunting at times.

Nevertheless, finding a common ground and sharing perspectives did result in a huge learning curve for community and PCT representatives. This joint understanding was crucial to managing expectations and defining realistic goals and outcomes for projects.

Inevitably, this work throws up challenges regarding expectations, methods of working and organisational constraints. These issues have been openly discussed in many projects, resulting in mutual learning about and responding to these different models and ways of working.

4.5.6 Utilising HSE support and expertise

The HSE has a wealth of expertise and potential on the ground to support the development of community participation in primary care. A number of projects have utilised the expertise of community workers, social workers and health promotion officers, for capacity building and training, for facilitation, in making the arguments about the benefits of community participation, and in providing ongoing resources.

Utilising this expertise has been particularly important to building capacity and connections between PCTs and community groups, and ensuring that 'local champions' in the HSE are supported and networked. This will be crucial for future developments in community participation and also in supporting and mainstreaming community participation in the roll out of PCTs.

The role of HSE expertise is discussed further in Chapter 5 and highlights the need for a more systematic national approach to addressing staff roles and activities in community participation, particularly to find a way in which community participation in primary care can be identified as a core work task.

Community Workers

In many projects key roles have been played by HSE community workers whose expertise and experience provide the basis for HSE liaison and support in the community. Establishing a network of advocates and community workers working within the HSE has been identified as an important step forward.

Some key issues were raised at an early stage in the Initiative about the need for a national approach to harnessing the expertise and support of community work staff, and particularly how workloads and job descriptions can be more effectively targeted towards community participation in primary care. However, the evaluation does suggest that this requires a more systematic approach to developing shared ownership of models of community participation in primary care.

There are some very good examples of how HSE community workers have actively participated in and helped to shape community participation in primary care at local level. For example:

- In Finglas a Community Worker participated in the project on a part-time basis and the Senior Community Worker helped to provide strategic direction and expertise to three projects in the Blanchardstown / Finglas areas.
- In the Wexford project, the Principal Community Worker played a key role in supporting the project.
- In the West Cork Islands project the Principal Community Worker identified the project as one of her core priorities and provided a coordination and resource role for the project.

However, these were resources provided for the duration of the project and it will be important in the future to ensure that these resources are provided in more systematic ways to support community participation.

Social Workers

Social workers, by the nature of their work and training, have a very positive role to play in supporting community participation. This is particularly important because social workers are PCT members and in some cases have open job descriptions from which community participation can be built in as core work. This was the case with the social worker in the Offaly project and the Social Workers working with the PCTs in Tallaght. The active participation of the Social Workers from the PCTs has given a positive bonus to the planning and facilitating of community consultations. In the case of the social worker in Offaly, this was a new post in the PCT and it was possible for him to identify community participation as a priority area of work. However, two Social Workers from the PCT in Corduff were pulled from the Team to work on emergency child protection work, which undermined the autonomy and role of the PCTs work. This was particularly relevant because the Social Workers had become active champions of community participation and their exit from the Team left a significant gap and a degree of demoralisation in the PCT and in the community.

Health Promotion Officers

The role of health promotion is particularly important to the evolving framework of community participation, particularly in providing a perspective on the social determinants of health and the links between population health and primary care. The evolving framework for HSE health promotion services will be important to

ensuring that this links with the roll out of PCTs in the future, and the provision of support for community participation and engagement.

Some projects have developed good working relationships and involvement with HSE health promotion personnel. For example, the two projects in Mayo received training from the HSE Health Promotion Officer (Iorras le Cheile and Mayo Intercultural Action). In West Offaly the Health Promotion Officer has played a very active role in the project development and management, and has inspired much of the thinking and methodology on the social determinants of health that has underpinned the project. In Westmeath the Health Promotion Officer worked directly with the Community Health Forum representatives to improve capacity to respond to health issues around the social determinants and community need assessment.

It is also interesting to note that community engagement has energised and developed health promotion roles, and in the case of one Health Promotion Officer the project has enabled her to bring health promotion to life:

“I am now very confident about how the community can address needs and carry out a Community Health Needs Assessment. This is a most exciting time and can help health promotion to come to life in the HSE. People in the community are very good at naming the social determinants of health whereas in the HSE we have a much narrower definition of health as being treatment and illness rather than the person. This can have a real impact on changing practice” (Health Promotion Officer, Athlone linked to the Westmeath Community Development Ltd project).

Social Inclusion Officers

Social Inclusion Officers have also played a key role in supporting a number of projects. Social inclusion staff provide important perspectives on how to engage with and target disadvantaged and marginalised groups in the community, and this links into national priorities and the strategic direction given by the Social Inclusion Care Group.

The Pavee Point project was supported by the Social Inclusion Specialist for the Dublin Mid-Leinster area, who has played a key role in championing Traveller health services. The Social Inclusion Officer in the Monaghan project acted as the HSE Project Coordinator for the project and has prioritised community participation in his work role in order to continue to develop and further sustain community participation, including rolling-out the learning from the Monaghan project to other PCTs in Monaghan and Cavan. In the project based in Lifford, Donegal, the Social Inclusion Manager provided expertise and has played a key role in supporting and developing community participation in primary care. She has been an important source of inspiration for local community representatives, whilst also providing a bridge between the community and the HSE.

4.6 Conclusions and learning from the joint community participation in primary care projects

4.6.1 Overall outcomes from projects and challenges for the ongoing development of community participation in primary care

The Initiative has led to some very promising outcomes for community participation in primary care. These are summarised under the following headings:

- Improved capacity for the community to participate
- Understanding of the value of community participation
- Development of new models of community participation
- A shared understanding of the wider context of health
- Joint approaches and working
- Improved capacity to identify community health needs
- Improved knowledge of PCT and community-led services
- Commitment to sustaining community participation
- Representation on PCTs

Improved capacity for the community to participate

Community representatives and HSE staff have improved capacity, skills and confidence to engage in community participation initiatives, for example, in identifying local health needs, in focussing on the specific challenges faced by disadvantaged communities and target groups and in sharing information about local health and community-led services.

Understanding of the value of community participation

There is a much greater awareness amongst community representatives and PCTs of the value and importance of community participation. This also includes understanding of the processes of community participation.

Development of new models of community participation

New models of community participation have emerged and these reflect different starting points for PCT areas, depending on the level and history of community engagement and community organisation. These can be seen as being part of a continuum of community participation from information through to co-decision making. Establishing representative structures in the form of Community Health Forums and Community Participation Working Groups, has enabled community organisations to mobilise local people and community organisations into structures that have the potential to be sustained into the future.

A shared understanding of the wider context of health

Many of the community participation projects have focussed on the wider context of health using the social and economic determinants of health as a framework for their work. This is on the basis that health and well-being are closely related to the social and economic conditions in which people live. The projects have highlighted many of the factors that affect people's health, encompassing community concerns about how issues such as poverty, marginalisation, access to social networks and social isolation impact on health and well-being. Anchoring these issues in primary care can be transformational and can widen the scope and impact of primary care in local

communities. Inevitably this also helps to focus attention on how the factors that impact on health can extend beyond the role of primary care and in so doing can make connections between primary care and other services in the community. It is interesting that these are issues that PCTs consider to be increasingly important to long term health outcomes, and through their work with local communities are able to tap into local community support services. As some PCT members have found, knowing what is available in the local community can play a key role in assisting people whose ill health arises from social factors, such as social isolation.

Joint approaches and working

Joint approaches and collaborative activities have supported Team building, joint ownership of project activities and outcomes, sharing of information, trust and joint working. This has resulted in the creation of local community health 'champions' and 'advocates' in local communities and PCTs. This has resulted in joint problem-solving and finding the common ground between community and HSE expectations. The projects have shown how HSE and community organisations can reconcile their different backgrounds, roles and working methods through dialogue, joint decision-making and joint actions. This has led to hugely important outcomes in terms of relationship building, mutual learning, shared ownership of participative methods and joint activities.

Improved capacity to identify community health needs

Community Health Needs Assessments have identified broad based community health needs, and located them in a framework of the social determinants of health. These have been important in informing service planning and developments, particularly regarding preventative health care, the utilisation of locally based community services and support groups, and the need for a focus on inter-sectoral working around health. Community Health Needs Assessments, for example, can help to identify community based solutions to health problems, for example, community based initiatives to reduce mental ill health resulting from social isolation. For this reason engagement with the community in needs assessment can promote real change. Evidence from the nineteen projects is that once local people knew about the parameters within which PCTs work, they did not make unreasonable claims or where issues were raised that were outside of the remit of the PCT a dialogue was opened about how these problems could be resolved. This could concern, for example, local sports facilities, play areas, child care or other services that fall within the remit of the local authority.

Improved knowledge of PCT and community-led services

Amongst the nineteen projects there has been a significant exchange of information about services. Community knowledge of health services and the role of PCTs, and PCT knowledge of community-led support groups and services has enabled community-led and HSE services to be better integrated and utilised. In some cases there have been positive changes made to service provision in the light of consultations that have taken place with local communities.

Commitment to sustaining community participation

The projects have led to a commitment to and a motivation on the part of local communities and HSE personnel to sustaining community participation and sharing the learning and good practices that have developed. It is clear from the evaluation that there are a number of formalised structures for community participation on

PCTs. However, it will be critically important for community representatives to be supported through this process of engagement, particularly because engaging with health services providers can be intimidating and isolating. As a result, local community organisations have a key role to play in connecting with primary care developments and in supporting the ongoing representation of community representatives on PCTs.

Representation on PCTs

A number of projects have successfully developed structures and processes for representation on PCTs. Where formal structures of representation have been put in place there are some important questions about how best to engage with PCTs. In Donegal, community representatives expressed concern that community representation on the four PCTs represented in the Lifford-Castlefinn project was at times hampered by a lack of planning for mainstream service developments and an uncertainty about how the PCT could respond to community needs. For example in one PCT the scheduling of meetings are determined by the availability of the GP. Hence if the GP is unable to attend the meeting is cancelled. As well, the move from monthly to two-monthly meetings with the community was viewed by the community as a way of reducing community impact. Although there were some very positive examples of joint projects developed to respond to identified needs, these took place in parallel to rather than integrated with mainstream services.

4.6.2 Community participation in primary care: critical success factors

Community participation and the levels of engagement between communities and PCTs are affected by four critical factors, which are discussed below:

- The readiness of the community to participate
- The extent to which the PCT is ready, prepared and willing to engage
- The availability of support structures and resources in the community
- The extent to which there are existing structures and forums for participation

The readiness of the community to participate

An important starting point for community participation in primary care is that there is a vibrant and effective community infrastructure with which PCTs can engage. It should not be the responsibility or role of PCTs to create and build community structures, rather PCTs should link with existing organisations on the ground as a basis for developing community participation on their Teams. This readiness to participate depends on whether there is a history of community organising and community consultation, and community organisations on the ground with the resources to devote to community participation. All of the projects in the Initiative had the active participation of community organisations that were functioning in the community.

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

This is affected by the level of Team development, the extent to which performance management and Team development have incorporated community participation, the levels of awareness of the benefits and opportunities of community participation, a preparedness to engage in community participation and the role of the Transformation Development Officer (TDO) / Primary Care Development Manager in supporting and championing community participation. Of the nineteen projects the majority were working with PCTs that were either partly or fully functioning and there

were varying degrees of willingness to engage in community participation. However, as projects progressed and as awareness grew this engagement progress developed in very positive and constructive ways. There are some structural and organisational factors impacting on this, for example, in some cases PCTs have experienced problems in giving a focus to community participation because the Teams do not have one base and are considered to be virtually functioning.

The availability of support structures and resources in the community

Having resources in the community to support and build capacity for community participation requires the resources and expertise of experienced community development workers to build capacity, motivation and interest. In some cases these resources can be found in the HSE from Community Workers, Social Inclusion Officers, Health Promotion Officers and Social Workers. In the nineteen projects the availability of project funding and the shared management and ownership of the projects between community organisations and the HSE, provided the context for the development of support structures and resources for community participation.

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

Having structures for participation is crucial if community participation projects are to be successful. The majority of the nineteen projects had no established or existing structure for community participation and as a result many of the project actions were geared to building a process for participation through project activities.

The process of engagement was significantly strengthened in those projects that established joint terms of reference for participation on PCTs. In two projects existing structures were already in place and this enabled the projects to build new activities to reinforce and further develop community participation.

“Reducing inequalities in health and the delivery of personalised, integrated health services will only be achieved by working closely with communities, recognising difference and tailoring provision of services accordingly, a 'one size fits all approach' is just simply not possible. Health professionals, services and organisations need to work together, across traditional boundaries, for the benefit of all service users, particularly those whose voices are seldom heard” (Project Coordinator, HSE Office of Consumer Affairs)

4.6.3 Learning from the projects for the roll-out and sustainability of community participation in primary care

The learning from the Initiative suggests that this has a number of implications for the roll-out of community participation in all PCTs in the future:

- There is a real added-value to providing resources for community participation and thereby enabling joint working to develop and grow. Ongoing resources are needed to support existing projects and the roll-out of the learning from the Initiative if realisable processes of community participation are to take shape and have a lasting impact on PCTs.
- The community participation projects have shown that it is important to prioritise the participation of and consultations with disadvantaged communities. The focus on the broader context of health can be both enabling and challenging. However, it can assist in meeting broader HSE objectives for the social inclusion of marginalised communities and it can be a means for addressing inequalities in health.

- 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 resources, incentives and tools to be 'champions' of community participation.

There are also important implications for 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 Teams are poorly developed or if there is a lack of clarity around eligibility there will be implications for engagement. Similarly, there can be limitations on PCTs in responding effectively to community engagement, particularly if their roles are limited to clinical matters and not rooted into service planning and monitoring that can influence the development and prioritising of local health services.
- HSE staff, including community workers, social workers and health promotion officers, have provided important expertise and support in a number of projects. 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.
- The role of external facilitation, training and support has been very important to project activities; in particular external facilitation can be very helpful as it brings objectivity and independence to meetings. The role played by external consultants in providing research services and the Community Action Network in the provision of technical support and regional training has been crucial to developing participative methodologies and partnership working.
- The Initiative has shown that Community Health Needs Assessments have been crucial as a method to identify local health needs and through the process of their design and implementation they have helped to engage PCTs and local communities in new and creative ways. It will be crucial that they are tied into and complement the development of the evolving national framework for needs assessment for PCTs.
- It will be critically important in the future for community organisations to be effectively resourced and managed by representative structures, so that there is a solid community infrastructure with which PCTs can engage. A number of projects in the Initiative are currently undergoing restructuring of their funding and representative structures. The loss of local management committees in Community Development Projects and the integration of staff into local development companies was highlighted as a concern by some projects as these networks and staff were utilised to support community participation on Primary Care Teams. By contrast, in some other areas, community representatives viewed local development companies as being important key players for the promotion of community participation in primary care, particularly under the new funding priorities and goals established under the Local Community Development Programme.
- 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. The

- More attention will need to be given to the measurement of the impacts and outcomes of community participation in primary care. One of the problems of measurement is that improvements in health or changes in health status of disadvantaged groups can take many years to realise in practice. However, there are a number of indicators that can be developed to measure issues such as community satisfaction with local services, improvements in access to and uptake of local PCT services and improved levels of community and social support.
- The learning from the projects will form an important evidence base for the development of new community participation in primary care projects. These will need to be supported by a strengthened national framework on community participation in primary care, including robust guidelines and indicators so that actions are implemented and reported upon. This also relates to the need to develop a model /template for capturing the qualitative and quantitative impacts of community participation in primary care, from a community and from PCT a perspective.

Section 5: The role of the Initiative nationally

5.1 Introduction

This section has two purposes.

- First, it gives an overview of the Initiative at the national level and actions that were put in place to connect projects nationally. It also provides an assessment of the role of the project's National Working Group and how this has acted to steer the project and develop a national framework by connecting with key decision-makers.
- Second, it examines the national service and policy implications of developing community participation in primary care.

5.2 National actions to support the nineteen projects

Being part of a national Initiative has meant that the nineteen projects have benefitted from being part of a network of projects that have been supported through national activities. The evaluation found that project partners saw the value of being part of a national initiative for two reasons. First, it gave local projects the opportunity to learn about other project activities, approaches and methods, and thereby enable them to develop their projects using this learning. Second, it enabled them to have a voice that could potentially influence national policy.

National project activities have included:

- National networking events
- Regional technical support training
- Individual project technical support
- Regular information through Community Participation Bulletins
- Support from the two national Project Coordinators.

5.2.1 National networking events

The Project Coordinators jointly facilitated four networking events, two of which were held in 2009 (in Dublin and Tullamore) and two in 2010 (in Dublin). Each networking event was very well attended, with participants from both the HSE and the community in attendance. Event activities were further supported by CAN.

The networking events were an excellent opportunity for project partners to:

- Meet and exchange experiences of methods of community participation
- Define and shape project goals and key messages
- Gain feedback about national policy developments, for example, in relation to primary care and HSE policy
- Have feedback on the evaluation of the Initiative and to gain information about broad developments across projects
- Make recommendations about the sustainability of project actions.

Participation in the networking events was rated very highly by both community and HSE representatives. The most value was gained from sharing experiences with other projects. As one community representative said "it has been useful to meet

people who are struggling with some of the similar issues that we face". A small number of projects with more experience in community development and participation stated that they would have liked more grouping of projects that have issues and experience in common.

Networking has been equally important for both HSE and community participants and there was overwhelming feedback from the evaluation that the networking events have provided an added-dimension to their work and in helping projects to address challenges and identify ways of resolving them.

A large number of community projects stated that they would willingly be part of the planned national community development and health network.

5.2.2 Technical Support

Technical support was provided by CAN, who were contracted to provide twenty-seven days of technical support for individual projects through five regional training workshops.

Technical support has been a vital element of the project and has provided projects, particularly those that were starting from a low base and experience of community participation, with understanding, tools and advice needed to develop project activities and partnership working.

CAN carried out an assessment of technical support and training needs at the beginning of their contract. A number of issues were identified including building community involvement, holding community consultations, carrying out assessments, and creating and sustaining partnerships in the community. The three most requested areas for training were building community participation, developmental methods for working with large groups and sustaining partnerships.

Technical support for individual projects

Technical support was offered to all projects. Some of this support has been provided by telephone and was provided in face-to-face meetings with six projects (in Blakestown/Mountview, Donegal, North West Monaghan, Roscommon, Equal Access Tallaght and West Cork Islands). This included one-to-one support for Project Coordinators, support in evaluating project activities and identifying key learning, Team building, training for PCT and community representatives in developing and sustaining community participation and the facilitation of joint PCT and community meetings.

Projects availing of technical support rated the support very highly and this particularly enabled projects to gain additional support in areas where they needed clarification, an independent and autonomous perspective on developments, expertise in facilitation and Team building, and advice on developing a strategic input into project activities. As one Project Coordinator from the community stated "the technical support enabled us to draw out learning from our work and to stand back and identify what we had done". Technical support was particularly important for projects that were new to community participation.

Several projects stated that they would have valued having technical support at the early stage of project development, particularly as this would have helped them to get started and avoid some of the pitfalls that they experienced along the way. However, because the technical support did not commence until September 2009

many projects had resolved initial difficulties and problems and no longer required technical support.

Regional training workshops

CAN also hosted five regional training workshops, three in 2009 (Castlebar, Dublin and Cork) and two in 2010 (Dublin and Castlebar). Each workshop was attended by between twelve and eighteen participants from community and HSE backgrounds, and this also included community volunteers who had become involved in the projects through a local Community Health Forum.

The regional workshops were valuable in establishing principles of and understanding of community participation. This highlighted the importance of planning for community consultations, building on what is already happening and identifying potential challenges.

Overall there have been very positive outcomes from the regional workshops, the most important of which come from the sharing of learning and networking between groups. This has also been important for relationship building within projects and between the HSE and community organisations. The information sharing has been important in generating new ideas and approaches, learning from different experiences, and for community organisations learning from HSE staff about the barriers that they face and in implementing a culture of change in their own organisations, and in measuring progress and achievements.

As with the technical support, the first regional workshop did not commence until October 2009 when projects were well under-way. In the evaluation several projects stated that it would have been useful to have had the regional workshops at an earlier stage of the project's development, rather than mid way through the Initiative.

5.2.3 Project information sharing and support

HSE Land

A web resource was provided for project networking and information through HSE Land www.hseland.ie, which is an on-line resource for learning and development in the HSE.

This was found to be very useful as a source of information by some project partners, but failed to take off as a method for on-line networking and information sharing between projects. Reasons for this were cited as being related to unfamiliarity with and a lack of time for on-line networking, and difficulties in accessing the site and in getting passwords to work. Many people found the site difficult to access and not 'user friendly'.

A large number of project partners suggested that in the future a web-based resource would need to be easier to access. This has the potential to provide a useful base for sharing information and resources developed through the projects, including project reports of community consultations, local project evaluations, terms of reference drawn up by Community Health Forums as well as reports, leaflets, newsletters and other information resources produced by projects. Several project partners stated that they would find on-line networking a very useful way of staying in touch with projects and of sharing experiences and learning as community participation develops across PCTs.

Community Participation Bulletins

As part of the formative evaluation monthly *Community Participation in Primary Care Bulletins* were produced. These provided an update on the evaluation and an opportunity to disseminate learning from the projects on an on-going basis. Updates and information about HSE policy developments were also included.

The Bulletins were widely disseminated amongst project partners and across the HSE by email and via the HSE Internet. The value of the Bulletins was seen as being twofold: one as a useful source of information about project developments, and two as an opportunity to disseminate the learning from the evaluation on an on-going basis for key decision-makers, policy makers and primary care professionals.

Ongoing support from the national Project Coordinators

The nineteen projects were supported by the two national coordinators:

- The Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs (and prior to that, in 2009, located in the former the Combat Poverty Agency)
- HSE Office of Consumer Affairs

The two Project Coordinators played an extremely important role in:

- Supporting the projects nationally through advice about project activities, work plans and budgets
- Organising and preparing the agendas for the project Working Group and the Evaluation Sub-Group and the national networking events
- Supporting the evaluation process
- Providing a link between the projects and national policy.

Both Project Coordinators highlighted in the evaluation the importance of the mutual learning from working together in the development of shared goals, in the area of policy formation, working methods and organisation learning from the respective organisations. Feedback from the nineteen projects highlighted the crucial role that the Project Coordinators played in providing ongoing support and advice to individual projects and within the context of the Initiative overall.

5.3 National policy and service delivery related activities

5.3.1 National partnership context for community participation in primary care

A key feature of the Initiative has been the development of a national partnership under the auspices of the HSE's Oversight Implementation Group of the Service Users Strategy. The Combat Poverty Agency was involved in a programme of work on health at the same time that the HSE was developing its Service User Involvement Strategy. Both organisations were concerned with the participation of people experiencing poverty and social exclusion in health services and began to collaborate in 2005. This partnership has been particularly important to developing shared actions and progressing community participation in primary care nationally.

“The roll out of the joint funding initiative from its inception to implementation and evaluation mirrors the process that each of the nineteen projects went through. We too had to work in partnership, ‘forming, storming, norming and performing’ throughout the process. I trust that the energy and goodwill that this partnership has created will result in strong trusting relationships that will meet any future political, bureaucratic and financial hurdles in progressing community participation and primary care” Director of Advocacy, Quality Clinical Care Directorate, HSE.

5.3.2 The joint management of the Initiative and the benefits of partnership

Social Inclusion Division (DCEGA, formerly in DSFA and Combat Poverty)

The DCEGA has played a key role in the Initiative not only in jointly managing the project with the HSE, but also in terms of the learning that they have brought to the Initiative. This learning has included many years of experience of working in the area of inequalities in health and community development, in bringing skills for mobilising community participation through the *Building Healthy Communities Project*. The Building Healthy Communities project was originally initiated by the Combat Poverty Agency in 2009. In 2010 the Combat Poverty Agency was integrated into to the Social Inclusion Division of the Department of Social and Family Affairs, during which time they continued to manage the Initiative.

Having dedicated resources for the Initiative is regarded as being crucial to achieving real engagement between the community and the HSE, and has provided an opportunity for new forms of partnership working. The development of a governance structure through the Working Group has also helped to embed learning about the project across the HSE.

The Initiative is regarded by one stakeholder as being “one of the best opportunities in the history of the Combat Poverty Agency (Social Inclusion Division) for real engagement with a statutory agency, with real and definable outcomes”.

HSE Office of Consumer Affairs

For HSE Office of Consumer Affairs, the relationship building between the Social Inclusion Division and the HSE in the joint management of the Initiative nationally has been a very positive outcome. The experience of and learning from the Combat Poverty Agency/Social Inclusion Division has been hugely important in setting out the parameters for community participation, expectations for projects, and anticipated outcomes. According to one of the Joint Project Coordinators:

“The opportunity that this has afforded would never have happened without the Combat Poverty Agency, their experience and role has provided a level of experience that is impossible to put a price on...The project has given community participation a chance to showcase what can be done for so little and has proven to be a powerful reference point for the HSE”.

Finally, there is an awareness that the Initiative has created significant learning and has helped to create community participation champions in the HSE, but also a reflection of a need to ensure that high level champions take responsibility for the diffusion of this Initiative throughout the service.

5.3.2 National Working Group on Community Participation in Primary Care

A National Working Group was established from the outset of the Initiative as a sub-group of the HSE's Oversight Implementation Group of the Service Users Strategy. The membership of the Group can be found in **Appendix 3** and included a broad membership with representatives from HSE Office of Consumer Affairs, the Social Inclusion Division (DSFA), HSE 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. The Group was chaired by Mary Culliton, HSE Office of Consumer Affairs. Terms of reference were drawn up by the group and participants provided information about their areas of expertise and expectations in relation to the role of the Working Group and the outcomes of the Initiative.

The group played a very active and engaging role in leading the project, while also providing feedback to projects about national initiatives. The Working Group were highly motivated and received feedback from projects as they progressed, via the Formative Evaluation, coordinator site visits and reports from networking events. This was described by one member of the group as:

“A real achievement for the projects and for the Group [and provided] a powerful reference point for all stakeholders...members saw things happening and this was really motivating”.

Mapping Sub-Group

A key issue raised in the National Working Group was the need to develop a profile of the expertise within existing HSE staffing that can be utilised to support community participation in primary care projects. As a result the group initiated a Mapping Sub-Group to carry out a national mapping exercise to identify where community development / community work and social inclusion staff are located and to examine how their skills and expertise could be structured in the future to contribute to supporting the development of community participation projects. This mapping exercise aimed to update an exercise carried out in 2009. This would provide an important evidence base upon which further recommendations can be made about redefining staff roles so that they can be more effectively targeted to work on and support the roll-out of community participation initiatives in primary care.

It is evident that if community work and social inclusion staff are to become more focussed in their work on community participation this will require substantial reconfiguration of their roles and work profiles. As a result this raises key issues about the need for:

- Job descriptions to include community participation in primary care and the provision of training on models of community participation
- Further discussion and a national and regional approach and strategic direction from RDOs, the National Director for Integration, regional managers of community and social work services and the Social Inclusion Care Group to ensure a strategic approach is taken and shared methodologies for community participation are developed
- Further discussion to establish how existing and new performance indicators on community participation in primary care can be delivered and built into the performance indicators of health promotion, social work and social inclusion. This is particularly important as staff in these areas are well-placed to provide strategic and operational support under the KRA on community participation relating to PIs

Formative Evaluation Sub-Group

An evaluation sub-group was formed and this provided a reference point for the Formative Evaluation, discussion of findings and recommendations, as well as a conduit for feeding issues into the National Working Group. The group met on four occasions during the Formative Evaluation and this provided an opportunity for the evaluator to provide progress reports and outline recommendations which could be fed into the ongoing development of policy and practice on community participation in primary care.

Appendix 4 lists the members of the Evaluation Sub-Group of the National Working Group on Community Participation in Primary care.

5.4 Evaluation of national service and policy development shaping community participation in primary care

There are a number of key service and policy developments that are shaping community participation in primary care. Section 2 of the report highlighted the policy developments that have under-pinned community participation in primary care, including the various strategies and policy frameworks that provide the basis for the Initiative.

As part of the evaluation interviews were held with decision-makers, key stakeholders and the Project Coordinators. The objectives of this element of the evaluation were to gain feedback on the Initiative and to identify the key policy developments and enablers that will further shape and build community participation in primary care, and recommendations for the sustainability of the Initiative and the mainstreaming of project learning throughout the HSE.

In addition, discussion of national policy issues took place in the Working Group on Community Participation in Primary Care.

Appendix 4 lists the people with whom interviews were held.

5.4.1 Progressing and developing community participation in primary care

As Section 2 of the evaluation report has shown there are a number of recent service developments in the HSE that have resulted in a new structure for health care delivery that will have an impact on primary care. These include the HSE's Transformation Programme and the development of Integrated Service Areas. These provide the backdrop to progressing community participation in primary care.

A number of suggestions were made about developing community participation through:

- 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 socio-economic status
- A better understanding of the backgrounds, roles and capacities of community organisations and the need for community infrastructure on the ground. In particular, this has raised awareness of the wealth of expertise and resources in

- An awareness of models of community participation and the processes and time required for successful engagement. This includes having dedicated resources, for example, to bring in external facilitation and support.

There is wide agreement that the dissemination of the learning from the nineteen demonstration projects and the models of community participation that have been developed will be particularly important to sustainability and mainstreaming. Several stakeholders were clear that guidance needed to be given to PCTs and health professionals and that this needed to be clear, simple and easy to follow, and set out simple steps for implementation. This includes the need for developing better systems for embedding the learning about community participation in the DoHC, and for the development of a DoHC national policy framework in this regard. The National Primary Care Services Manager stated that there was a need to build community participation into the roll-out of all existing and future PCTs and, in particular, to sustain the learning from the Initiative and ensure that it is embedded into the national policy agenda. For example, community participation can be linked into a range of HSE strategies and policies, as has been achieved in the Report of the Commission on Patient Safety and Quality Assurance (DoHC 2008) and in the National Service Users Strategy (DoHC & HSE 2008).

The programme for integration and the creation of RDOs in the four regions of the HSE is seen to have the potential to create a coordinated framework and a regional dimension to community participation in primary care. However, the National Primary Care Services Manager recognises that there is still a great deal of work that needs to be done before HSE services are fully integrated across Care Groups and functions, and for community participation to be a mainstream activity for PCTs.

It is anticipated that improved coordination between Care Groups will provide improved opportunities for synergies with primary care on the ground, so that the needs of all groups in the community can be included in community participation initiatives. As a result the new structures for coordination between and across Care Groups, as part of the Integrated Services Programme, provide an opportunity for a more coordinated approach to service delivery nationally and regionally. This structure has the potential to link into the work of PCTs and PCT networks and provide better integration between hospital services in areas such as early discharge and measures to prevent hospitalisation.

The new Integrated Service Areas in the HSE are widely regarded by all stakeholders to be a very positive development. According to the Director of Advocacy, HSE Office of Consumer Affairs, “the opportunity afforded by the development of new integrated service areas will enable both service user involvement and community participation to be more effectively embedded into the HSE”.

5.4.2 Ring fencing of resources at the regional level

The need to ring fence funding at the regional level for community participation projects was raised by the two Project Coordinators who highlighted the need for specific dedicated resources to be made available to support community participation initiatives and projects.

The National Primary Care Services Manager similarly stated that the implementation of an action plan at each RDO level will provide an opportunity for PCTs to plan more effectively for community participation. In particular, he argued for a specific budget to be allocated for Teams and for performance targets to be put in place to monitor outcomes regarding community participation. He suggested that this could be implemented at a regional level by ring fencing resources for community participation activities, such as training, facilitation and support for community organisations, through the RDOs.

5.4.3 Key Results Areas and Performance Indicators

The development of Key Result Areas (KRAs) and Performance Indicators (PIs) on community participation in the HSE's 2010 Service Plan was a direct result of the learning from the Initiative and the need to structure community participation as a core element of PCT development and implementation. This was a major achievement for the Initiative and a first step to providing more robust indicators in the future.

The HSE Office of Consumer Affairs and the Office of Primary Care see the potential for a better system of reporting on the PI for community participation. Having indicators that can measure progress has become crucial to ensuring that 'what gets measured gets carried out in practice'. Several stakeholders referred to the need for a robust framework for national reporting on community participation outcomes and the development of PIs in areas such as mapping of community and HSE services, community participation and needs assessment. Because community participation is a process an issue was raised as to the potential for more robust and quantifiable performance indicators to be developed to capture the qualitative outcomes from community participation.

As a result, the outline indicators in the 2010 HSE Service Plan are widely welcomed as a step in the right direction. The KRA "Systematic plans for implementation of involvement practice developed and implemented in acute hospital services and primary care" (HSE 2101: 12) is located in the *Quality and Clinical Care Directorate* with a PI indicating "the number and % of PCTs with engagement with the local community" (HSE 2010: 13). The PIs and KRAs are viewed as being to some extent misplaced in the 2010 HSE Service Plan. Although the Quality and Clinical Care Directorate has a high priority and status in HSE policy, it is seen that it would be more appropriate for the PI on "the number and % of PCTs with engagement with local communities" to be located in the Primary Care Directorate alongside KRA CP23 which states that:

"Opportunities for engagement with local communities provided through PCTs in a systematic way in accordance with the principles and guidelines endorsed in the *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*" (HSE 2020:pX).

This definition has a depth and scope to define community participation through more detailed indicators.

5.4.4 HSE Staff roles

In the current climate it is unlikely that significant new resources will be found to support and develop community participation in primary care. However, a number of decision-makers referred to the need to think more creatively and strategically in order to embed community participation into the development of primary care. In

particular, harnessing and coordinating the resources of staff was seen by the Working Group to be important in this context.

At the start of the Initiative the HSE Project Coordinator quickly realised that it was not possible to make assumptions about the roles that HSE community development and health promotion staff could play in supporting community participation initiatives. At an early stage this raised some key issues about how the work roles and job profiles can be more effectively tailored to directly support community participation.

The National Primary Care Services Manager highlighted the need for practice standards to be put in place to guide roles and functions in promoting and supporting community participation initiatives, which could be developed through HSE Office of Consumer Affairs, Health Services Executive (HSE) and with the four RDO Social Inclusion Specialist Leads. With this in mind the National Primary Care Services Manager identified the need for a regional focus for community participation and this has been initiated through correspondence to the four RDOs with a view to developing a list of contact persons from existing community development / community work / social inclusion staff who can support community participation projects. The objective is to find a structure to coordinate staffing resources and provide a strategic direction for the deployment of existing staffing resources in the future.

Various decision-makers referred to the need to have a more strategic approach to HSE staff roles by ensuring that internal HSE staffing resources and expertise can be mobilised in the future in a more structured way to support community participation in primary care. This included having a dedicated HSE community resource on the ground, for example, by tapping into the expertise of the network of community workers in the HSE. This was identified as being critical to the successful roll-out of community participation in primary care. Several stakeholders raised the need for community participation to become a core competency and expertise for HSE managers and staff, so that it becomes an integral part of their work. This included suggestions for there to be a framework for valuing the expertise of staff in this area and for utilising and further developing their skills and knowledge appropriately. An example of how this is being done is in the development of standardised work practices for health promotion staff, under the Health Promotion Strategic Framework.

5.4.5 Learning and development

All stakeholders raised the issue of the integration of learning about models of community participation into PCT learning and development and performance management activities. This includes the need to provide training for PCTs and TDOs / Primary Care Development Managers on community participation. This could be developed through a variety of training and development settings for PCTs, including new and more innovative ways of delivering learning and development, for example, through peer review and on-line learning.

5.4.6 Training for community participation

There is wide agreement amongst all stakeholders interviewed that PCTs require training in community participation, either as part of Team development and/or through dedicated training at a regional or network level. This would provide PCTs with the tools to carry out community mapping, local community based needs

assessment and a range of community participation methodologies. Several decision-makers highlighted the need for this training to be rooted in the social determinants of health. This broad framework is seen to be particularly important to ensuring that PCT staff become aware of inter-agency processes and the appropriate channels for referral of health issues, that fall out of the scope of PCT work, to relevant agencies, such as local authorities.

5.4.7 Models of community participation

All stakeholders were clear that there needs to be a greater awareness of and guidance about models of community participation, and that this could be further developed under the framework of the National Service Users Strategy. In particular, there is awareness amongst stakeholders of the need to allow time for community participation to develop and the need for qualitative measurements, since the gains of community participation may not necessarily be realised immediately.

5.4.8 Community Health Needs Assessment

A national framework for needs assessment is in the process of development under the remit of the National Strategy Group on Primary Care. This is being carried out by the HSE's Health Promotion Directorate through needs assessment pilots in four PCT pilot areas, with a view to establishing a standardised needs assessment methodology. The outcomes of these pilots will be valuable for PCTs, particularly in providing a workable methodology and framework for needs assessment. A crucial issue raised by a number of stakeholders is how community participation can be built into needs assessment work, and particularly how this can ensure compatibility with and connection to Community Health Needs Assessments carried out as part of the engagement process of community participation.

One of the issues identified from the four needs assessment pilot projects is that PCTs lack the capacity, time and resources to carry out needs assessments in their area. This can also result in duplication of activity and a lack of synergy between needs assessment and community participation. As a result consideration is being given to how a first level needs assessment can be facilitated at network level and then linked at PCT level to local data collected through Community Health Needs Assessments and evidence from other local consultations. This could form the basis for an action plan at PCT level.

Several decision-makers highlighted the importance of ensuring that there is synergy between HSE needs assessments and Community Health Needs Assessments carried out by the community. Developing a common approach will help to provide consistency across the country, which will enable more effective measurement of results and an opportunity to build community participation into processes of needs assessment. There were some differences of view about the role played by local communities in needs assessment. For example, the view from Population Health and the development of a national structure for needs assessments is that Community Health Needs Assessments should complement PCT needs assessments, whereas the Deputy Chief Medical Officer was of the view that local communities should be integral to the development of local needs assessments.

5.4.9 Community mapping

There is a shared view amongst stakeholders that community mapping needs to take place at an early stage and in advance of community participation and needs assessment. PCTs should be provided with guidance and a mapping template, so

that they have the tools to build awareness of the wide range of community based services in the locality, including local community groups, support groups for older people, people with disabilities and people with mental health difficulties, women, young people, sports activities and walking clubs, to name a few. This mapping exercise is seen as crucial since many PCTs are often unaware of community resources and supports in the community. This is seen as an area of activity that can be carried out in partnership with the local community and forms an important basis for relationship building between local communities and PCTs. It is also suggested that needs assessment should take place after community participation has been developed with a PCT, so that needs assessment links into community participation.

The Deputy Chief Medical Officer raised the need for social inclusion in health to include poverty as a focus and for there to be attention given to mapping health by socio-economic status based on local social inclusion profiles; RAPID data, including data on the numbers of medical card holders; data on educational or occupational status; and mapping poverty by electoral districts. The need for an identified person to map community organisations and structures in a PCT area and to identify gaps in community supports is regarded by the Deputy Chief Medical Officer to be particularly important to ensuring the inclusion of invisible or socially excluded people.

The introduction of the *Health Atlas*, to map health services and the location of GPs and other services is seen as a potentially valuable tool for PCTs, particularly if this can be extended to the mapping of community organisations. To date the *Health Atlas* has mapped homeless services and addiction services, and could be extended to other target groups and community organisations. For example, this could provide the location of Traveller Primary Health Projects and community development projects. Utilising this technology could provide a valuable health and community dataset for the planning of PCT services, Community Health Needs Assessments and community consultations.

5.4.10 A lens on socio-economic disadvantage

A number of stakeholders referred to the need for the HSE to have a lens on socio-economic disadvantage and poverty. This is seen to be particularly important to broadening the awareness of the role of PCTs in tackling inequalities in health. The HSE highlighted the importance of the role of the Social Inclusion Care Group in promoting the engagement of disadvantaged groups in community participation in primary care. The HSE focus on social inclusion is on a target group approach, of which socio-economic disadvantage is not a specific area of action. It is evident that a broader focus could, in the future, be given to inequalities in health as an overarching framework for social inclusion and particularly to improving the interface between the community and the HSE. By focussing on health inequalities and poverty the Assistant National Director for Social Inclusion stated that this “shines the lens to other care groups experiencing inequalities”. As a result this can provide a better focus for looking at health inequalities across a broad spectrum, of which social inclusion is one aspect, and thereby avoid the stigmatisation that results from the provision of targeted services. An example was given of a recent introduction of prescription charges for people on low incomes, which was regarded as being detrimental to disadvantaged communities and led to a joint submission from the Social Inclusion Division, the Citizens Information Board and the HSE Social Inclusion Care Group.

This need for a focus on inequality and poverty was reiterated by a number of decision-makers who also highlighted the importance of linking the development of

anti-poverty and social inclusion policy into learning and development in primary care. For example, building community participation into the policy framework established under the National Action Plan for Social Inclusion 2007-2016, and beyond, is seen as being crucial to creating 'joined up' approaches to social inclusion and anti-poverty work. This can also be informed by the work currently being carried out by the Social Inclusion Division on Poverty Impact Assessment and could be further developed through PIs on levels of engagement and policy impact.

5.4.11 Acknowledging champions

Both the National Primary Care Services Manager and National Lead for Advocacy, HSE Office of Consumer Affairs highlighted the importance of support to develop champions of community participation in primary care. This could be achieved, according to one HSE manager by "nourishing and acknowledging champions who promote and strive towards community participation" through Achieving Excellence Awards, showcasing projects through Health Matters and What's New, and providing regular updates through the HSE intranet.

5.4.12 Engagement of key decision makers

Engaging senior decision-makers was widely regarded as being critically important to ensuring that community participation becomes a core activity and is championed by the HSE at all levels. The need for 'Agents of Change' will be crucial to this process. There is a specific role to be played by the four new Regional Directors of Operations (RDOs) in providing a strategic regional role and in ensuring that this is a priority for Local Health Managers. There was agreement that the Assistant National Directors for Social Inclusion, Health Promotion and Primary Care, along with the RDOs and the Deputy Chief Medical Officer should be tasked with providing a key role in sustaining the learning from the Initiative and act on recommendations from the evaluation. This was summed up by the National Lead for Advocacy, HSE Office of Consumer Affairs who stated that "the HSE needs to ensure that community participation in health is a mainstream way of working in the future and a core activity of all health professionals".

5.4.13 Opportunities under the Department of Community Equality and Gaeltacht Affairs

The new Department of Community, Equality and Gaeltacht Affairs provides some new opportunities for synergies to be created between functions from three previous departments (Social and Family Affairs, Justice Equality and Law Reform and Community, Rural, and Gaeltacht Affairs). This is particularly relevant as the Social Inclusion Division has been moved to this new Department. The Department will include the areas of community development, social inclusion, family policy, equality, disability, integration of minority ethnic communities, human rights, drugs, and rural isolation. The new LCDP which funds local development/ partnership companies and the Family Support Agency, which also funds Family Resource Centres, are both under the umbrella of this Department. Along with other areas such as Drugs Task Forces, rural development, equality and social inclusion, this has the potential to provide some valuable strategic linkages between programmes.

Representatives of the DCEGA who will be located in the new department stated that the new department provides an opportunity for a new focus to be given to poverty, inequality and social inclusion, and synergies with the National Action Plan on Social Inclusion and the LCDP. The importance of building these synergies was highlighted by a number of stakeholders as having the potential for developing shared learning and best practice approaches.

5.5 Conclusions and national learning from the Initiative

All stakeholders believed that the Initiative had provided important learning about community participation. This has resulted in a better understanding of the backgrounds, roles and capacities of community organisations and the need for community infrastructure on the ground. For example, the Project Coordinator from HSE Office of Consumer Affairs, Health Services Executive (HSE) stated that the Initiative had been particularly valuable in raising awareness of the wealth of expertise and resources in the community and the critical need for a full-time dedicated resource in the community to support and develop community participation, as well as resources for external facilitation and expertise.

The feedback from key decision-makers and stakeholders about the Initiative has been very positive and suggests that the Initiative has gained substantial buy-in to national policy processes. This section has shown that for community participation to be sustained in the longer term and for its relevance to be integrated into joined up policy making processes across government departments and the HSE, a number of strategic measures need to be put in place. This includes a strategic policy commitment from the DoHC to community participation in primary care, strengthened and reorganised Key Results Areas and Performance Indicators in future HSE Service Plans, as well as the embedding and dissemination of the learning from community participation into Primary Care and HSE Office of Consumer Affairs activities.

Section 6: Conclusions and recommendations

The evaluation of the Initiative has shown that community participation has been broadened and developed through the nineteen local projects and the national initiatives undertaken. This has led to 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. While community participation has not yet achieved a significant shift in changing power over decision-making, planning and resources from professionals to joint approaches between communities and health professionals, there is now a huge potential for this to take place in the future if certain conditions are fulfilled.

This requires a political commitment and a strategic policy framework to support and resource community participation in the future. Alongside this community participation will only be successful if there is an adequately resourced and representative community and voluntary sector in Ireland. Ensuring the viability and sustainability of the sector requires resources and a commitment to community empowerment.

The Initiative demonstrates a wealth of innovative and creative approaches and outcomes that have gone beyond what many projects had anticipated. The methods developed, the structures created and the approaches taken will need to be sustained, mainstreamed and resourced if the roll-out of primary care across the country is to be implemented in a way that meets the vision and expectations of the HSE.

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 policy framework for community participation in primary care

- Produce an annex to the Service Users Strategy on community participation, setting out a policy framework (under the National Oversight Implementation Group of the Service Users Strategy).
- Develop community participation as a strategic policy objective and commitment (Department of Health and Children).
- Examine ways in which community participation can be integrated more systematically into the existing National Action Plan for Social Inclusion 2007-2016 and beyond (Social Inclusion Division, DCEGA).
- Promote community participation in primary care in the new LCDP (Department of Community, Equality and Gaeltacht Affairs / Pobal).
- Enhance and further develop KRAs and PIs on community participation in primary health care in future HSE Service Plans (HSE). This will require further elaboration of indicators in the following areas:
 - Joint actions including structures for representation on PCTs and/or networks
 - Training and capacity building activities
 - Community mapping

- Community consultations
 - Participation of key target groups
 - Information sharing and dissemination
 - Community need assessment
 - Levels and methods of participation
 - Measurable enhancements in engagement and service quality
 - Actions within a social determinants of health perspective and impact on other agencies
 - Partnership working with other agencies
- The development of specific standards for community participation in primary care could be drawn up to inform and guide practices on community participation across the country. Reference should be made to the very useful *National Standards for Community Engagement* drawn up by the Scottish Office and the Convention of Scottish Local Authorities in this regard.
 - Integrate Community Health Needs Assessment methodologies into the proposed national structure for needs assessment and implement community participation as part of the national framework for needs assessment (HSE).
 - Provide guidance tools and templates for community mapping, and provide resources to support the mapping process, for example, utilising the technology available through the *Health Atlas*.
 - It will also be important for RDOs to show how community health needs and community participation can be fed into a wider context of health care, including hospital care. This is an issue that has relevance for the establishment of the Integrated Services Areas. This will be important in enhancing visibility in the HSE on inequalities in health (HSE).

Recommendation 2: Create a senior commitment in the HSE to community participation

- A high level group on community participation in primary care should be formed under the remit of the National Oversight Implementation Group of the Service Users Strategy. The high level group should be composed of the four RDOs, the Assistant Directors for Social Inclusion, Health Promotion, Primary Care, and the Deputy Chief Medical Officer in the Department of Health (HSE Office of Consumer Affairs). This group could be tasked with developing a strategic policy framework on community participation in primary care and with the implementation of the recommendations of the Evaluation.
- There is also a need for the HSE to standardise community activities, using learning from best practice, so that it becomes more integral to community participation activities in primary care.

Recommendation 3: Enhance the focus of social inclusion on socio-economic equality and inequalities in health

- It will be important for the HSE Social Inclusion Care Group to create greater visibility for socio-economic disadvantage as a cross-cutting issue. This will be particularly important in keeping a lens on poverty and socio-economic disadvantage and the intersection with specific target groups, such as Travellers. It is crucial that the focus on socio-economic disadvantage, which shapes and informs other disadvantages, be made more explicit in the HSE, particularly in

- In doing this work it will be important in the future for the HSE to identify the geographic indicators of inequalities in health (using data from RAPID areas and inequalities identified at electoral district levels etc.) so that there is a better evidence base of the social inclusion profiles of local areas.

Recommendation 4: Disseminate the learning on community participation from the Initiative within the health services for new PCTS

- There are a number of resources that could be developed, including a simple 'how-to' guide to community participation targeted at PCTs and local communities. It is suggested that a series of fact sheets be developed outlining:
 - **Fact sheet 1:** Models of community participation, with practical examples of how different models have been used in the demonstration projects. This should set out very simple processes, structures and tools for participation.
 - **Fact sheet 2:** Setting up a Joint Community / PCT Steering Group and establishing a plan for community participation
 - **Fact sheet 3:** The social and economic factors impacting on health, setting out the impact of the social determinants of health and how this can shape awareness of community and PCT roles
 - **Fact sheet 4:** Carrying out Community Health Needs Assessments and community consultations to identify the main health needs for local areas, as well as for specific disadvantaged groups
 - **Fact sheet 5:** Setting up a Community Health Forum, with examples of terms of reference, types of activities and representation on PCT structures, with guidance on how to set up a Forum, how to select Forum representatives, roles and responsibilities, ways of managing expectations, developing representative structures etc.
- Develop short guide to the nineteen demonstration projects, setting out objectives and goals, actions carried out and outcomes. Contact details of community and PCT representatives should also be included as contact points for new projects.
- The learning from the initiative should be disseminated widely through seminars and regional workshops organised by the RDO, through articles in HSE and other journals and through a dedicated website to showcase projects.
- It is suggested that a regional workshop be held for community groups/organisations and HSE representatives in each RDO in 2010 to disseminate the learning.

Recommendation 5: Sustainability of community participation

- Ring fence funding in each RDO for community participation in primary care projects. This funding should be sufficient to ensure that all PCTs have access to a budget to support community participation. This should also include financial support to sustain existing projects as well as those that are starting their work.

- This could also be supplemented by a 'community chest' fund (established by the HSE and disseminated regionally) for projects to gain small amounts of funding for events.
- Put in place measures to ensure that existing staff from community participation projects can act as 'champions', 'advocates' or 'experts', sharing learning and expertise for new projects and initiatives. This could be supported and encouraged through the development of excellence awards and publicity.
- This could be facilitated through regional or national network meetings and through the dissemination of project outlines and contact information from the nineteen demonstration projects.
- There is a rationale for continuing the excellent technical support role which was provided by CAN in the Initiative. This provides a resource of expertise and knowledge of community participation and partnership working, facilitation and project development that could be vital for new community participation projects and could be funded either regionally or nationally.
- As mentioned above a dedicated and easy to access website should be developed to provide relevant information, sharing of information and networking opportunities for community groups and PCT representatives within the community and voluntary sector.

Recommendation 6: Provide resources for training, technical support, external facilitation and other networking supports

- Regional training for PCTs and community organisations on community participation methods and processes will be required to support new and emerging community participation initiatives in local areas. This training should provide for different models of delivery to community organisations, to PCT representatives and for joint training for community and PCT representatives.
- The proposed RDO budget for community participation should earmark specific funding to:
 - Support and train community and PCT representatives
 - Enable representatives to meet and network
 - Provide resources for independent external facilitation and expertise to enable PCTs and community organisations to find common ground and build relationships.
- The HSE and the Social Inclusion Division should draw up a training module on community participation, with built in flexibility, to be delivered on a regional level. This module could also be developed into an on-line training resource.
- Develop a more strategic approach to the role played by HSE Community Workers, Social Inclusion Officers and Health Promotion Officers so that they can effectively support and help develop community participation in primary care. This requires organisational coordination and a commitment to sharing resources in the HSE.
- Community participation should be written into the job descriptions of these dedicated HSE staff and training in community participation in primary care should be provided where necessary. Where changes in job profiles are planned there should be early engagement with trade unions.

- Establishing a network of advocates (community workers and social inclusion officers) working in the HSE has been identified as an important step forward for the mainstreaming of community participation initiatives across PCTs. Once established this network of advocates and community workers should be publicised by the HSE and standards of practice put in place to ensure consistency of actions.
- There is a crucially important role that can be gained from closer engagement around population health issues, and this could be included as one of the indicators measuring the impact of PCT work on the ground and linked into the social determinants of health.

Recommendation 7: Build community participation through a wider network of agencies

- The learning from the project establishes some interesting and useful models of how a range of organisations can engage in community participation including Family Resource Centres, Local Development Companies, Community Development Projects, Local Regeneration Agencies, City and County Development Boards / Local Authority Community and Voluntary Forums etc. The dissemination of learning, models and activities on community participation to these audiences will be important to ensuring that community participation in PCTs comes within the scope of all community fora and structures.
- Examine how a network of community participation projects could be supported and networked through the newly formed Community Health Network being coordinated by Community Development Health Network (CDHN).

Recommendation 8: Build the capacity of PCTs

- Community participation needs to be built into the formation and team development of all PCTs and resources and expertise devoted to this.
- PCTs should be resourced to engage in community participation, and be supported to engage with local communities on critical issues in the community such as suicide, domestic violence, mental health etc. This will need to be built into the work profiles of PCT members.
- Support and train TDOs, in community participation methodologies and practices so that they have a strategic role in supporting community participation.

Appendix 1: Summary of the nineteen projects: organisational background, agencies participating, project activities and participation on PCTs

Table 1: Organisational background of community partners

Lead community partner	Community Development Project	Community & Voluntary Forum (County Council)	Local Development Company / Partnership	Family Resource Centre	Other community / statutory organisation
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					✓
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Table 2: Agencies participating in each project on Steering Group or other project activities

Lead community partner	PCT members	TDO / Primary Care Development Manager	HSE Community Worker/ Social Inclusion Manager	HSE Health Promotion Officer	Community Development Project(s)	Community & Voluntary Forum (County Council)	Local Development Company	Family Resource Centre	RAPID	Re-generation agency	Other community/ statutory organisation
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		✓	✓		✓						

Table 3: Summary of project activities



Lead community partner	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 ▲
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

Table 4: Participation on PCT

Lead community partner	PCT operational	PCT not fully operational	Informal process / information sharing	Formal process for engagement (PCT / LIG)	Procedures and TOR in place
HSE West					
NW Roscommon CDP, Ballaghaderreen	✓		✓	✓	✓
Mayo Intercultural Action, Castlebar	✓		✓		
Leitrim Development Company, Co Leitrim	✓		✓	✓	✓
Iorras le Cheile, Belmullet, Co Mayo	✓		✓	✓	✓
Monaghan Community Forum, Monaghan	✓		✓		
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	✓		✓	✓	✓
Paul Partnership, Limerick City	✓		✓	✓	
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	✓		✓	✓	✓
Finglas South CDP, Finglas, Dublin		✓	✓		
Pavee Point, Dublin	✓		✓		

Appendix 2: Summary of project objectives, actions and learning

1. Westmeath Community Development Ltd, Athlone, Co Westmeath
2. North West Roscommon CDP, Ballaghaderreen, Co Roscommon
3. Mayo Intercultural Action, Castlebar, Co Mayo
4. Paul Partnership, Limerick City
5. Leitrim Development Company, Mohill, Co Leitrim
6. Equal Access CDP, Tallaght, Dublin
7. Fatima Regeneration Board, Dublin
8. Blakestown CDP/Mountview FRC, Blanchardstown, Co Fingal
9. Corduff CDP / Blanchardstown CDP, Blanchardstown, Co Fingal
10. Monaghan Community Forum, Monahan County Council
11. West Cork Islands, Bantry, Co Cork
12. Wolfe Tone CDP Community Health, Wexford, Co Wexford
13. Finglas South Community Development Project, Finglas, Dublin
14. Pavee Point (Traveller project), Dublin
15. Lifford Clonleigh Resource Centre, Lifford, Donegal, Co Donegal
16. Iorras le Cheile, Belmullet, Co Mayo
17. Offaly Local Development Company, Banagher, Co Offaly
18. Follain Community Health Project, Waterford, Co Waterford
19. South Tipperary Community Forum, Clonmel, Co Tipperary

1. Westmeath Community Development Ltd and Athlone Primary Care Network ■■◆●▲▲

Project Aims

- To develop community participation in primary health care services in Westmeath;
- To carry out community consultations to identify health needs;
- To establish a Community Health Forum;
- To establish a joint Primary Care Network and a community representatives Forum.

Background to the Project

The Project has been jointly run jointly by Westmeath Community Development Ltd (WCD) and the HSE Primary Care Development Officer covering the Athlone area. There are five Teams in the local PCT network, four of which are based in Athlone and the fifth based in Moate. The Project grew out of a realisation that health rarely came onto the agendas of community organisations, and as a result the RAPID coordinator and the WCD highlighted this as a priority for future community development work. In addition, several local representatives had completed the HSE Midland's Certificate in Health Promotion, which has a specific focus on the social determinants of health. Concurrently with the evolution of PCT's in the area it became apparent that this would be the ideal way to create the best link for two way communication to allow for effective community participation in the planning of services.

The initial stage of the Project was very ambitious and sought to establish a Community Health Forum from the outset, using the networks of local groups through the County Council Community and Voluntary Forum. However, it was realised that processes of community capacity building needed to be put in place on the ground in order to achieve this, particularly because the Project was targeting disadvantaged communities that had little experience of community participation. A Community Development Worker in Westmeath Community Development Ltd and a Health Promotion Officer from the HSE supported the co-ordination of the Project on the ground.

Project actions

1. **Community Participation Steering Group.** A Community Participation Steering Group was established with wide representation (including Westmeath Community Development co-ordinator and Development Worker, the RAPID coordinator, the HSE Health Promotion Officer, HSE Social Worker, HSE Community Services manager and the HSE local Primary Care Development Officer). This provided a focus to the work of the project and particularly to the building of relationships between the community and the HSE and for their active involvement and 'buy in' to the Project.
2. **Community consultations.** The Project partners in the community and the HSE put a great deal of time in consulting with community groups and individuals on the ground, with a view to establishing a Community Health Forum in the area. The Community Development Worker recognised the need to discuss the issue of representation with as wide a network of people as possible and to identify and meet potential Forum members. In addition, a public meeting and consultations were held with representatives from the Athlone Community and Voluntary Forum and the RAPID Area Implementation Team, which also resulted in nominations for representatives. This development work paid off and the face-to-face contact with people and groups in the local community was deemed necessary to providing information, managing expectations, building confidence and trust and in persuading representatives from the community to join the training programme for representation on the Forum. There have been some notable successes in involving people from marginalised communities and representatives from different target groups.
3. **Training and capacity building of community representatives.** As a result of the community consultations a group of sixteen community representatives has been formed. A series of training sessions were provided for the group, including an introductory information workshop and monthly two to four hour training sessions over a period of six months. Keeping the process flexible and responsive to participants has been important to the success of the training. The training focussed on health and well-being, establishing Team roles and responsibilities. setting a vision for the Forum, how to

4. **Establishment of a Community Health Forum.** The Community Health Forum has been established with sixteen representatives from different target groups and geographic communities. A key first task was to agree terms of reference and to agree realistic expectations. Community representatives have expressed a need for regular information from the PCTs as a basis for realising tangible outcomes. This is seen to be critical to sustaining the motivation and interest of the community representatives. A particular challenge has been to build confidence in the group and in managing different levels of experience and capacity. Forum members are highly motivated and enthusiastic about their roles and view the support and training to have been essential to building capacity, confidence and cohesion in the group.
5. **Community representation on the PCTs.** Participation on the PCTs has not yet taken place, but a first meeting with the Community Health Forum and the Primary Care Network is planned to take place in the next month. Two representatives from the Forum, and two alternate representatives, have been elected to be represented on the Primary Care Network. As a first step to representation a joint training session was organised between the community representatives and the PCT representatives to share information, build engagement and plan the next steps for the Project. Other activities planned in the future will include a community needs analysis that will be supported by the HSE's Health Promotion Officer.

Project learning

- A solid basis to partnership working on the Steering Group has been created. This took time and required discussion and learning of different organisational roles, backgrounds and experiences. It was particularly important in the Steering Group to improve understanding of community participation and the role it could play in informing PCT activities and roles.
- Time constraints on behalf of some Steering Group representatives has been an issue and reflects the need for community participation to be further embedded in the development of work roles and processes of community and HSE staff.
- The Project took a 'grass roots up' approach and this has been very time consuming and intensive work. However, the Project believes that this was the correct approach to take as it has built community capacity and led to a genuine engagement with community representatives.
- The ongoing support and training for and facilitation of the Community Health Forum are identified as a priority for the sustainability of the process.
- Having a dedicated community development worker in Westmeath Community Development has been critical to the success of the Project. This has been important in terms of the development work and community consultations, the training and support of the Community Health Forum, and to sustaining the motivation and interest of the Forum members.
- The HSE representatives put huge effort and time into the Project and there was a significant learning curve about community participation.
- A key issue is raised about the ongoing support of the Primary Care Development Officer as a key person driving the process. Mid-way through the Project the Officer moved to a new post in the HSE. However, she stayed with the Project owing to her commitment and in the light of the fact that there is no Primary Care Development Officer in post.
- The broad range of partners on the Steering Group, the support of the RAPID Coordinator and the links with the Community and Voluntary Forum in the County Council have been

2. North West Roscommon Community Development Project



Project Aims

- To facilitate the participation of disadvantaged and marginalised communities in the planning and delivery of primary care services;
- To build the capacity and knowledge of community participants and members of the PCT
- To create a community health forum that is representative of community groups and disadvantaged communities in the Ballaghaderreen PCT area.

Background to the Project

Roscommon has six PCTs and the community participation Project was established with the Ballaghaderreen PCT, which was formed in 2008. There has been sporadic GP participation in the Teams and there was limited engagement with the community prior to the Project. Community participation in primary care is a new experience for the community and the HSE in the area. However, there is a high level of commitment to community participation processes from the Primary Care Development Officer/TDO who has acted as a champion for the Project. Community participation in health was also a new area of activity for Ballaghaderreen CDP.

The Project sought to develop a process whereby the views, needs and values of the communities in Ballaghaderreen PCT area can be represented through a Community Health Forum and representation on the PCT. From the start the Project wanted to create a strong, sustainable and robust mechanism process of participation.

Project actions

1. **Community Participation Steering Group.** A Community Participation Steering Group was established at the start of the Project with representatives from the HSE and community partners. The Steering Group provided the direction, planning and monitoring of the Project.
2. **Recruitment of community volunteers.** A lot of work had to be carried out in the early stages of the Project to recruit volunteers and develop and deliver a training programme to volunteers. Local community groups, representing men, women, disabled people, mental health service users, carers, Travellers, older people, asylum seekers, ethnic minority groups and young people, were contacted with information about the Project and an invitation to attend a meeting. Two representatives from each group were invited to attend the meeting, which provided an introduction to the role of primary care services and an explanation of community participation. This process proved very effective in engaging local people in the process and in recruiting local people to join the community participation in health training programme. People from the Travelling community, young parents and young people did not attend the meeting and the Project is continuing to find ways to represent these groups.
3. **Community Health Forum.** The Project has created a Community Health Forum and representatives have been nominated from local groups, e.g. carers association, Pakistani Association, older people, mental health, rural men's group etc. There has also been attention to ensuring that the different disadvantaged target groups and geographic areas are represented. The objective is that the Forum will provide information from and about local communities to the PCT and that information from the PCTs can be fed back to the community.
4. **Training programme.** A six-week training programme was organised and an external facilitator and trainer appointed to work with the group. From the start the group established its own objectives based on a framework of the social determinants of health and community development. Fifteen local people have attended the training and this has enabled them to gain knowledge and understanding of community health issues and a better understanding and capacity to act as community representatives. As one

5. **Links between the community and PCT.** An initial meeting between PCT members and community volunteers took place mid way through the Project and this was followed up by a joint visit to the Community Health Forum and PCT in Lifford-Castlefinn. A programme of joint training was developed after the visit which has provided a solid base for information sharing, Team building and relationship building. A number of local activities have been put in place, for example, in informing PCT members of local community resources, such as a local walking group, active ageing group, events on violence against women (as part of the 16-days of action campaign) and in connecting PCT members to the community through talks on primary care and health promotion. A number of awareness raising activities and health promotion events have been held in the community, for example, in promoting breast check in the area.
6. **Representation on the PCT.** The Project is now working to determine its representative structures, including terms of reference, scope of activity and how it will engage with the PCT. A Community Participation Sub-Group of the Ballaghaderreen PCT has been established and two meetings have been held to date with representatives from the community representatives and the PCT. This has involved information sharing, and discussion has taken place about what model of community participation can be put in place and how best to engage the community. It has been agreed that two community representatives, and two alternates, will sit on the PCT, one male and one female. Community and PCT representatives have requested a further training session be organised with a view to supporting community participation. This will be provided by CAN and the HSE Health Promotion Officer in Roscommon.
7. **Joint Action Plan.** A joint Action Plan has been drawn up in the Community Participation Sub-Group with priority themes identified on drug awareness for young people, production of a quarterly newsletter, a falls prevention programme, lower back pain clinics, obesity and exercise, joint emergency plan for local communities, engagement with the local GP out-of-hours service, and community gardening.

Project learning

- The Project has initiated community engagement from a very low starting point since there have been few possibilities for community engagement with the HSE and community participation has been relatively under-developed. The Project has achieved a great deal in a short space of time and community and PCT representatives have engaged enthusiastically with the Project. It has led to a new way of working for health service providers, clinicians and the community.
- There was uncertainty at the start about the roles that community representatives could play, and it is evident that the training has been critical to preparing and motivating community participation.
- The CDP is now more confident to participate in health related activities. They have learnt that community participation will not happen overnight and that there is a huge investment of time and resources required. The CDP also needed time to gain clarity of the issues and of their focus. They now recognise that there is huge potential for community participation in primary care.
- The learning is that community participation and an understanding and capacity to participate in health issues is very time consuming. The Project has learnt that bringing disparate groups together takes time and commitment. There are also implications for the sustainability of the Project and for the further development of actions, for example, in areas such as domestic violence, mental health and access to information.
- Taking time to build relationships and share information has paid off. At the start of the process there was a noticeable separation between community and HSE representatives, but as the Project progressed this separation diminished significantly. The learning is that this relationship building takes significant time; it requires the building of trust and a mutual respect and understanding of different backgrounds and perspectives. Most

- A health needs assessment is currently being carried out and Project partners believe that on reflection that the assessment should have been carried out in tandem with the start of the Project and should also have involved community consultations.

For the PCTs, there is recognition that a national commitment to community participation on PCTs is needed with access to sustained funding so that community development can be progressed across all networks and LHO areas. One of the difficulties identified is that there is no coordinated approach towards developing community participation in conjunction with undertaking Community Health Needs Assessments.

3. Mayo Intercultural Action



Project Aims

- To promote participation for migrant communities in the Ballina PCT;
- To improve health information and outcomes for migrant communities;
- To build the capacity of the migrant community in Ballina to enable meaningful and effective participation;
- To carry out a needs assessment and analysis of primary health care needs of migrants

Background to the Project

Mayo Intercultural Action (MIA) was established in 2004 in Co. Mayo to promote the positive role of integration and inter-culturalism in Mayo. MIA gives support to asylum seekers living in direct provision (Ballyhaunis), refugees including KAREN refugees from Burma, as well as for migrant workers and other minority ethnic groups living in the area. A key recommendation from the 2006 report by MIA *Building a Diverse Mayo* was the establishment of a County Mayo Liaison Forum for Immigrant Communities.

The Project has been established in Ballina, a town of high deprivation, with a large population of migrants. Evidence of poor access to health services, including primary health care services, and a lack of knowledge and understanding of services was documented in *Building a Diverse Mayo*. The Project has developed a model of community participation for migrant communities in Ballina, based on community development principles. It was agreed from the outset that a Migrant Community Health Forum would be established, building on the evidence based from Mayo Intercultural Action's (2006) research *Building a Diverse Mayo*.

The Ballina PCT has been established and although there is active participation within the PCT, including some GPs, the Team is still in an early stage of development. The objective for the HSE is to ensure that there is a structured working relationship with the HSE so that it can work in partnership with the Community Health Forum. The HSE had identified the need for training for PCT members to raise awareness about the benefits and processes of community consultation.

Project actions

1. **Community consultations.** Development work was carried out with local agencies and community organisations, and information circulated to members of the PCT and community groups, with a view to holding community consultations to identify health needs and recruit members of the migrant community to join the Community Health Forum. Publicity was made through the local media and flyers and posters circulated in the town. Consultations included an open evening for migrants and interested parties, attended by 25 people, and focus groups were held to identify the health needs of migrants.
2. **Consultations with Ballina PCT.** A presentation was given to the PCT to promote the Project and the PCT members were asked about their experiences of working with the migrant community and their perception of the barriers experienced by migrants in accessing health care. In addition, semi-structured interviews were held with PCT members to provide a more detailed record of how health needs are met and the barriers

3. **Community Health Needs Assessment.** A Community Health Needs Assessment was drawn up as a result of the consultations with the migrant community and the PCT, setting out priorities for health care delivery and barriers in accessing health services. Issues raised include language and translation/interpretation, improving access to services, information about the organisation, the provision of inter-cultural services and the costs of accessing services. Many of the issues identified have been highlighted in the consultations undertaken for the HSE's National Intercultural Strategy in Health.
4. **Ballina Migrant Health Forum.** An active group of migrants came forward at an early stage in the Project, which were supported to form a Ballina Migrant Health Forum. Working through the local community groups and the Family Resource Centre, and from the community consultations, a group of interested migrants living in Ballina were nominated onto the Ballina Migrant Health Forum. Sufficient numbers came forward to join the Forum, and as the Project developed new members joined. Given the relatively short time frame for the Project it was decided to create the Forum at an early stage, in order to devote sufficient time to capacity building and training. The Forum has representatives from Brazil, Poland, New Zealand, Nigeria and the KAREN community. It is anticipated that this will form part of the County-wide Forum for Migrant Communities that is currently being established. The Community Health Forum has met regularly and is supported by Mayo Intercultural Action and the HSE. A work plan and terms of reference have been drawn up by the group. The group has an informal structure and is supported by the MIA Development Worker. Having a support person was deemed crucial as members of the Forum are volunteers and identified a need to be coordinated and facilitated. The Forum is now represented on the County Mayo Liaison Forum for Immigrant Communities.
5. **Training for Forum members.** The first step was to organise training for the members of the newly formed Community Health Forum. A four-day training course, run in partnership with the HSE Health Promotion Officer and an external trainer covering: capacity building skills (group skills, Team building and listening skills); rights and entitlements; community development principles and practices; community participation in primary care; cultural competences and intercultural training; working with vulnerable people and understanding depression. The training was highly successful and there were very positive outcomes in the evaluation of the training. A core group of seven Forum members have completed the training programme.
6. **Representation on the Ballina PCT.** At this stage there is no community representation on the PCT. However, discussions have taken place to create a sub-group of the PCT to provide an opportunity to kick start the process of examining ways to address the findings from the Community Health Needs Assessment. This is seen to be very important to sustaining the work carried out on the Forum, keeping momentum and finding a mechanism to support community participation in the interim.
7. **Toolkit on community participation.** A toolkit was developed in the Project on community participation, community development principles and practice, and cultural competence. This provided a resource base to raise awareness for PCT members and community groups.

The Project has identified a number of areas for future work, including events and meetings on themes such as mental health and depression, accessing medical cards and health care services and how the HSE works. The Forum is planning to produce a small business card to be disseminated to migrants living in Ballina, with information about the Forum and contact details. A newsletter is also planned.

Project learning

- The Project found the importance of good communications and mutual support between Mayo Intercultural Action and the HSE TDO and Health Promotion Officer. The ongoing partnership and communications with the Family Resource Centre has been very important to wider networking with groups in the area.

- The creation of the Forum has raised an issue about what stage to engage with the PCT; whether this should be at an early stage when the Team is in its formative stage or once it is established and working. Because the PCT was in an early stage of development it was agreed that a formal engagement with the PCT would take place once the Team was fully formed.
- There is some important learning about how the Project can impact on a wider range of PCTs and how the Project's outcomes can inform how PCTs engage with and provide services to migrant communities across the country.
- Taking a broad approach to the health needs of migrants in Ballina has raised the issue of how the Forum can extend its scope beyond the PCT to engage with hospital and other services in the town.
- Having a core person, in the form of the MIA Development Worker, has been critical to the development, coordination and ongoing support of the Forum.
- The sustainability of the Ballina Migrant Health Forum is raised as a critical issue, particularly because there is uncertainty about whether there will be a worker in MIA in the future to support the ongoing work of the Forum. In addition, community participation has not been established on the PCT and the future role of the Forum will be in question without this.
- There is also a challenge about how new members can be brought into the Forum. This is particularly important as the group has become very cohesive and have undertaken training and development together. Bringing in new members will be important to the sustainability of the Forum, but there will need to be attention given to the induction and training of new members.

4. Paul Partnership, Limerick

Project Aims

- To design a training resource to support community engagement in the PCT;
- To recruit community representatives and PCT staff to participate in the training;
- To support community representatives and PCT staff to engage with the local community in relation to their health needs;
- To develop a local Health Forum that will ensure sustainable and meaningful community representation on the PCT, and
- To gather and analyse data on local health needs and concerns.

Background to the Project

The Project was a partnership between PAUL Partnership, the HSE (Primary Care and Health Promotion), RAPID and the communities of Thomondgate, Ballynanty, Moyross and Kileely. These communities are characterised by high levels of social and economic deprivation, social housing, ageing populations, unemployment, lone parenthood and poverty. There are eight PCTs in place in Limerick. The Ballynanty/Moyross PCT on the northside of Limerick City, which has been in place since 2007, was the focus for the Project. This PCT covers the communities of Ballynanty, Kileely, Moyross, Thomondgate, Woodview, Redgate and Old Cratloe Road.

Project actions

The Project has achieved a significant number of positive outcomes, some of which have exceeded the original objectives. These have included the recruitment and training of volunteers, the organisation of community consultations, the collection and dissemination of data on health needs, the dissemination of these findings to the community and the production of leaflets and resource materials.

1. **Community Participation Steering Group:** The Group was established at the outset, using an inter-agency approach, with representatives from PAUL Partnership, HSE, Ballynanty/Moyross PCT, RAPID, Limerick Regeneration Agencies and community representatives. Although the Local Authority was not on board from the start of the

2. A **Joint Project Plan** was developed with the participation of all partners. This process needs to be allowed sufficient time as partners need to develop relationships and a shared understanding of the objectives of the Project. As a result, the initial stages of the Project required frequent and intensive meetings. This ground work was seen as crucial to establishing a joint approach to the ownership of the Project. In the initial phase of the Project, two sub-groups were established. One was responsible for community recruitment; the other was responsible for developing the training programme on Participatory Appraisal (PA) methods.
3. **Joint training for community representatives and PCT staff.** A training resource on Participatory Appraisal Methods (PA) was designed by the training group and delivered to four Primary Care staff and seven community representatives. The purpose of this was to give the participants the skills to engage with the community on health related issues. The resource provides a useful model for a joint approach to training. There is some important learning from the methods of training used and the approach taken. In particular, the training has been very successful in helping to build relationships between community representatives and primary care staff and to build their joint capacity to engage with communities. The key learning from the training is that it needed to be flexible to respond to community and HSE needs.
4. **Community consultations.** The training provided the basis upon which community consultations were held with local groups to identify local health needs and expectations. The participants on the training programme, from the community and the PCT, carried out a series of consultations with different groups in the community using PA methods. The Group then summarised the findings from their consultations. The summary presentations, along with the data that was collected, was then displayed at community centres and the Health Care Centre in the area. An open day was held in November 2009 in the Moyross Health Centre. The purpose of this day was to provide the community with information about the PCT and the health services available in their local area as part of the Project and was jointly planned by the community representatives and the PCT.
5. **Local Health Forum.** A local health forum is planned, although it is expected that this will be an open, fluid and inclusive structure. It is anticipated that this will be made up of both community and PCT representatives. The health forum aims to ensure that there is ongoing and sustainable community participation in the PCT. It has been agreed that several community representatives will participate directly within the PCTs and attend the PCT's business meetings. The longer term objective within the HSE is to find a mechanism for community participation on the other PCTs within Limerick.

Project learning

- The Project partners believe that there has been significant learning, capacity building and relationship development throughout the process. Some of the positive and practical outcomes have emerged from the process of information sharing and consultations. For example, the Project has had a positive impact in changing the delivery of local health services and in adding counselling, psychology and social work services to the PCT. There is also a momentum and commitment to sustaining community participation into the future.
- The Project has highlighted the importance of allowing sufficient time for relationships to develop and for all partners to develop a shared understanding of the Project objectives. The importance of involving a wide network of partners, and allowing them to participate fully in the process is crucial to developing effective inter-agency responses. A final area of key learning is that the Project has remained flexible and responsive to developments as it has progressed, and this is viewed as being a strength.
- Community organisations had a limited understanding of primary care at the start of the Project. The Project showed that time needed to be devoted to ensure that people in the community have a clear understanding of what primary care is, what primary care services are available in the community and how to access them.

- The community consultations focussed on health in a broader context, on the basis that the Project partners recognised the importance of reflecting how people think about health. This allowed rich and varied data to be collected.
- The capacity building, skills development and training of community representatives and members of the PCT, has been important both in building relationships between these two groups and in establishing a group of people who have the skills to engage effectively with members of the community.
- The PCT members has had some initial contact with local community groups, but gained hugely from the community participation process, particularly in developing a greater understanding of the range of groups/services that are available in the community and how they operate. They are now engaging with these local community groups and services in very constructive ways.
- At the start, the PCT members had had have had some involvement in the identification of needs for the PCT area. However, as part of the Community Participation Project, a number of the PCT members consulted directly with the community on their needs in partnership with the community representatives. The importance and value of consulting with local communities is now a key priority for the Team on an ongoing basis.
- The concept of community participation for the PCT was new, and required some education/ discussion on what it was all about. At times the commitment and the work involved were challenging for the members due to service commitments, but the PCT now recognises the value and benefits of engaging with the community.

5. South Leitrim Primary Care Team Community Participation Project (Leitrim Development Company and HSE West)



Project Aims

- To develop a model of community participation for the South Leitrim PCT area;
- To carry out a Community Health Needs Assessment;
- To establish a Community Health Forum and elect representatives to the South Leitrim PCT.

Background to the Project

The Project was established between South Leitrim PCT and Leitrim Development Company. The PCT covers three towns (Mohill, Carrigallen and Ballinamore). There is a population of approximately 11,000 people, which is rurally dispersed and has higher than average dependency ratio. South Leitrim PCT was launched in December 2008, and is one of eleven PCTs in Sligo-Leitrim. The PCT has received some training on Team development. A Community Health Needs Assessment was carried out by health professionals in 2007, which identified significant levels of deprivation in certain parts of South Leitrim. It highlighted the need to involve people living in South Leitrim in the design and improvement of services that impact on health. The PCT has received training from an external trainer who has built community participation into Team development and community participation is an agenda item at all Team meetings. This is important to ensure that the PCT is prepared for community participation.

From the start of the Project there has been a high level of commitment to and support for community representation on the PCT. Part of this stems from a good local relationship between HSE and community representatives, as well as a high profile given to social inclusion in the NW HSE and wide ranging experience of consultations through, for example, Consumer Panels. There is also in the NW HSE a long tradition of developing primary care services, including a NW Regional Primary Care Strategy that pre-dated the national Primary Care Strategy.

An external facilitator was employed to support the Project and assist in the development and implementation of a Project Plan. The facilitator supported the consultations for the Community Health Needs Assessment and the development of the Community Health Forum.

Project actions

- 1. Community Participation Steering Group.** A Steering Group was established to ensure a joint and equal sharing of decision making between the HSE, Leitrim Development Company and community representatives. Community participation was built into the implementation and monitoring of the Project from the outset and this helped to create engagement with local communities and tap into local knowledge. The Steering Group was made up of three community representatives from each of the three geographic communities covered by the PCT. The steering group also comprised the Community Development Coordinator from Leitrim Development Company, HSE representatives including the TDO, Primary Care Facilitator and the Health Promotion Development Officer for Primary Care and a member of the PCT. The Steering Group was very effective and early community engagement was deemed to be important to the Project outcomes. Another critical success factor was the effective engagement of the HSE representatives who acted as important champions for community participation. The Steering Group met monthly.
- 2. Community Participation Plan.** The PCT and community representatives drew up a plan for community participation, community consultations and a Community Health Needs Assessment which aimed to access and include the views of individuals and groups who may experience marginalisation including Travellers, people with literacy problems, the socially isolated, people with mental health problems, migrants, refugees and asylum seekers. This Plan guided the overall Project.
- 3. Mapping of groups in the area.** An important and valuable first step was to provide a review and map of all of the groups that fell within the geographic area of the PCT. A total of 73 groups were identified in the area including older people, childcare, youth, women, men, Travellers, lone parents, asylum seekers, disabled people, residents and community development groups.
- 4. Community Health Needs Assessment.** The Community Health Needs Assessment was carried out over a four month period in the three geographic areas of the PCT. A lot of work went into the planning of the consultations including public awareness raising, advertising and publicising of the consultations, liaison with community groups and media involvement. A number of methods were used to identify needs. First, twelve focus groups were held with specific target / care groups, including groups representing older people, disabled people, lone parents, Travellers, asylum seekers, young people and people with mental health difficulties. The information collated from each focus group was summarised and given back to each group to ensure that there was ownership and accuracy in what had been said. Second, written submissions were received from eight individuals and groups that were unable to attend focus groups or public meetings. Third, consultations were held with local agencies in the PCT area e.g. MABS, Garda Síochána, Leitrim County Council. The findings from the focus groups and consultations were written up into a report, which highlights the needs identified and the strategies proposed to resolve them. They concern issues such as transport; support for independent living; integration of existing services; health promotion and prevention programmes; out of hours and localised services; anti-social behaviour; crime and drugs; local clinics and waiting times; housing; dental services; safety; community facilities; and support services for parents and children. Additional resources were provided to consult with some of the hardest to reach groups and organisations representing mental health service users and people with an intellectual disability, older people living alone, people with difficult family circumstances and gay and lesbian people. Consultations were attended by both the facilitator and community representatives and a HSE primary care worker. The Facilitator attended a PCT meeting to update the Team on the consultation process.
- 5. Feedback to the community.** Three public meetings were held in each of the three towns in the PCT area in October 2009 to provide feedback about the consultations and to inform local people about the role of the PCT. The meetings were widely advertised in local newspapers and local radio and enabled those that had not participated in the focus

6. **Community Health Forum.** A Community Health Forum has been established and structures and methods of representation on the PCT have been agreed. The Project has favoured an approach that is representative of the three geographic communities in South Leitrim, and therefore has proposed three community representatives on the PCT. The Project's facilitator worked with the Forum to build capacity and to develop terms of reference, policies and procedures for the effective running of the Forum. A key objective is to ensure that the membership of the Forum is sustained and broadened. The next stage identified is to elect the three representatives on to the PCT to attend business meetings, which has been agreed is the best forum for building relationships and establishing community participation as an integral part of the Team.

The Project partners have identified the development of a County-wide Community Health Forum to cover the eleven PCTs in Sligo/Leitrim as a future goal. The County Forum would form the basis of representation on the LIG.

Project learning

- South Leitrim has a well developed PCT and Team members are supportive of community representation on the Team. This has been of critical importance to the progress achieved in the Project. The active engagement of the TDO, HSE Health Promotion and Primary Care representatives and the Community Development Co-ordinator from Leitrim Development Company with the Project has also been critically important to the Project. There has been sustainability built into the Project and the Primary Care Facilitator and the Community Development Worker will continue to provide the support and links between the PCT and the Forum in the interim, while in the longer term it is recognised that a local support person will need to be identified.
- Because the Project was located in an area with a rural dispersed population, the Project required time to establish a model of community participation. A lot of work on the ground had to take place to engage local people. The outcome was that local people were very willing to engage and participate in the Project, including the Steering Group. The Project partners believe that there is important learning to be taken from the Project with regards to the amount of time and commitment required to create community consultations and representative structures.
- Some learning exists regarding the need for clarity about the role and representation of community health forum members, and particularly whether this should be open to County Council elected representatives. For example, the Project partners believe that there should be established criteria for selection onto the Forum in advance. Providing this guidance to projects in advance would be considered helpful.
- There has also been some learning regarding the co-ordination of services in rural areas. It has also been difficult to align the large number of community groups already in existence in a relatively small area. This has also raised issues about the provision of HSE services which do not always have the same geographic remit, for example, between Sligo/Leitrim and Cavan. Other key issues raised concerned suicide, out of hours health care provision and child care facilities.
- The Project partners would ideally like to have seen community participation taking place earlier in the process, as the process of engagement can be time consuming. However, they are of the view that community participation should not take place at the beginning of the process since there are many issues that need to be resolved between the HSE and the community, and time is needed to build relationships, trust, understanding, processes and procedures.
- The preparation and development of the PCT is seen as a vital step for community participation. There is also important learning about how PCT representatives and community representatives can build trust, understanding and joint working.

- The project partners are of the view that external facilitator plays a key role, offering skills, impartiality, independence and time. In some cases the independent facilitator can act as a broker between the HSE and the community and help to manage expectations, define common goals and establish common ground. However, the Project partners are aware that it is important for a facilitator to be aware of both HSE and community structures and their policy contexts, in order to be effective. The role of facilitation is also seen as important in the future, particularly in managing goals and expectations.
- A key challenge and learning from the Project is that it can be very difficult to consult with and reach some of the most vulnerable groups. It was recognised that in some cases public health nurses, community psychiatric nurses and home help services can play a key role in making contact with these groups.
- The Project partners have identified the need for mechanisms to feed health and social care issues back into the HSE and to the County Council.

6. Equal Access Community Development Project

Project Aims

- To create a process for community consultations in the five communities covered by the Tallaght West Health and Social Care Network:
- To carry out consultations to inform the structures for community representation:
- To develop and carry out training to support the process of participation.

Background to the Project

Four Teams have been established in Tallaght West (Network 1). They were chosen as a priority because of the disadvantaged profile in the area and also because some developments had already taken place in primary care before the Teams were established. The launch of the four Teams in Tallaght took place in November 2009. Four of the five communities that are covered by the Tallaght West Health and Social Care Network are designated RAPID areas. Social workers and Community Workers in the four Teams have engaged effectively with the Project and have helped to raise the profile of community participation.

Equal Access CDP was the community partner in the Project, which submitted the application as part of the RAPID Health Strategy Group, with whom the Project was carried out in partnership.

The Project builds on the experience of community participation in health from the Fettercairn Building Healthy Communities Project and priorities established by the Rapid Health Strategy for West Tallaght, which established community participation in primary care as a key priority. However, the CDP suffered losses in staff during the year that the Project was operational and since then has been disbanded. In Belgard/Springfield there is little or no community development or community participation activity, which has resulted in challenges for the development of community participation structures. Engaging in dialogue about health service provision is very new and the Project represents the first real engagement for the Tallaght West communities with the HSE.

Project actions

1. **Community Participation Steering Group.** A Steering Group was established at the outset of the Project and was made up of representatives from the PCT, the HSE TDO, Equal Access CDP, the Rapid Health Group and the Fettercairn Health Project. A great deal of relationship building and information sharing took place between the community organisations and the HSE to positive effect. This was particularly important as the CDP had not previously worked in partnership with the HSE.
2. **Community consultations.** The Project engaged a facilitator to conduct a consultation process with all key stakeholders including local communities, community and voluntary organisations and statutory services. The initial vision was to create a representative community structure on the Tallaght West PCTs. The Project has pulled back from this

3. **Representation on the PCT.** At this stage the Project does not envisage community participation on the PCT as the Project is only at the stage of informing the community of the concept of developing a representative structure such as a Community Health Forum. However, the community consultations and partnership building has impacted on the work of one of the PCTs and there is now a strategy in place to create a West Tallaght Community Health Forum.

The next steps for the Project will be a launch of the community consultations and local residents who identified an interest in being part of the Project will be supported to participate in the Project. A West Tallaght Health Forum is also being established in the area. A series of lunchtime training sessions/workshops on community participation and community development are planned for the PCT and community organisations. The objective will be to share information and discuss expectations for participation on the PCT. It is also planned that the Rapid Health Strategy Group will implement the recommendations for the Community Consultations and to examine the options within existing structures before establishing a Community Health Forum.

Project learning

- The implementation of the Project, including the hiring of a consultant, took more time than had been anticipated and raised the issue for the Project Coordinator of the need to spend more time in project planning at the start of the project.
- There was important learning from the consultation process regarding the importance of starting from where 'people are at'. This is a particular issue in Tallaght where there is currently a climate of low community engagement, community participation and empowerment, and where many community development workers have left the sector. The learning is that it is important not to be too ambitious. The approach has been invaluable to providing relevant information and community engagement and as one community representative said 'in planting a seed in the community'.
- There has been some useful learning about models of community participation from this Project and the fact that the process of information sharing and participation exist at 'two different ends of the spectrum'. Managing expectations has been important as part of this process.
- The learning for the community consultation process is that the community has to be ready to engage with the PCT; in some cases this may mean that the capacity of the community and its representative and networking structures need to be in place for the PCT to consult with. There is a general view from the HSE it is not a valid or appropriate role for the HSE to develop these community structures. It is very clear from the Project partners that healthy communities need to be built if community participation is to succeed. This requires a core staff of community workers who can work in local communities and build capacity and participation.

- There is also some learning about how expectations are managed. This has proved difficult for the CDP, working with limited resources. The disbanding of the CDP has implications for the sustainability of community participation, and there is a real need for community and statutory organisations to continue to engage in the process in the longer-term.
- The RAPID Health Strategy Group has played an important role in the Project and will be crucial to the sustainability of the actions carried out. The Group is made up of the HSE Community Team, HSE PCT, RAPID, Dodder Valley Partnership, Fettercairn Community Health Project, Tallaght Traveller's CDP, and local residents. However, the loss of two CDPs from the area has diminished the resources to support the establishment of a Community Health Forum. However, the RAPID Health Strategy Group is committed to sustaining the process within existing workloads.
- There has been an active engagement of two social workers on the three PCTs that were the focus of the Project in the community consultations and the establishment of the Steering Group. It is clear that social workers, through the nature of their work, can play a key and positive role in supporting community participation.

7. Rialto Community Health Forum (Fatima Regeneration Board)



Project Aims

- To develop joint information sharing workshops between PCT members and local community groups;
- To produce a guide to community groups and local primary care services;
- To support the representation of community participation through the Rialto Community Health Forum in the PCT Management group.

Background to the Project

The recently established PCT in Rialto is one of five Teams in the Dublin 8 network area, and one of fifteen Teams in the LHO area.

The Project has its roots in the *Health and Wellbeing* theme prioritised in the Fatima Regeneration Board Social Regeneration Plan. Rialto is an area with high levels of poverty, disadvantage and health inequalities. There has been a significant investment of resources in the area and particularly in tackling health inequalities, with a Community Health Co-ordinator employed by the Regeneration Board and local Community Health Development Workers employed by Fatima Groups United and Dolphin House Community Development Association working on the ground in Rialto, Fatima and Dolphins Barn. The Rialto Community Health Forum has been established with around twenty community representatives.

A Participatory Research and Action Programme was carried out in Rialto in 2008, which resulted in over 250 local people participating in public consultation meetings and focus groups sessions. The programme was facilitated by CAN and a Health Action Planning process formed the basis of consultations in the community and discussions with local residents and community workers. A report of the initiative, *Community health, community wealth. Rialto's health and wellbeing: local needs and community solutions*, was published in 2009. As well as reporting on the findings from the consultations, the report sets out a *Rialto Community Health Action Plan 2009-2010*. Six actions are listed which aim to: tackle inequalities in health in Rialto, work creatively to challenge and change the systems and structures that perpetuate poverty, build a caring community in Rialto, work collaboratively with community and statutory organisations to create a healthy living environment, promote health in Rialto and promote people-centred service developments in Rialto. Many of these actions are targeted to work alongside or within primary care. As a result of this work the Rialto Community Health Forum was established in 2009 and launched with the research report.

A focus has also been given to human rights through the *Partnership and Participation in Rights* Project, facilitated by CAN. This has led to an assessment of how human rights approaches can be applied to diverse areas such as drug treatment options, damp housing conditions and play areas.

This important ground work forms the backdrop to the Community Participation Project. On this basis the Project has employed a social determinants of health approach to tackle these issues at a local level and to influence policy. There are a large number of community groups and projects in the area, and the Community Participation Project has engaged widely with these groups and projects.

Project actions

1. **Information workshops.** Six local workshops, held monthly, were organised jointly between the local community groups and PCT staff. A set of guidelines was drawn up for the organisation and running of the workshops and the themes to be covered. The objective was to develop shared understanding and approaches, information sharing and also to map community and HSE services. It was found that lunchtime workshops worked well, with around 35-40 representatives from the PCT and the community participating in each of the workshops. The workshops were described by the Project partners as a “resounding success”. Each workshop had a balance of speakers from community and HSE backgrounds around the following themes: mental health supports, supports for older people, supports for people affected by addiction, promoting health lifestyles and presentation of the Rialto health research, family supports and early intervention. As well as presentations from the community and HSE, the workshops also provided an opportunity for facilitated small group work to encourage relationship building, identify local health service needs and information about services in the community.
2. **Directory of local health and community services.** An outcome from the Project is that a local directory of community and statutory services and organisations has been produced and launched at a community event in December 2009, *What's out there? A profile of health and wellbeing groups and services in the Dublin South Inner City Area*. This guide was produced in response to the identified needs from community and HSE personnel for more information about local services and groups.
3. **Community Training Programme.** Training was organised as a follow up to the information workshops. Two ASIST suicide awareness training sessions of two days each were attended by sixty participants comprising local people and workers from the statutory and community sector. Further training on improving accessibility to services took place through a lunch time workshop.
4. **Community Health Forum.** The Rialto Community Health Forum was established prior to the Project. However, the Project helped to raise the profile and relevance of the Forum to primary care. Several Forum members took the role of facilitating the information workshops. It is planned that the Forum will have four meetings a year.
5. **Community participation in the PCTs.** The Rialto Community Health Forum has three representatives sitting on the Primary Care Management Team. The first meeting took place in October 2009 with attendance from GPs and other HSE professionals, three community representatives from the Community Health Forum including the Community Health Coordinator and two Community Health Development Workers. Terms of reference for the meetings have been agreed. The information workshops provided an important opportunity for relationship building between Forum representatives and PCT representatives, and this was deemed to be hugely important to the openness of both community and PCT representatives to discussion and information sharing. In the future it is anticipated that as the Forum develops a system for electing representatives onto the Primary Care Management Team and Rialto PCT will take place.
6. **Joint community launch.** A community launch event was organised jointly by the HSE and the community to launch the Rialto PCT and the Guide to services *What's out there? A profile of health and wellbeing groups and services in the Dublin South Inner City Area*. It also celebrated the Project and the ownership of the community participation process by a wide range of organisations and groups. The launch was attended by over seventy

Project learning

- There is important learning to be drawn from the approach taken to consultations. The workshops, jointly held between the community and the HSE, focussed on information sharing and this provided a neutral and safe space for Community Health Workers and community representatives to meet and share information with PCT members and other service providers. This was seen as an important first step for more formal community consultations in the PCTs and a response to an identified need by both community and PCT representatives. This, along with the training and other activities, has stimulated an openness to community participation in primary care.
- The impact of this approach is that a process of mutual learning took place. Community representatives and local people became more aware of PCT services and PCT members became more aware of services provided by community groups. This has resulted in the development of cross sectoral relationships and joint working. For example, the Social Worker on the Community Mental Health Team now refers clients to community run groups for support and social contact.
- Keeping the focus on the social determinants of health has added richness to the engagement process and enabled wide ranging discussions to take place on health issues related to primary care. For example, it has led to joint work in a number of areas including support for community health activities from Dublin City Council's Sports and Recreation Officer.
- A critical success factor has been the appointment of a Community Health Coordinator to steer and coordinate the Project. This has enabled a whole range of actions to be implemented that would not have been initiated without this full-time support. Without this role it will be difficult to sustain the Project and the Community Health Forum in the long-term. As a result there are key issues of sustainability of the Project and the ongoing work of the Community Health Forum, particularly because the funding for the Health Coordinator's post is not permanent.
- There is also valuable learning to be drawn from the initial model of community consultations that took place prior to the Project and from the model developed with CAN. It is interesting to note that even though these consultations provided a backdrop to the Project, many in the Project believed it was important to go back to the basics of community participation in establishing a model for Rialto.
- The Project has found that the health issues raised in the consultations and information workshops extend beyond the remit of the PCT. The Project has approached primary care in the broadest sense and sees the value of taking a wide perspective based on the social determinants of health and particularly to influence health promoting activities in primary care. This approach has been important as HSE staff now have a better understanding of the value of engaging with the wider community and of the role played by the community in promoting health and well-being.
- The joint approach taken from the start has been a key to the success of the Project. This approach helped to build trust and relationships, sharing information, understanding of the different roles and approaches of partners, and in supporting the planning of joint workshops.
- A very important element of learning from this Project is that the huge engagement, enthusiasm and interest from the PCT members to engage in community consultations, and of community representatives to participate in primary care. This has resulted in very successful joint approaches and joint outcomes.

8. Blakestown Community Development Project and Mountview Family Resource Centre

Project Aims

- To carry out a consultation with local communities and to explore how the social and economic conditions in which they live impact on health:
- To build the capacity of local community representatives through community based training:
- To provide the capacity, knowledge and information needed in the local community so that it can influence the PCT when it is established.

Background to the Project

There are six primary and social care networks and 24 PCTs in the LHO North West Dublin. The Mountview / Blakestown/ Coolmine PCT covers a population of 10,774 and is located in Network 3. At this stage the TDO for LHO North West Dublin and community organisations are examining what type of community participation can take place on the PCT, as well as examining how this could be developed at network and LHO level.

The Blakestown Community Development Project and the Mountview Family Resource Centre submitted a joint project proposal as their geographic communities fit with the PCT area. Good working relationships have developed between the two projects and with the TDO. A model of community participation was developed with CAN. The objective has been to involve the most disadvantaged communities and build their capacity to influence positive change in the area. There has been an important emphasis on starting from the experiences of people in the community and in recognising the importance of recognising the 'distance travelled' by local people in building awareness, empowerment and participation.

The Project anticipates that the work carried out will form the basis for future participation in the PCT. It is hoped that the interest and involvement of local people in the Project will enable local communities to have a better awareness of the issues that impact on their health and well-being so that they can be participants in building healthier communities. It is also anticipated that the Project will have an impact on and promote the active engagement with statutory organisations and agencies.

Project activities

1. **Project Working Group.** A Project Working Group was formed between the Blakestown Community Development Project (CDP), Mountview Family Resource Centre (FRC) and the TDO (HSE)
2. **Community Training Programme.** Local residents and groups in the area participated in a six-week training programme run by CAN. Workshops were organised for different target groups to build up a picture of the issues impacting on health. This has been very successful and has engaged a group of local people and representatives with local community organisations and agencies. The emphasis of the Project has been on developing awareness of the broad social and economic determinants of health, by training and building the capacity and involvement of local people on health related issues in their community. Representatives of the two community organisations and the TDO participated in the training. The training formed the basis of community consultations.
3. **Community consultations.** Following the training a series of consultations were held with local people, facilitated by the CDP and FRC Project partners and community representatives. This has been hugely successful and has engaged local people in a way that had not been achieved in the past. By working with local groups and taking the consultations out to local people, there was significant engagement on the ground. Some of these consultations have taken place with existing target groups in the CDP and FRC. For example, the FRC has used its contacts to carry out focus groups and consultations with key target groups such as men's projects and local drugs task force projects. Health and well-being are issues that have really interested and engaged local people who have not been engaged in any local groups in the past. A great deal of effort was put into providing information for local people and with local groups in order to encourage participation. A key issue raised is how the health of the area can be improved through the process of consultations and also in feeding health issues in to their local PCT. The findings of the consultations have been collated together in a report produced by CAN and forms an evidence base for further activities.

4. **Establishment of a local PCT.** The Mountview / Blakestown / Coolmine PCT was established following the community consultations. Members of this PCT have met local community representatives and the PCT is currently identifying PCT representatives who will work closely with the local community groups.
5. **Community participation on the PCT.** The Project is continuing discussions with the TDO with a view to working towards community participation on PCTs. Consideration is being given to a model of community participation that has been developed jointly by two other CDPs and members of the other two PCTs in this Network area.
6. **Training of volunteers in the local community.** This has been key to planning for this participation, although the Project recognises that the community is really at a very early stage and that additional resources and support are required to enable this participation to be realised in practice.

The main achievements to date have been to raise awareness of the social and environmental factors that impact on health and wellbeing in their local area. The Project has found that people in the Blakestown and Mountview area are very engaged with the Project and have been willing to respond to questions and discuss the issues that impact on their health. The consultations have found that issues such as social isolation and anti-social behaviour which impact on health and well-being are key concerns for the in the community.

An example of a positive outcome from the Project arises from the identified impact of the anti-social behaviour of young people on the health and well-being of older people. Working with local youth groups the Project has established an inter-generational initiative whereby young people have invited older people to a breakfast meeting. The young people will cook breakfast for older people in the community as a basis for discussing how they can have better connections with each other.

Project learning

- The model used provides evidence of a process that was tailored to the needs of the community. This model, based on training with community volunteers with CAN, provides an excellent framework for community consultations using community development approaches and is extremely useful learning for other projects in the future in supporting local disadvantaged communities to participate, particularly where there has been little history or experience of participation in the local area.
- There is huge learning from the approach taken, in particular the importance of working with local people in the places where they meet, for example, with older people attending the local bingo group, or through the local men's group.
- The CDP and FRC have found that community consultations are time consuming and complex, but help form the basis for other development work.
- The TDO has been very active in the area and has been an important champion of community participation. This had added a real value to the Project and to the support given to the community consultations.
- There are significant uncertainties for the CDP and their integration into Blanchardstown Area Partnership (BAP). The CDP does not know if community participation in health will be a priority for BAP and whether their presence at community level will be sustained. There are similar concerns expressed by the FRC about sustaining funding and support for the Initiative, despite the local commitment to this.
- However the model has been very valuable in the approach taken to community empowerment by focussing on people's real lived experiences and their views of the issues in their communities that impact on their health and wellbeing.

9. A Model for Community Participation in Primary Care for Corduff, Mulhuddart and Tyrrelstown (Corduff Community

Development Project and Blanchardstown Community Development Project)



Project Aims

- To establish a joint approach to community participation in primary care;
- To develop a model for community participation in primary care;
- To build on existing research conducted in these areas on community health needs so as to develop meaningful and ongoing community participation in primary care;
- To develop community involvement and participation in the planning and delivery of primary care services;
- To develop training for the PCTs and the Community Health Forum.

Background to the Project

Two PCTs cover the geographic area of the Project. The Mulhuddart/Tyrrelstown PCT covers a population of 7,856 and Corduff PCT covers a population of 7830. . These two PCTs are part of Network 3 area of LHO North-West Dublin.

The Project has brought together two community organisations, Corduff Community Development Project and the Greater Blanchardstown Community Development Project to develop community participation in the PCTs and to build the relationships between the PCTs and the local community.

The Project builds on some important research and ground work carried out by these community organisations as part of the *Building Healthy Communities* Project and a number of local consultations carried out in Corduff and Mulhuddart, resulting in several reports detailing community health needs and how disadvantaged communities can influence primary health care¹¹.

This Project developed a model for community participation in primary care by the Local Health Action Groups (LHAGs). One of these LHAGs is located in the Corduff area and the other is located in the Mulhuddart / Tyrrelstown area. These are the fora from which community representatives are selected to represent the community on the Community Participation Working Group (CPWG). An important element of this is to increase community awareness of health issues and the role that the community can play influencing community based health issues. The model also identifies the need for the local PCTs to identify members from those Teams to be PCT representatives that will engage on behalf of the PCTs on the Community Participation Working Group.

The rationale for the Project was to ensure that the local community and agencies working within the community have a structure through which to have a say in shaping the development and delivery of primary care services in Corduff, Mulhuddart and Tyrrelstown.

Project actions

1. **Community Participation Steering Group.** A Community Participation Steering Group was initially established with representatives from the two community organisations participating in the Project and the two PCTs. Through discussion and consultation a draft Model for Community Participation in Primary Care was drawn up.
2. **Community consultations.** An external consultant was employed to facilitate a consultation process with local people and service providers to elicit feedback on the draft model of community participation. Although the consultations in Corduff were well attended it became necessary to find other ways of engaging with local people and

¹¹ Cosgrove S (2004) *Mulhuddart Primary Health Research Report*; Corduff Health Action Group (2004) *Corduff's Right to Care: The Voice of the Corduff Community. Health Action Plan*; and Burtenshaw Kenny Associates (2008) *A Profile of the Needs of the Tyrrelstown Community*.

service providers in the other two areas. A detailed report of the consultations was produced, which set out the planned *Model of Community Participation in Primary Care*. The report provides an overview of the steps of the model and recommendations for the development and implementation of the model. This report also identifies the main achievements, evidence and rationale for community participation in primary care, as well as an assessment of the challenges identified from the process and the supports and enablers to the process, as well as key lessons learnt. The consultations were also important in identifying gaps in service provision, for example, mental health services for 16-18 year olds, and the need for family planning and a well-women's centre in the area.

3. **Model of community participation.** The model includes the establishment of structures of for representation through LHAGs and PCTs. It also identifies the need for the establishment of a Community Participation Working Group for Network 3 area in LHO North West Dublin PCTs and the establishment of a Community Participation Steering Group for the LHO area with relevant issues being brought from that group to the LIT. On reflection the CPWG has proved to be a more effective Forum for discussion between the community and PCT representatives, than representation on the PCTs. Recommendations have been made in the Report about participation and representation on the Local Health Action Groups, the development of feedback mechanisms to the community, the nomination and selection of community representatives onto the Community Participation Working Group as well as the scope of health issues to be addressed by the Local Health Action Groups and at the Community Participation Working Group. A report of the consultations *A Model for Community Participation in Primary Care for Corduff, Mulhuddart and Tyrrelstown – Final Project Report and Action Plan* (Siobhan McGrory, 2009) has been produced and this is being widely circulated and disseminated.
4. **Local Health Action Groups.** A Local Health Action Group (LHAG) has been established in Corduff and Mulhuddart and plans are in place to establish a LHAG in Tyrrelstown. The objective has been to ensure that there are representatives from different geographic areas as well as representation from women, older people, disabled people and travellers. Terms of reference and job descriptions/contracts for representatives have been drawn up. The ongoing work of the project is to ensure that the LHAG(s) are sustained through relevant local events and activities. For example, plans have been put in place to run regular events and to invite speakers from HSE services to meet the groups.
5. **Health Information Fairs.** Two health information fairs '*Respect your Health*' and a '*Wellness Fair*', have been held in community centres in Corduff and Mulhuddart, and were jointly organised by members of the PCT and community representatives. These provided free blood and cholesterol checks and information about different HSE and primary care services as well as information about community groups and agencies. Over 25 different agencies were represented at each event and provided good evidence of the HSE and community working together. It is anticipated that as a result of the significant interest from local groups and service providers that the events will be held annually.
6. **Directory of HSE Services and List of Community Services.** An up-to-date mapping of the community structures, organisations and services has been carried out as part of this process and a Directory of local HSE services was compiled and circulated to local communities.
7. **Local action plans.** In each of the partner projects (Corduff Community Development Project, Greater Blanchardstown Development Project and the PCTs in the LHO North West Dublin) an action plan has been drawn up setting out the steps that need to be implemented and the milestones to be achieved for the implementation of the Community Participation Model.
8. **Training programme.** A joint training programme was developed and run for both the community and PCT representatives. This involved five evening training sessions, run by the Project's facilitator/researcher. The training was carried out in the evening in order to maximise participation of local people. The training covered community development, partnership working and built in information sharing and discussion about the development of the Community Participation Working Group. The training provided the

9. **Participation on the PCT.** At this stage it has been agreed that there will not be a community representative on the PCT, and that an overall structure for community participation will be developed through the CPWG that has been established to bring together representatives from both the community LHAGs and from the PCTs in Network 3 area it was agreed that each Local Health Action Group would nominate 2 representatives and each PCT would also nominate 2 representatives to sit on the CPWG. This group is being co-chaired by a community representative (nominated by the community Project partners) and a HSE representative (nominated by the HSE PCT Project partners).

Project learning

- Community groups have developed solid working relationships with the PCTs and the Transformational Development Officer (TDO) and there is very positive buy-in to the model of community participation that has been developed. All partners have given time and commitment to the Project, to developing joint working methods and a model for community participation. There is important learning from this process about the need for effective communications and joint working, as well as the time commitments required to effect community participation.
- Although extensive Community Health Needs Assessments were carried out in Corduff and Mulhuddart six years prior to the Project, the Project partners recognise the importance of updating these and going back to the community on the ground. In Mulhuddart the Community Health Needs Assessment carried out in 2004 was agency, rather than community-led. Therefore, engaging with local people has been seen as vital, particularly because there is a lack of community based needs information in Mulhuddart, compared to Corduff.
- As in other Projects organising community participation has been an ongoing challenge and is never straightforward. There are significant investments of time needed to establish representative community structures. In the Project this has involved significant investments in time in door knocking, working with local groups and identifying local community representatives.
- The Project's partners are concerned that the investment of time and resources to build a core group of community volunteers could be lost if there is no funding built into the process in the future. The learning is that a huge level of support and time needs to be invested in community consultations, and this is particularly the case with the most marginalised communities who do not necessarily have the experience or capacity to participate.
- Despite investment of several years of time and resources on health inequalities there remains uncertainties about the sustainability of the process and the extent to which the Action Plans that have been drawn up can be fully implemented. This is particularly a concern as there is uncertainty about future levels of community funding. A key question was raised by the CDP about maintaining interest and sustaining the Project "How do we ensure that a sustainable voluntary group is left in place?". The Project has identified the need to have a voluntary action group in place and to ensure that it is strong and that representatives are supported and trained. Having resources is seen as key to this process.
- There has been some important learning for the Project in working with areas where there are different levels of community development and community readiness to engage in the primary care process. The Project found difficulties in getting participation in those areas where there were no active community organisations. One key area of learning according to the CDP is that 'nothing can be taken for granted but always has to be worked at'. The learning is that the importance of Community Development Projects locally is essential for the process to continue.

- Having an experienced facilitator, researcher and training has helped to keep the Project on track. The Project partners are very clear that there is a need for resources to support community participation in practice, including having a dedicated support worker. However, there is an added-value from having an external facilitator as this can bring impartiality to the decision-making table.
- The Project believes that the actions carried out to date have been very much the start of a process that empowers and encourages the participation of local people. The direct engagement with the community has been very uplifting and motivating for the community and there is real evidence that the Project has had a direct impact on community awareness and involvement. This is very important learning for other projects that are embarking on community consultations.
- There is also some learning about how to sustain groups once established and to ensure that new people are encouraged to join the group. This does raise the issue, and identified in other projects, about how to keep group cohesion and how to ensure that new members are trained and included in established groups.
- The Project has had a huge impact on local awareness of health issues and important new channels of communication have opened up in the community and within the HSE. The development work has really paid off and the Project believes that there has been significant learning about how to engage with the community and sustain the initiative so that there is buy-in from the community. The distance travelled by the community and the HSE and the work carried out has given a real sense according to the CDP lead in the Project: 'that we have come a long way in 12 months'.

10. Monaghan Community Forum

Project Aims

- To develop a model of community participation that will engage with the two PCTs in North Monaghan;
- To consult with marginalised groups in the community and give a voice to their health needs;
- To develop sustainable methods of community participation and a Community Health Forum.

Background to the Project

Monaghan Community Forum is the community partner in the Project. The Forum provides a platform for 350 groups in the County, and operates on a thematic basis. It is through the Forum that community participation has been organised.

Two PCTs have been established in North Monaghan both of which will have a base in the HSE campus at Rooskey, Monaghan. The PCTs are holding clinical meetings and the GPs and have generally been very positive about community participation.

The original Project aim to develop a 'planning for real' process of community consultation had to be revised in the light of the fixed location of the PCT in Rooskey. It had been envisaged that a simulated model of the location of the PCT would be designed to enable community representatives to influence the physical planning of the building in which the Team were to be located. This was not a structure that the community was able to engage with and therefore the focus of the Project shifted.

Project actions

1. **Community Participation Steering Group.** The Steering Group is made up of the HSE Social Inclusion Manager, the County Council Social Inclusion Officer, the Family Resource Centre in Mullaghmatt, a representative from the Community and Voluntary Forum and Monaghan Integrated Development Company. Good working relationships have been established between the partners and the Steering Group provided the direction for the Project and helped to build relationships between different agencies.

2. **Community consultations.** An independent facilitator was employed to facilitate consultations with marginalised people. The objective was to consult with service users and local people, provide information and discuss options for consultation with PCTs. Information about PCT services was provided through a presentation of services and supported by an information leaflet and a visual display of the location of the PCTs in Monaghan. The consultations also identified issues and concerns faced by local communities and made suggestions for issues affecting service delivery for PCTs to address. Consultations were held with ten groups representing older people, new communities, Travellers, young people, parents with disabled children and other advocacy groups. Consultations were organised at times and in venues that were accessible to the groups consulted. The PCT members were briefed about the consultations and this helped to gain buy-in to the process and a connection with the Project. Each consultation had a representative of the Steering Group and at least one member of the PCT or HSE to answer questions. It was intended that the consultations would also lead to the identification of local community leaders to participate in a Community Health Forum.
3. **Information leaflet.** Local community representatives supported the production of an accessible leaflet on the role of the PCT and the services that it provides, which was widely disseminated as part of the consultation process in the catchment area. The engagement with the community in producing the leaflet was seen to be a very positive early initiative and particularly ensured that the language and format of the leaflet was informative and accessible.
4. **Project final report.** A final report of the Project *Community Participation in Primary Healthcare in North Monaghan* has been produced, with information and resources about primary care and community participation, the outcomes of the consultations, contact information and referrals. Follow up meetings are planned with groups consulted with to provide them with feedback of the process and to further develop the engagement process.
5. **Next steps planning.** A facilitated planning meeting was held at the end of the funding phase of the Project to examine the next steps, extend the Project learning out to other PCTs and build in sustainability to the Project. The meeting was facilitated by CAN and included representatives of the Steering Group and the HSE TDO. It was agreed that the model developed could be built upon and that the consultation and information sharing process would be carried out in other PCT areas in Monaghan in 2010 and that this could be extended to PCTs in Cavan in the future. It is also planned that a representative from the Steering Group will attend the meetings of the LIG in the future. It is also planned that training on community participation will be provided for PCTs and the Project partners at the network level (for each of the four networks in the North East).

Project learning

- Getting the buy-in from and engagement with the PCT was very important to establishing the community consultations. This helped to raise awareness and understanding of community needs and models of participation. The ground work in building relationships and trust between community representatives and the PCT has been very effective and took time, and requires a step-by-step approach. Project partners realised that the Project took four times as long to deliver than they had originally anticipated, and there is important learning about the time and resources needed to consult with disadvantaged groups.
- Having an external facilitator was regarded as being very important as it provided independence to the process of consultations; it was not deemed appropriate that the sessions were chaired/facilitated by either the HSE or the community representatives. Sustaining the Project and rolling-out the model to other PCTs in the longer term does require additional resources for external facilitation. Without this resource the Project partners will work with local community organisations to identify what capacity they have to conduct consultations with their own communities.
- The PCT were unfamiliar with models of community participation and they have engaged with the learning experience in a very positive way. It is clear that joint work and

- The consultations were a valuable element of the Project, particularly in providing information sharing and in improving understanding of the issues faced by marginalised groups. The experience of holding the consultations has provided important learning about having flexibility to respond to local needs and the targeting of the most disadvantaged groups. The Project partners have stressed the importance of allowing the Project to develop organically and flexibly so that it can be responsive to local needs.
- There were some concerns that the community consultations would have as their focus the closure of Monaghan hospital. The Steering Group were very aware of the need to ensure that the engagement process remained focussed on community and primary care.
- The consultation process has been completed and the local evaluation of the Project suggests that feedback should be given to the groups that were consulted. This is also an opportunity to develop further engagement with the Project and consult with other target groups that have not to date been consulted with, including consideration of methods to engage young people. This is now being planned as part of the next stage of the Project.

11. West Cork Islands

Project Aims

- To develop a community representative model from the seven inhabited islands and the HSE to feed into PCTs (Mizen, Skibbereen, Bantry and Castletownbere);
- To hold regular meetings of the representatives of the seven islands and the HSE to strengthen the voice of Island communities;
- To develop a health forum for the seven West Cork Islands;
- To review the West Cork LHO Area Islands Health Plan in association with the HSE;
- To hold training workshops for health care professionals and Islanders on community participation.

Background to the Project

The Project grew out of a concern about the vulnerability and isolation of the West Cork island communities, and particularly the health impacts of islands experiencing rural depopulation, unbalanced population structure, low income, lack of social and recreational services, isolation and social exclusion.

The Project has been developed and managed by the HSE and the three representative organisations covering the seven inhabited islands off West Cork (Bere Island Projects Group Ltd a Community Development Project covering Bantry Bay islands; Sherkin Island Development Society Ltd a Community Development Project covering the Roaring Water Bay islands; and Comhar Cumann Chleire a representative cooperative organisation for the Gaeltacht island of Cape Clear). The Bere Island Community Development Project has been the lead Project for the island community organisations. The Principal Community Worker in the HSE in West Cork has provided the overall Project coordination and the West Cork LIT formally appointed four representatives to the Project Steering Group.

Some of the ground work for community participation in health was established under an Islands Health Plan that was finalised in 2002 and reviewed in 2004. This resulted in a community work model for the provision of services to children and older people and the creation of an Islands Health and Social Group in the County Council. The provision of health services in a small, dispersed and geographically spread population raises a number of challenges for health services, and particularly the engagement with the four PCTs in the area (Mizen Head, Skibereen, Bantry and Castletownbere). There are to date no community representatives on any Team in West Cork and the Project has had to grapple with how best to represent the particular needs of island communities while recognising that the populations on the islands in each of the four Teams is very small compared to the population covered by each of the four Teams.

The Project is not typical of other community participation Projects because it deals with a dispersed community of interest whose particular needs do not fit neatly with the geographic base of the PCTs.

The West Cork LHO Area has adopted a principled stance that Island residency status should not result in any individual or family receiving a lesser service.

Actions carried out

1. **Community Participation Steering Group.** The Steering Group was initially established with representation from the TDO, representatives from the LIT, the HSE's Principal Community Worker and representatives of the three West Cork Islands community organisations. These members subsequently formed a Project Management Group that invited representatives from all of the seven islands to participate.
2. **PCT representation.** An agreed formal structure has been put in place for the West Cork LIT and island representatives to meet twice a year in a special meeting. This has provided a strategic role whereby all of the island communities can be represented together and across all Teams. Draft terms of reference have been agreed.
3. **Community consultations / information.** The first major activity was a health information day / seminar which was attended by HSE services and community organisations (including the partner projects, the Citizens Information Centre, rural transport, education providers, West Cork carers etc.). This enabled the Project to be introduced to community and other agencies, and for PCT staff to give presentations to the community about the role of the PCT and for the community to provide information about its roles and services. This was a very positive experience for community and HSE representatives and it was viewed as important for not only providing information but also in managing and clarifying expectations. Public meetings have been held on three islands (hosted by the three CDPs) and an external facilitator was employed to facilitate and report on the meetings.
4. **Service mapping.** A mapping of services exercise has been carried out on the islands providing a list of HSE and community island services. An information leaflet about these services has been printed and disseminated.
5. **Training.** A training day for community and HSE representatives was carried out towards the end of the Project. The aim was to develop and formalise the terms of reference for engagement with the LIT and to discuss how Island community issues can be represented on the PCTs. A training day is scheduled with Island representatives, Mizen PCT and representatives from the three Community Councils in the Mizen area. The aim of the day is to agree ground rules and terms of reference for community participation on locally based PCTs. The LIT anticipates that this will inform/facilitate community participation in PCTs across West Cork.
6. **Community Health Needs Assessment.** The development of a Community Health Needs Assessment has been planned with all islanders on each of the island. This is to be facilitated by the HSE Community Work Department and replicates the original Community Health Needs Assessments carried out in 2002 and 2004. The community representatives view this as being crucial to the development of services for island communities.

The Project has gone further than the scope set out in the original application. For example, the Mizen PCT has met with representatives from the three Community Councils in the Mizen area. The aim was to develop a model of engagement for the other PCTs and extend this to the other areas. Other activities have included the review of emergency protocols and procedures for the islands, originally developed as part of the 2002 plan.

Project learning

- A joint Project between the HSE and the community organisations was considered to be a major factor leading to the creation of a collaborative and equal way of working.
- For the HSE engaging with established community groups on the ground has been crucial to the Project's development, and this would have been very difficult to progress without this local community infrastructure.

- The Project has engaged in a significant amount of discussion particularly in enabling Project partners to build trust and understanding, as well as managing expectations and developing realistic goals. This takes time, but is a hugely valuable and necessary component of community participation. This has been particularly important because of the geographic spread of the Islands.
- Finding a process for engagement between seven Islands and four PCTs raises a number of challenges, particularly in developing representative structures across the islands.
- There has been huge progress achieved in nine months, and this process has shown that the process of engagement takes time. There has been important learning for community and HSE representatives and working together has led to excellent relationships and engagement.
- There is also important learning about how the Island communities engage with a wider range of groups, particularly through the County Community and Voluntary Forum. In addition, networking with a wide range of groups including parents groups, childcare groups, active ageing and carers groups, has been important to ensuring that the Project keeps a wide focus.
- The Project has provided the ground work for the Initiative to take off in a constructive way. This ground work was essential to building trust, engagement and terms of reference. As one community representative stated “we are just starting, we now have a model and now we are working with the island development groups and developing community consultations of health needs of Islanders”.

12. Wolfe Tone Community Health Project

Project Aims

- To carry out a needs analysis in three RAPID communities in Wexford;
- To draw up local community health plans and develop methods for participation in PCTs;
- To carry out training and capacity building for community representation;
- To engage in information sharing between community and PCT representatives.

Background to the Project

The Project builds on the work of the Wexford Community Health Project, which had been supported by Wolfe Tone Community Development Project as the lead agency since 2008. The Wexford Community Health Project works on community health issues using community development principles and methods, with a particular focus on those that are the most marginalised and excluded. In 2004 a group of twelve people from RAPID communities participated in a ‘Building Healthy Communities Programme’ which used community development principles to tackle health inequalities.

The aim of Wexford Community Health Project has been to bring together a group of community activists/volunteers from the RAPID areas in Wexford to participate in training and carry out a needs analysis in each area as a basis for locally based community health plans. It is envisaged that these plans will form the basis for community input into the PCT for Wexford. Wexford Community Health Project has been working directly with community volunteers since February 2009, in order to develop the skills of volunteers to participate in PCTs. The objective is that this will form the basis for the development of a community participation model for primary care.

There are currently two virtual Teams in Gorey and North Wexford, while the Wexford Town Team has not yet been fully developed owing to disagreement with the GPs regarding their participation. The development of the PCTs has not included community participation and there are still some difficulties for the community in fully engaging with the PCTs. The Project will be seeking representation on the Wexford Town PCT when it is fully established.

Project actions

1. **Community Participation Steering Group.** An inter-agency Community Participation Steering Group has been established with representatives from the Community Development Projects, the Family Resource Centre, the HSE Community Worker, RAPID and the VEC. The group meets monthly.
2. **Community consultations.** During the year three seminars were organised – Caring for the Carer, Elder Abuse, and finally the launch of the Health Needs Analysis. The Seminars engaged with specific groups within the community, to share and disseminate information. The final seminar launched the Needs Analysis and also created an awareness of the Community Health Project.
3. **Training for community participation.** The main focus of the Project has been to deliver leadership and partnership training for community volunteers who are participating in the Project. Two accredited FETAC modules: Community Development Practice and Understanding Community Development, delivered with a Community Health Focus, have been carried out with twelve people living in disadvantaged communities. Further training has introduced participants to the structure and policies of the HSE, medical terminology, primary care services, as well as leadership, speaking, research and advocacy skills. This training is seen to be crucial as participation in primary care is a new issue for local communities. It has enabled participants to build their capacity and confidence to discuss health issues that affect the whole community. The training has provided the basis for participants to join a Community Health Forum. At this stage the Project has not created a Community Health Forum. Nine of the trainees are still very active in the Project and are engaging in direct community health work. The Project Coordinator considers the skills and competencies achieved in the training have impacted on the profile of community health and the importance of communities having a voice in health policy.
4. **Community Health Needs Assessment.** A Community Health Needs Assessment has been carried out in the three Rapid areas by a researcher, working with community representatives and the Project Steering Group. An important element of the research has been to involve community representatives in the research, for example, in the drafting of research questions and assisting with interviewing, so that they can acquire research and writing skills. The research provides a rich resource of data on health and well-being that includes the impact of housing, employment, unemployment, poverty, education, neighbourhood and the local environment and health and lifestyle issues on the health of people living in Wexford Town. The Community Health Needs Assessment provides a wealth of baseline quantitative and qualitative data that will be fed into the PCTs in Wexford.
5. **Launch seminar.** The report of the research *Growing Healthy Communities: Community Needs Analysis*, was published and launched at a seminar in December 2009. The seminar was attended by representatives from community groups, community and statutory organisations and PCTs. It provided an overview of the Project's achievements, a presentation of the research findings and workshop sessions were built into the day to identify next steps.

The Project has provided the capacity and the basis for community representatives to participate in primary care. A wealth of data and information about health needs in the local community also provides a benchmark against which to measure progress in meeting community health needs.

It is anticipated that the Project will continue in the future with a range of activities planned including themed workshops on the health needs of specific target groups, such as older people and young people and health information days.

Project learning

- In terms of sustainability it has been crucial to have ongoing funding for a Project Worker to plan, develop and sustain the Project. The current development worker is in post until November 2010 under funding from the Dormant Accounts, after which the project's sustainability may be in question.

- The support provided by the HSE's Community Worker in the Project has been very valuable, particularly because there is currently no TDO/Primary Health Care Manager in post in the area.
- Inter-agency work has been of real benefit to the Project, in drawing on a range of perspectives, resources and skills. There has been a mutual process of learning between different agencies and organisations.
- The training has been hugely important to empowering and building the skills of the volunteers. Many now feel confident enough to make presentations and to speak in meetings. The group are regarded as being very strong and capable.
- Time is a key issue for volunteers and the Project has recognised the value of supporting and working closely with volunteers in order to sustain their interest and to motivate them in their work.
- The Project is clear that community participation has to be resourced if it is to be sustainable and effective. In particular, it is very difficult for local people to be representative and informed without access to ongoing resources.
- The engagement and training of PCTs in Wexford is seen to be critical to future community participation.

13. Finglas Community Participation in Primary Care (Finglas South Community Development Project) ■■●▲

Project Aims

- To explore different models of community participation through community information and consultation sessions;
- To establish a model for community representation and participation that engages with the most disadvantaged communities;
- To provide supports and training for effective community participation.

Background to the Project

Finglas is an area with high levels of poverty and social exclusion, with several parts (including Finglas West and parts of Finglas North and South) designated as RAPID areas. Finglas has higher than average unemployment rates, Traveller population, and lone parent families. A study carried out in Finglas by the Department of Community Health and General Practice (TCD 2003) found significant gaps in GP services, mental health service, services for older people, addiction support services, children's services, family planning and women's health services and in the provision of 24 hour primary care services.

The Project is a collaboration between Finglas South Community Development Project, St Helena's Family Resource Centre, Tolka Area Partnership, Finglas East Regional Network (of local community organisations) and the Community Development Section of the HSE. The Finglas area has extensive forums representing the voice of the community and this led the Project to consider what type, form and structure of community participation would best suit primary care, and what representative structure could facilitate this.

There will be twenty-four PCTs across six Primary and Social Networks in the LHO North West Dublin Area. Five PCTs are in the process of being established in Finglas (Network 1): Finglas West, Finglas North, Finglas South, Glasnevin and Ballygall/Finglas East. There are three health centres in this Network Area: Wellmount Health Centre, Ballygall Health Centre and Botanic Health Centre. It is planned that the five PCTs in the catchment area will form a CPWG, and that each PCT will have two representatives on the CPWG.

Project activities

1. **Steering Group.** A Project Steering Group was established to oversee the Project with representation from the four community organisations participating in the Project and the HSE. An Action Plan was developed for the Project.
2. **Consultation exercise.** A consultation exercise was carried out by an external facilitator to examine different models of community participation on PCTs and networks. A cascaded community consultation process was facilitated by and through the Finglas Breakfast Club, a network of community organisations in Finglas. Seventeen community development workers, representing different groups in the area, gathered the views of nearly 150 people in the community through focus groups and a questionnaire. There was a cross-section of the community, including travellers, people with disabilities, ethnic minorities, lone parents, and representatives from community networks. The community consultations aimed to identify the extent to which local people knew about the planned PCTs, to identify gaps in health services and to elicit views regarding community representative structures. The consultations were also an opportunity to provide information about primary care services and a briefing document about services was circulated prior to the consultations.
3. **Training on effective community consultation processes.** The seventeen Community Development Workers, linked through the Breakfast Club, were trained to carry out the consultations with local people. The training was carried out by an independent consultant with expertise in community consultations. The training also extended the consultation process to the wider community.
4. **Report on the proposed model of community participation.** An external facilitator and researcher produced a report of the consultations: 'Report on Proposed Model for Community Participation in Primary Care in the Finglas/Glasnevin Catchment Area', with proposals for different methods of and structures for community participation in primary care. The report identifies the need for PCTs to address current service gaps, provide locally based services and facilities, the provision of services 24/7, to ensure that clients are treated with respect, the provision of seamless services and to provide easily accessible information on health services.
5. **Community feedback meeting.** A community meeting provided feedback on the findings of the consultations and provided a forum to discuss and agree the most appropriate structure for community participation. Three options were presented. The first was an expansion of existing local forums/networks to include a health focus; the second was to establish an overarching Community Platform for Finglas (based on the model of Fatima United and Meitheal Forbartha na Gaeltachta/Comhar Dhuibhne); and the third was to establish two Community Health Forums in Finglas and Glasnevin, which could act as an interim arrangement while the Community Platform is being established. The second option of a Community Forum was the preferred option of local community groups and organisations.
6. **Community Health Forum.** A Community Health Forum has been created as a spoke of a planned new Community Platform in Finglas and twenty community representatives attended the first meeting. The first task of the Forum will be to develop an action plan on community health. The advantage of a Community Platform is that it brings together community development organisations and local agencies into one structure in Finglas, linked to the Community Platform in Dublin City Development Board. The Forum will be the mechanism for community representation on the local CPWG. The Community Platform has the backing of key stakeholders, including Dublin City Council, local CDPs, the HSE, the Director of Community and Enterprise of the Dublin City Development Board, Local Drugs Task Force and the Tolka Area Partnership.

The next stage will lead to the selection of community and PCT representatives on to the CPWG, the development of a communication strategy, the identification of training and supports required to sustain participation and the identification of mechanisms to ensure accountability. The Project has identified the need for new resources to carry out other activities including the holding of local health fairs to provide information and awareness of health care issues and promote community participation as well as resources to visit other projects that have well-developed structures for participation on PCTs. The Project has also

identified a need to revisit the Community Health Needs Assessment carried out in 2004 and update it.

Learning from the Project

- It has been a challenge for the Project to establish representative structures when the five PCTs are in the early stage of development. However, this has enabled the community to carry out preparatory work, build capacity and develop a representative structure. Even though the PCTs are not up and running in Finglas there have been excellent relationships developed between key people in HSE and the organisations involved in the Project Steering Group. This has proved to be critical to the success of the Project.
- The area that will be covered by the five PCTs is diverse. Some PCT areas have representative Forums, for example, in Finglas West, which is supported by Dublin City Council and Rapid, while Finglas North and Glasnevin have no local forums. Some PCT areas experience high levels of social exclusion, compared to the relative prosperity of Glasnevin.
- There are also issues regarding the HSE catchment area for the PCTs. These do not have the same boundaries as other service providers / organisations. For example, the five PCTs are spread across four Area Based Partnership catchment areas.
- The involvement of a wide range of organisations in the Community and Voluntary Sector in conducting the consultations has proved instrumental in securing a broad spread of community responses and engagement with the process. The Project has opened up a new space for community development as part of the process of primary care.
- The strong relationships between the HSE and community organisations have been particularly important; this includes the active support of the Transformation Development Officer (TDO) and the active participation of the HSE's Team Leader in Community Development.
- The Project has achieved a great deal because it was able to draw on external consultants to provide expertise, training and research, made possible through the Initiative.
- There is some learning from the process developed in this Project, particularly in identifying an appropriate representative structure. One of the key issues is that there is no overarching structure in the Finglas area from which to agree priorities with the communities overall and it is anticipated that the Community Platform will fill this gap.
- The consultations have found that community groups, forums and networks change over time and that existing forums require extensive support in developing and sustaining representative structures. The consultation process has been important in generating energy and interest in primary care. A key challenge will be to keep the momentum going, particularly in the light of reduced resources.
- A further challenge is to ensure that local people have the capacity to engage with the process; however, this has proved difficult with limited funding and resources.
- Finally there is clear learning from the Project that if there is a combination of commitment from community organisations and the HSE and resources to support activities, a great deal can be achieved. Sustaining this activity in the future will require staffing resources from the HSE, for example, from Community Development Workers, as well as resources from local community organisations to provide support, training and capacity building to enable community participation to be community-led.

14. Pavee Point ■■●▲

Project Aims

- To promote and ensure the community participation and inclusion of Travellers in PCTs
- To inform and strengthen HSE initiatives addressing the links between poverty and health inequality in the Traveller community.

- To enable members of the Traveller community to link in with and participate in local PCTs and networks
- To design and implement a pilot training programme and develop guidelines on a model of best practice in partnership with HSE staff (PCTs) and Traveller Community Health Workers in the Eastern Region.

Background to the Project

Pavee Point is a partnership of Irish Travellers and settled people to improve the lives of Irish Travellers, of which health has been a key area of priority. Through the Primary Health Care (PHC) for Traveller's Project, established in 1994, Pavee Point has giving a focus to improving the health status and quality of life of Travellers and to addressing the social determinants of health and inequalities in health from a human rights perspective.

Travellers experience significant inequalities in health status, while racism, discrimination, poverty and social exclusion, and their unique social and cultural identity raises specific health needs. The Traveller National Health Strategy (HSE 2002) and the Intercultural Strategy in Health (HSE 2009) have documented the extensive inequalities in health experienced by Travellers. It is anticipated that the outcomes of the All Ireland Traveller Health Study, commissioned by the Department of Health, will provide important up-to-date data about the current health status of Travellers in Ireland. Primary care is particularly relevant to Traveller health and poor access to primary care services has been documented by Pavee Point.

Through the PHC for Travellers Project there has been active partnership and participation of Travellers and their representative organisations in developing community-led responses to health care. Training is provided to develop the skills and capacities of Community Health Workers to provide community based health information and health promotion and to improve access to and engagement with health services. The Project works with a social determinants of health model and has a specific a focus on health inequalities. A key objective is inter-sectoral collaboration to improve the economic, social, environmental, political and cultural issues that impact on Traveller health status and access to health care services. In this regard community participation is defined as a process by which Travellers have more control over these factors impacting on health by participating at all levels of decision-making in order to improve awareness of health services and promote health and well-being in the Traveller community.

The Project anticipated working with the ten PHC for Traveller Projects and with specific PCTs in the region in order to develop a model for engagement between PCTs and the Traveller Community. After consultations with PCTs, a Pilot Project was identified in the Wicklow area for a model for engagement between PCTs and the Traveller PHC Project in Wicklow.

The ten PHC Projects in the region employ 14 coordinators, five assistant coordinators, fifty-five Community Health Workers and thirty trainees.

Project actions

1. **Consultations with Travellers.** The Project has drawn on a wide range of recent consultations held with Travellers and policy documents to identify health needs, which have been summarised and documented in a position paper on Primary Care for Travellers. The position paper is intended to inform PCTs of Traveller health needs. Key issues highlighted in consultations include the impact of poverty, social exclusion and Traveller culture and identity on access to health care services. Specific health concerns have been identified in relation to mental health, suicide, addiction and poor access to primary health care services.
2. **Awareness raising resource materials.** The Project has developed and draws on a set of resources to promote awareness of Traveller health issues in a primary care context, which have been designed in partnership with Travellers. This includes a number of training modules relevant to Traveller health, covering factors impacting on Traveller Health such as suicide awareness, cardiovascular health and cancer prevention. This will form the basis of training for Community Health Workers. Resources for PCTs have also

3. **Pilot Project with Wicklow PCT.** A Pilot Project has been established with Wicklow and Bray Traveller health Projects to train members of three PCTs in Wicklow. This required a great deal of effort on the ground to engage with and build relationships with the PCTs and to gain their buy-in to the Project. A training programme has been developed that will be delivered by Traveller Community Health Workers and will form the basis for relationship building and engagement between Traveller health Projects and PCTs. It is anticipated that this will be a two way process, first, by up skilling PCT members as a model for other PCTs across the country, and, second to raise awareness of the role of the PCTs in Traveller PHC Projects.

Learning from the Project

- There is huge learning and experience from the Traveller PHC Projects across the country, which form a basis upon which PCTs can engage with the Travelling community. The Project partners are aware that a lot of information and awareness raising of Traveller health issues needs to be carried out nationally, regionally and locally, including information about the location and contact points for Traveller Community Health Workers attached to Traveller PHC Projects.
- Awareness raising amongst PCTs is considered to be crucial if engagement with Travellers is to become a meaningful in a primary care context. To date there has been limited engagement of PCTs with Traveller health issues. This has led Pavee Point to highlight the need for the HSE to develop robust and measurable performance indicators for Traveller community participation.
- There is a lot of ground work that needs to be carried out in building relationships and trust with PCTs, particularly because it is the experience of Pavee Point that Travellers are often not included in community consultations and invited to participate on Community Health Forums.
- The Training Pilot Project that is in development in Wicklow has highlighted the importance of spending time on the necessary ground work to develop relationships and engagement as a basis for raising awareness about Traveller health issues and Traveller culture.
- The Project partners have highlighted the importance of developing trust and relationship building between the HSE and Travellers at national, regional and local levels. Having a representative structure at all of these levels, and a voice to inform policy, are seen as critical to the ongoing community participation of Travellers in PCTs.

15. Lifford Clonleigh Resource Centre ■■◆◆●●▲▲

Project Aims

- To build on the comprehensive model of community participation to ensure the continued development of effective community participation in primary care in Donegal;
- To undertake joint training and joint projects between community representatives and staff in PCTs;
- To influence local, regional and national policy.

Background to the Project

The Project has built on a comprehensive model of community participation based on a CPAG, whose membership is drawn from local Community Health Forums, CDPs, and HSE representatives from Primary Care, Community Development and Social Inclusion. The

Group is responsible for ensuring the continued development of effective community participation in primary care in Donegal.

Lifford-Clonleigh Resource Centre and the HSE in the NW have been working on community participation in primary care since 2003 and are widely regarded as being a model for other projects. The Resource Centre is a CDP and works in a rural area of low population density, an active community sector and higher than average numbers of older people and people with medical cards. Substantial HSE resources have been devoted to the development of Community Health Needs Assessments and community representative structures in the area.

The initial Pilot Project took place in Lifford-Castlefinn and this received ongoing support from the HSE in the NW, and external funding initially as part of the Primary Care Pilot Implementation Project, and later through funding from the Building Healthy Communities initiative. The Lifford Primary Care Implementation Project included community consultations and multidisciplinary Team building.

Community consultations took place with a range of disadvantaged groups and a community need assessment was carried out by a Public Health Nurse who was seconded from the HSE to work on the assessment. Particular needs were identified for services for young people, including sexual health, teenage pregnancy, positive mental health, and services for older people. The needs assessment and feedback from local communities helped to identify key issues for development, for example, activities in the area of diabetes, support to older people and their carers, and services for people with dementia. The utilisation of a community development model has contributed to enhancing the voice of people from disadvantaged communities. The engagement with the local community and service users through consultations and focus groups led to the establishment of a Community Health Forum, with two representatives nominated onto the Lifford-Castlefinn PCT.

Since the establishment of this ground-breaking Project, four PCTs have participated in the Community Participation Project in Lifford-Castlefinn, Ballyshannon-Bundoran, Finn Valley and the Lagan Valley. Four Community Health Forums have been established to participate in the four PCTs, which are coordinated through and represented on a GPAG. The learning from and the procedures and structures developed in Lifford-Castlefinn formed basis for establishing these other three Community Health Forums.

PCT development training has been carried out with PCTs in Donegal, and the objective is to ensure that Teams are aware of the benefits of community participation as part of the Team development process. There has been a very positive engagement with the GPs in the process of community participation on some of the Teams.

Project actions

- 1. Development of the Community Participation Model.** The community participation model has been developed through a County CPAG, made up of community and HSE representatives and community representation on each of the four PCTs. The Project has worked across the four PCTs and has built on the work already undertaken in the County through joint training and joint projects, by bringing together PCTs and the Community Health Forums in each of the PCT areas of Lifford-Castlefinn, Ballyshannon-Bundoran, Finn Valley and the Lagan Valley. The CPAG has become an important forum for networking and discussion, including the identification of strategic goals and objectives.
- 2. Establishment of a County Network.** Three meetings of the newly formed County Network have been held and have provided an important source of support and networking for Community Health Forum members. The networking sessions were organised and attended by the HSE and community representatives of the initial four, and currently eight, Primary Care areas. These meetings have been very important for information sharing and supporting the development of community representation on the LIG. The development of an action plan for the PCTs has been discussed and further work is being carried out on this.
- 3. Representation on the LIG.** Community participation is now an agenda item at each LIG meeting and community representatives have been nominated to sit on the group. While some representation was in place at the start of the Project, the Project has sought to strengthen participation and to further develop partnership approaches to this work. To

4. **Capacity building.** One of the main actions carried out in the Project has been to build the capacity of the County's CPAG and of community representation on the LIG. This has enabled community representatives to be better placed to inform primary care policy.
5. **Specific projects.** As a way of engaging community representatives and PCTs in tangible outcomes specific projects, in Lifford/Castlefinn and Finn Valley, have been put in place in local communities. Examples include projects on adolescent mental health, meals-on-wheels and a parenting programme. However, to implement the projects at community level it has been necessary to identify new resources to coordinate the projects as there are insufficient resources within existing community groups to resource this.
6. **Policy work.** The Project has engaged in a range of activities to influence local and national policy. One example is that the CPAG commissioned a survey of the economic benefits of community participation in two PCT areas, covering 125 organisations. The research, *The Economic Impact on Health of the Community and Voluntary Sector in Donegal*, has been critical to providing evidence of the benefits of community participation to saving resources in health care. The outcomes of the survey were presented to the LIG and recommendations are being developed by the LIG.
7. **Community Health Needs Assessments.** In order to update the Community Health Needs Assessments carried out in 2004, a questionnaire has been circulated to groups. 250 questionnaires have been returned to date. It is planned that the PCT will devote a day to discussing the findings of the survey.

Project learning

- The Project has had real benefits across Donegal County and a system of engagement created at County level that is linked up through a County-wide network. This is a structure that is considered to be sustainable for the future.
- The Project enabled a facilitator to be appointed to progress joint work through the networking events and the CPAG. This role has been crucial to progressing joint work across the Project. Having external facilitation is seen to be crucial not just for the Community Health Forums but also for PCTs.
- Joint work between the community and PCTs needs to be driven and coordinated. This requires time and resources to be put in place. The Project has achieved this joint work in two Teams through a seminar to gain the views of how the Community Health Forums and the PCTs can work together, with areas identified for development.
- A key element of the success of the Project relates to the ongoing resources that have been devoted to supporting community participation, which has created a positive momentum of activity and engagement. Two part-time development workers are employed to work directly with the community and to support the process of community participation. Sustaining this will require these resources to be continued in the future. This is a particular issue in the implementation of new projects that have been agreed by the CPAG, and has raised the need for additional resources to coordinate and implement new projects on adolescent mental health and parenting.
- The experience of the Lifford-Castlefinn Project and the successful outcomes achieved does show the importance of having a key person managing and driving PCTs. When the manager left the Project to work in another part of the country much of this momentum was lost. Therefore, having a TDO who is engaged in championing the role and development of the PCT and in providing leadership in community participation is important learning for other Projects.
- Community representatives have played a very active role on the PCTs. This has been based on a huge amount of time and effort to gain respect, trust and support from HSE and PCT members. For example, the Lifford-Castlefinn PCT is chaired by the Community Coordinator from the Lifford-Castlefinn Resource Centre and the community plays a very active role in leading community based developments. A key element of this has been to

- Community representation on the PCTs has been supported by Community Development Workers, who also sit on the PCTs. The Community Development Workers are very clear that it is important to provide this support role on the PCT, in giving confidence and support to community representatives, particularly as they come from disadvantaged communities.
- The Project has benefited from the active involvement and championing of the process by the Social Inclusion Manager in Donegal. She has not only supported the process from its inception, but has brought expertise and knowledge to the community. She has played a key role as a 'broker' between the community and the HSE and plays a pivotal role in the LIG in enabling the community to participate, for example, through her knowledge of HSE structures and policy.
- The CDPs participating in the Project have highlighted the importance of locally representative Boards of Management to the process of community engagement and participation. In particular, having independent and autonomous Boards, drawn from local people from marginalised communities, has enabled the CDPs to work actively with target groups from marginalised communities. However, there are concerns that the integration of CDPs into the Donegal Development Company will have a negative impact on this community engagement process.
- While spin-off projects have been very important to developing joint work and activity between community and PCT representatives, an issue is raised about the fact that these do not engage directly and become integrated with HSE structures and the monitoring of service developments, and are often run as a parallel set of actions. One of the issues raised by community representatives is that the process really does not engage with service planning issues.

16. Iorras Le Chéile, Belmullet

Project Aims

- To establish meaningful participation with people who are marginalised and living in Erris in the planning, design and implementation of primary care;
- To create a Community Health Forum with representation for disadvantaged groups.

Background to the Project

Erris PCT was one of the HSE's original national Primary Care pilot Projects in 2002. Although this has helped to establish primary care services in the area, not all members fully appreciated the value of community participation at the outset of the Project. Nevertheless, there are some champions in primary care who helped to progress community participation. The community view this engagement to be critical to success. The Erris PCT has carried out a health needs assessment.

Iorras Le Chéile CDP, based in Belmullet, Co Mayo, was established in 2003 and has been working on a range of health related issues from a human rights perspective. A particular focus has been given to mental health in the area because of high rates of mental ill health and suicide in the community. The promotion of positive mental health has been identified as an important area for primary care, since this is recognised as being crucial to quality of life and participation within the community. A Working Group was set up to promote positive mental health in the area and peer-led support groups have been established, as well as projects on women's participation in decision-making, domestic violence, and drug and alcohol addiction amongst young people. Over 100 people in Erris have also been trained in ASIST Suicide First Aid.

Project actions

1. **Community Participation Steering Group.** A Steering Group made up of Project partners was established at the start of the Project. The Group worked in a collaborative way and notes of meetings were taken by the Health Promotion Officer. A good level of mutual respect and understanding of the different backgrounds of community and HSE members was established. The ground work carried out in the Steering Group enabled the Project to present a 'united front'.
2. **Community consultations.** During an eight month period community consultations were held with local people. This began with a consultation in each of the four parishes in the area. The meetings were widely advertised in local media, church bulletins, community groups, sports organisations, schools and local agencies. The meetings were organised around the theme 'Your Health is Your Wealth' and were organised in partnership with community voluntary and statutory agencies in the area and the PCT. At each public consultation people interested in participating in a Health Forum completed 'expressions of interest' forms. A final public consultation was held to discuss people's expectations of the Forum and community organisations and the PCT gave presentations of the challenges and benefits of the Forum, as well as identifying gaps in healthcare services arising from the consultations. During this time the Project partners consulted with local community groups and attended local events to publicise the proposed Erris Community Forum. The final consultation 'Shaping Health Care in Erris' was also an opportunity to launch the Project and received significant local medial coverage. Radio advertising was a critical success factor in getting people to attend the event and also for building awareness and information about the Project in the community. The event was attended by PCT representatives, the HSE, local people and community representatives. From this thirty-two people put their names forward expressing an interest in participating in the Erris Community Health Forum.
3. **Erris Community Health Forum.** Prior to establishing the Forum meetings were held with the representatives from the PCT and Iorras Le Cheile and the HSE's Health Promotion Officer. This formed the basis of a plan for the community consultations and identification of target groups for representation on the Forum. Target groups identified included carers, lesbian and gay community, men, migrants, older people, parents, people parenting alone, people who are socially isolated, people with a chronic illness, people with intellectual disabilities, people experiencing mental health difficulties, people with a physical or sensory disability, women and young people. Following the consultations and Project launch (discussed above) an Erris Community Health Forum was established and was attended by community representatives at monthly meetings. The Project recognised the importance of having representation from a range of groups in the community such as lone parents, survivors of domestic violence, people with mental health difficulties, lone parents and migrants. The feedback from the Project is that the Forum is working very well.
4. **Building the capacity of the Community Health Forum members.** A sub-group of the Project Steering Group was established with representation from the community and the PCT, with an external facilitator, to clarify the roles and objectives of the Forum. A training needs assessment was carried out as a basis for training potential Community Health Forum members, and this was followed up by training in Team building. Terms of reference and operating rules for the Forum were subsequently agreed by the Forum. The time devoted to this was considered to be very important in ensuring that community representatives have ownership of the process. Since then Team building sessions have been held, focussing on officer roles and responsibilities and an introduction to community development, and Forum members have participated in ASIST suicide awareness training. The creation of the Community Health Forum, with thirty-two members, is considered to be a significant achievement, particularly because of the dispersed rural community from which membership has been drawn.
5. **Representation on the PCT.** It has been agreed that two members of the Forum will attend PCT meetings as equal partners. These representatives were elected following the initial training and Team building.

Learning from the Project

- The Project built on a solid basis in the community and good relationships with other agencies in the area. Importantly, the Project enabled community organisations and the HSE to develop a new set of relationships, resulting in the building of mutual trust, respect and clear lines of communication.
- Community development principles have been integral to the Project and to embedding the process in the community and to building sustainable change. It is recognised that without this process change would be piecemeal. At an early stage in the Project it was agreed that time needed to be devoted to the process of engagement and in building a solid foundation to ensure sustainability. Having clear goals, established from the outset, was seen as critical to moving the Project forward.
- The Project found that it has taken longer than expected to develop partnership working. Time was needed to break down the fears expressed by the PCT members about community participation. This was also necessary to reconcile expectations and resolving tensions between community organisations and the PCT.
- The good relationship between the community and HSE TDO, the Health Promotion Officer and PCT members have really helped the Project to progress well, particularly because these representatives have acted as champions for community participation.
- Key issues arising from the community consultations concern social isolation and transport, which has implications for services outside of the PCT, for example, the County Council. There is also scope for the Community Health Forum to act beyond the remit of the PCT and to extend to issues concerning hospital care, particularly in the light of the formation of the HSE Integrated Service Areas. The Project has also raised the need for representative structures to be established in the HSE for specific care groups, for example, older people.
- A number of issues have been raised on the Forum regarding representation, particularly how to ensure that there are representatives from target groups and geographic communities. The Project agreed on the need for the establishment of clear terms of reference, setting out the roles and expectations of representatives, and to build in effective feedback mechanisms.
- While the HSE has been an active partner in the Project, there are implications of how the model developed in Erris can be developed and implemented in other PCTs. The HSE's TDO has raised the difficulties that this presents to the HSE, particularly because there are no Community Workers employed by the HSE in Mayo. While the Health Promotion Officer played a key role in training and in identifying the need for attention to be given to the broader determinants in health, her capacity to provide this role to other PCTs remains limited. This is also an area that needs to be prioritised by the LHOs and to ensuring that resources are made available for community participation.
- The Project highlighted the importance of having the resources to employ an experienced external facilitator to build the capacity of the Community Health Forum. There is also learning about the importance of ensuring that times of training and Forum meetings meet with the time schedules of participants.
- On reflection the Project has identified the need to map the availability of services in the area, and consider that this would need to be carried out at the start of a Project. A further issue identified is the need to examine whether the needs assessment carried out two years ago needs to be updated and taken back to the community.

17. Offaly Local Development Company and South Offaly PCTs



Project Aims

- To develop community participation in the planning and delivery of primary health care services in the South Offaly PCTs catchment area;
- To carry out community consultations to identify health needs;
- To establish a Community Health Forum

Background to the Project

The Project builds on successful ground work carried out by the Offaly Local Development Company as part of the Building Healthy Communities initiative. A unique feature of the Project is that an Inter-Agency Group has been established with representation from Offaly Local Development Company, including the rural development programme, the HSE (Health Promotion), Offaly County Council, Offaly County Childcare Committee, Offaly Sports Partnership, the VEC and FÁS. This has enabled the Project to engage with the broader determinants of health and introduce coordination actions in local communities to good effect. Consultations with local disadvantaged rural communities were previously carried out in a number of target communities in West and South Offaly to assess health needs and to promote community participation. The publication *The West Offaly Way* (West and South Offaly Building Healthy Communities Partnership 2008), set out the findings of the consultations, with identified health needs, recommendations and a framework for a population health model focussing on inequalities in health. The Community Participation in Primary Health Care Project grew out of this initiative and the initial ground work established an awareness and expertise of community consultations in addressing rural isolation and health inequalities.

The Project has been developed as a partnership between Offaly Local Development Company and the South Offaly PCTs, with active support from the TDO. Despite some difficulties in the formation of the Teams, with regard to funding for IT resources and the fact that the Team is virtual, there is openness to community participation. The active involvement of the social worker from the Birr Team has been particularly valuable, particularly in the joint organisation and facilitation of focus groups and consultations in the community.

Project actions

1. **Community Participation Working Group (CPWG).** The first step was to establish a CPWG with representatives from Offaly Local Development Company, the HSE, the Building Healthy Communities Steering Group, Birr PCT and the local communities of the area.
2. **Community Participation Plan.** The CPWG prepared a plan to conduct a community health needs assessment and to facilitate community participation on the PCTs.
3. **Public information and consultation session.** A public information and consultation session was held in Birr at the start of the Project and was attended by over 50 people. This helped to create awareness of the PCTs and to signal to groups that consultations would be taking place. Work was carried out to inform groups on the ground in the area and leaflets and flyers were circulated to groups and organisations in the area.
4. **Community Health Needs Assessment.** A comprehensive Community Health Needs Assessment has resulted from extensive consultation in the community, a questionnaire to community groups, service providers and school principals. An important part of the consultations was to inform groups about primary care services. Sixteen target groups were consulted with through focus groups and interviews, which were facilitated by members of the working group. The consultations captured a broad range of perspectives on the needs of the area, with a specific focus on the determinants of health. The consultations highlighted a range of health issues, including the key problem of drug addiction in the Birr area. This has resulted in an addiction counsellor joining the Team.
5. **Feedback session with the community.** The findings from the focus groups were collated and a feedback session was organised to inform the community of the findings of the needs assessment, identified gaps in services and to present a vision and action plan for community health in South Offaly. Feedback was given under the headings of information and community education, play and recreation, built environment, transport, support for community groups, support for young people, parenting, unemployment, parenting alone, older people, Travellers, non-Irish nationals, small holders, mental health

6. **Community participation included in PCT development training.** PCT development training has been carried out by the HSE Midlands performance and development unit (four half days), which has set out the roles and visions for the Teams, as well as sessions on the determinants of health, community needs, participation and consultation. The training has helped to enhance the engagement of the PCT with the community and facilitate community representation at the monthly development meetings.
7. **Establishment of a Community Health Forum.** A South Offaly Community Health Forum is currently being established with community representatives from the South Offaly Area Network Community Forum, the West and South Offaly Building Healthy Communities Project, and from the Birr and Sinrone/Moneygall PCT areas. The community representatives were carefully selected so that there was representation from the communities where gaps in representation existed. The Forum is being facilitated and supported by Offaly Local Development Company and the Primary Care Development Officer. A simple and accessible Action Plan will be developed for the Community Health Forum and it is anticipated that the forum will meet initially for one year and be reviewed in 2011.
8. **Community representation on the PCTs.** Participation on the two PCTs in South Offaly is planned for the future, as the Teams are still in development. However, the social worker from the PCT and the Primary Care Development Officer will attend the Community Health Forum in order to sustain the relationship between the community and the PCT.

Project learning

- The joint approach to project planning has been very valuable (including South Offaly PCTs; HSE; Offaly Local Development Company/Building Healthy Communities Project Worker / local communities).
- There has been a very positive engagement between the PCTs and community representatives, and the presence of the PCTs at the community consultation events was viewed very positively by community participants. This two-way process enabled the PCT to provide information about services and for the community to identify health needs.
- The need for a local champion on the ground in the PCT was crucial to the success of the Project. The social worker on the PCT played a key role in this respect. In addition, an HSE Health Promotion Officer provided valuable input into the social determinants of health and an HSE researcher assisted in the design of the questionnaire.
- Having a dedicated community development worker in the Offaly Local Development Company has been crucial to providing supports to the community, the planning and running of community consultations and events, and in facilitating the Community Health Forum.
- The Project has demonstrated that significant amounts of time have to be devoted to community consultations and in engaging with groups on the ground. The Project has identified the need to carry out a mapping process at the start of community consultations in order to identify which community groups fall within the geographic remit of the PCT.
- Providing training for the PCT members is seen to be crucial in raising their awareness of community participation and community health needs. Specific issues have been identified by the PCT about having time and resources to effectively engage with the community.

18. Follain Community Health Project, Waterford

Project Aims

- To promote the active involvement of service users from disadvantaged communities in the development of primary care services in Waterford City
- To raise awareness in disadvantaged local communities of the services that will be provided by the new PCTs
- To develop active involvement of services users from disadvantaged communities in the development of local services in Waterford City

Background to the Project

The Follain Community Health Project grew out of a wider women's network in Waterford. A Community Development Worker was employed on the Project, although funding for her position ended in 2009, leaving the Project with no paid worker. However, the community participation Project has continued to be managed by the voluntary management committee of Follain. The Project has worked closely with local community organisations, including three CDPs in Waterford.

There is currently no TDO in post in Waterford and this has led to problems in engaging at PCT or HSE level. One PCT has been established in Dungarvan and the West Waterford Team is currently operating in an unofficial capacity. There is also a newly established health centre, the Waterford Health Park based on the Rowe/Creavin GP practice, which is the largest health centre in the country. The Project decided to focus specifically on the relocation of primary health care services to the Waterford Health Park.

The restructuring of primary care services to facilitate new PCTs provides the backdrop to this Project. This Project sought to raise awareness of these changes to counteract potential fears and misunderstandings within disadvantaged communities about changes in service delivery, location, and how they will impact on service users from communities experiencing disadvantage.

Project actions

1. **Community Participation Steering Group.** A Community Participation Steering Group was established by the Follain Community Health Project, Waterford Partnership and the HSE's Senior Community Officer to oversee the Project and its development.
2. **Community Participation Working Group.** The initial objective had been to establish a Working Group, with representatives of the community partners and members of the PCT, in order to design a workable model of participation for Waterford. An initial meeting took place in May 2009 between the Folláin Co-ordinator, the Community Facilitator, the Director of Public Health Nursing, who was the previous TDO at the HSE South East. However, the PCT had not met regularly and there has been limited work carried out in developing the Team owing to the fact that the TDO had returned to her post as Director of Public Health Nursing. As a result the Project decided to contact individual heads of departments of the PCT members, inviting them to join the Working Group and permission was sought from the Chair of the Primary Care Implementation Team to carry this out. This resulted in a meeting of the PCT members, the Community Facilitator and the Coordinator of Folláin in July 2009. Members of the PCT were very supportive of the Project and appreciated the opportunity to come together and meet with the community.
3. **Planning process and development work.** An independent Community Facilitator, with a background in community development, was appointed to assist in the organisation of and to carry out the consultations. Informal meetings took place between the Facilitator and interested parties as a basis for organising public meetings, including the venues, equipment needs, dates and agendas. As part of these meetings the Facilitator raised awareness of the value of community participation and used examples from Donegal of community participation in primary care as a basis for this. The consultations aimed to involve service users from disadvantaged communities and organisations whose target communities use the Rowe/Creavin practice in Waterford City. This included Ballybeg CDP, Larchville and Lisduggan CDP, Waterford Traveller CDP, and members of the Waterford PCT. St Brigid's FRC were also included in the work during the planning process. The meetings were publicised through letters sent by the GP practice to service users, community notices in the print media, community notices on local radio and through the networks of the CDPs, the HSE and Folláin targeted through focus groups, posters and word of mouth.

4. **Community meetings.** A community development approach has been used to consult with the community through open meetings in the community to raise awareness of primary care services. The two main objectives set out at the beginning of each public meeting were to raise awareness of PCTs and to discuss the role and benefits of community participation in the PCT. The aim was to counteract potential fears and misunderstandings within disadvantaged communities about changes in service delivery and the location of services. The three CDPs hosted the public meetings in their three communities. The meetings attracted a total of 51 people: based in the areas covered by the Larchville/Lisduggan CDP, Inner City/Rapid Areas and the Ballybeg/Traveller Project. A social care allowance was provided to participants. The meetings were organised around a question and answer session with the Facilitators. A lot of issues were raised in relation to the re-location of the GP practice and services that would be provided, and a definite interest was expressed by participants about participating in the process further.
5. **Public meeting.** Following the local community consultations a public meeting was organised, which provided an opportunity for PCT members to meet with service users. It coincided with the relocation of the GP practice and primary care services. The meeting also gave local people an opportunity to gain information and awareness of the objectives in relation to community participation on the PCT. PCT members involved in the meeting included the Community Dietician, Health Promotion Officer, Occupational Therapist, Physiotherapists, Public Health Nurses, Speech and Language Therapist, the GP and the Business Manager from Rowe/Creavin Practice. The meeting focussed on issues related to the move of services to the new location and identified issues of personnel, transport and service provision, particularly in relation to treatments available to private patients and to medical card patients. Although there was low attendance at the meeting, there was an informal atmosphere and service users were able to get a sense of how they could become involved in the PCT.
6. **Information sessions with local community organisations.** Because of the interest in the local community about primary care services the Project provided a number of information sessions to local groups linked to the CDPs, providing an overview of services, referral procedures and contact details for PCT services. In addition to these information sessions the Project has facilitated information sharing between the GP practice, HSE staff and community organisations.
7. **Representation on the PCT.** Discussions have been held with community representatives about what would be an appropriate model of community participation on the PCT. It was agreed that rather than establish a new stand-alone Community Health Forum that the structures in place under the Follain Project were deemed appropriate as a Forum, as it could play a coordinating role to support and develop community participation on the PCT. It is planned that community representation will involve representatives from CDPs and community organisations. Because of the early stage of development of the PCT it is not anticipated that community participation will take place in the immediate future. Training has been provided by staff in the Follain Project and the independent Facilitator to prepare and develop the skills for community representatives in areas such as representation skills, advocacy and health information. It is anticipated that further training will be needed to enable community representatives to play an active role on the PCT in the future. PCT members and the GP practice have been very open to community participation and to engaging with the community around the social determinants of health.

Project learning

- Despite the fact that there was no TDO in place and that the Team was not fully functioning, the experience in Waterford was that early engagement with Team members paid off. In fact it appears that the pro-active role taken by the community has helped to bring the PCT together, and also to engage the GP in the local health centre.
- The Project has benefited from the active support of and the participation on the Project Steering Group of the HSE Community Development worker in Waterford of the three CDPs in the areas. This has enabled the Project to engage with a large potential community and to ensure that the three participating CDPs also had ownership of the Project.

- The independent community Facilitator has provided a pivotal role in the Project and has been key to the process, particularly because a significant amount of ground work, preparatory meetings and negotiations had to take place in the early stages of the Project. It appears that very skilful work was carried out, with positive outcomes.
- The Facilitator highlighted the difficulties faced in coordinating a large number of personnel, particularly because the Team was not meeting and in the light of communication problems between members of the PCT. This led to significant amounts of work to involve the PCT members, particularly in the light of the fact that there is no TDO in post and the Primary Care Implementation Team is not meeting regularly. This led to significant challenges in identifying, contacting and engaging personnel. Nevertheless, this time consuming work paid off and there was benefits gained from holding one-to-one meetings with PCT members and this resulted in a very successful meeting between the PCT and its service users. One of the successful outcomes of the community consultations is that a common language and a shared understanding between the community and HSE representatives, for example, in areas such as the impact of poverty on health, was developed.
- The difficulties for the PCT relate to staffing issues and staff changes and in some cases no replacement of staff that have left. The involvement of the HSE Community Development Worker was hugely important, particularly when there was no other HSE person to liaise with.
- Significant amounts of work went into the publicising the public meetings, through coverage in the media, notices in CDPs, and phone calls to service users. The turnout was considered to be lower than expected. However, representatives from CDPs also provided feedback to their local communities. It appears that those attending the meeting engaged fully, the feedback on the format used for the meeting worked very well.
- The learning from the Project is that community participation needs to be tangible and clear to the community; it appears that many local people found community participation hard to grasp in the early stages. There is also learning for community representatives in their engagement with PCTs and that is that it not the role for community groups to be liaising between PCT members, particularly where there are internal or communications difficulties.
- The approach taken has had very important results with regard to informing and engaging with the PCT, and particularly the business manager and GPs in the health centre. The Project saw a discernible shift in perspective of HSE representatives and a willingness to engage in the process. This is a particularly important achievement, in the light of there being no TDO in post.
- There has also been a wider community impact from the work carried out by Follain, for example, in feeding health promotion information into the RAPID areas and linking into HSE workers in the community.
- Finally, the ending of funding for the post held by the Follain Community Health Worker has meant that the Project has been sustained through voluntary activity of the Follain Board. The Project partners are very clear that it is essential to have a support worker on the ground to sustain community participation and to support the development of the Community Health Forum.

19. South Tipperary Community and Voluntary Forum



Project Aims

- To promote community participation in PCTs in South Tipperary by building the capacity of community groups and PCTs;
- To work with local communities to raise their awareness and understanding of PCT roles and processes;
- To establish community participation in the PCT in Cashel;

- To raise awareness of the social determinants of health and their relationship to primary care.

Background to the Project

The Project has been developed as a partnership between the South Tipperary Community and Voluntary Forum and the HSE. Nine PCTs are being established in South Tipperary, one of which is well established (Cashel). Five other Teams have commenced clinical Team meetings. The remaining three Teams are at development stage. There has been limited engagement of GPs in the process to date. Consequently there were significant variations in the readiness of PCTs to engage with the community. A decision was made to locate the community participation Project in Cashel, which had previously been a national Primary Care Pilot Project. This posed some challenges for the Project as Cashel is an area that has limited history of community and inter-agency task groups. The local FRC has provided an important connection for the Project, but only covers the urban area and not the rural catchment. By contrast, the three RAPID areas in South Tipperary have a stronger community interagency infrastructure.

The South Tipperary Community and Voluntary Forum was established in 2000 to represent the community and voluntary sector on South Tipperary County Council. It is the community partner in the Project and has liaised closely with community organisations in the County. A priority was given to developing training and support for PCTs and to build links between the community and the Teams. The Project drew on a range of resources and consultations that have been carried out in the area, including the Social Inclusion Profile carried out as part of the Cohesion process in South Tipperary in 2008.

Project actions

1. **PCT awareness raising.** Awareness raising on community participation has been carried out at PCT and LIG level and community representatives have met with PCTs in Cashel and Clonmel. Staff from the HSE's Health Promotion and Community Work Departments have played an active role in Team development and awareness raising on community participation, and it is anticipated that this will provide the support and direction for community participation on PCTs in the longer-term.
2. **Community information and awareness raising.** The Project has devoted a great deal of time in raising awareness of and providing information about PCTs through local community networks, via members of the Community and Voluntary Forum, through the newsletter and a dedicated mailshot by the Forum, local media, the RAPID Health Sub-Group in the three RAPID areas, and through Community Education and Community Development networks.
3. **Community training and consultation process.** An Interagency Forum was established in Cashel, facilitated by the Social Work Department, to develop training to promote an understanding of the social determinants in health and to carry out a needs assessment. The programme of training has been developed, run and facilitated by CAN. Participants on the programme have been drawn from the Tipperary Community and Voluntary Forum and community representatives in the Cashel area. PCT representatives from Cashel and the social worker from the Clonmel PCT also attended the training. The training provided the skills and capacity for representatives to carry out a local consultations, training and focus groups with their own local communities and groups. The social workers from Clonmel PCT were actively involved in the process and the training was cascaded across to members of the Clonmel PCT. Once the consultations were completed these were then brought back to the group in a final training session. This spin-off training was delivered in Slieveardagh, Carrick-on-Suir and in Clonmel. It is anticipated that the training and consultations will be the basis upon which a Community Health Forum is created in Cashel and provides a model for community engagement that will be cascaded to other PCT areas.
4. **Representation on the PCT.** Two representatives were elected from the South Tipperary Community and Voluntary Forum to sit on the LIG in South Tipperary. This has been a positive experience overall, and as one HSE representative stated 'this brings a different dimension and voice into the work of the LIG'. However, there have been some challenges for the community representatives. Discussions have also commenced for

Project learning

- There has been huge learning from the community participation Project and this has helped to build understanding of community objectives, expectations and the constraints that the HSE faces. In particular, there has been important learning about the time needed to embed the process of community participation.
- The Project has benefited from HSE support for and commitment to joint working from the start. It is interesting that the community representatives and HSE representatives (Community Worker and TDO) worked together from the start of the Project and have seen their journey as a joint one. This extended to the training and a joint approach to community consultations.
- An important element of learning from this process is that both community and PCT representatives have had to define clearly their roles and backgrounds. The strong support for the Project from the HSE Community Worker and the TDO has been very important to the success of the Project.
- Working with a well-established and well developed Team in Cashel meant that the Team was in a position to open up to the community; this level of engagement would not have been possible for Teams that were in the process of development. Having robust internal structures and effective Team development has proved important and has enabled the PCT members to have confidence to engage in new ways with the community.
- The representation on the LIG group has proved very important. Because the LIG group plays a strategic role, it has provided an open door for the community to feed into the process at a strategic level. However, one of the issues is that the LIG meetings tend to be very detailed and deal with internal issues rather than overall strategy. These issues will be addressed when the planned sub-group on community participation is put in place. It is anticipated that this will enable more of a focus on strategic policy issues rather than operational issues, including community participation.
- According to the Community and Voluntary Forum “The process of establishing PCTs is much longer and more onerous than we had envisaged...It is far more complex than we envisaged and PCT establishment has been far slower”. Their experience is that it was not appropriate to look for community participation at the start, particularly because the HSE staff were unsure of their own roles. For example, meeting the Clonmel Team at their first meeting was found to be not appropriate, whereas the meeting with the well established Cashel Team was a positive experience as “they were open and interested in working with us”. As a result the Community and Voluntary Forum have expressed concerns about involving communities in a structure that is not well bedded down and thus creating expectations which cannot be fulfilled in the current structure. As a result the community decided to refocus their activities on community training on social determinants of health and empowerment, as this was timely and not dependent on formal PCT engagement. However, it will feed directly into PCTs as they come on stream.
- The issue of time resources has been raised by both community and HSE representatives. In particular, the voluntary and community sector are very stretched, particularly arising from changes in the community structure and cuts in funding. For example, because of cuts in services a befriending project in Cashel, although very successful in reaching out to and supporting socially isolated and disadvantaged people, has had to be closed. The current realignment of structures at community level makes introducing projects at this time difficult.
- It is also clear that it is important to get the time right to participate with the PCTs. For example, the experience was that the Clonmel Team was not ready for community participation as it was in an early stage of development, while the Team in Cashel, because well-established, has been open to participation.

- Training and empowering communities with regard to health in general, means that community participation structures will be in place by the time the PCTs are on stream. Using the Community and Voluntary Forum to promote the process has been particularly valuable to this.
- There are also issues of how community groups link with each other and with health issues. Many are single issue e.g. older people, disabled people or young people, while others have a broader remit e.g. FRCs and CDPs. Some are large with paid staff, and others are totally voluntary. In rural areas there is little social inclusion infrastructure. Local Community development groups are being established under the LCDP, and these may be of use in promoting community participation. In each of the three RAPID areas, there is a dedicated subgroup to look at health issues which is chaired by a HSE rep. Again this is a useful forum for feeding information to and from PCTs and promoting community participation.
- From an HSE perspective the model developed has worked very well. However, the HSE faces a number of challenges regarding a lack of resources in terms of posts and the lack of clarity at a national level regarding structures and governance. For example, sustainability has proved problematic because of the ending of the contract of the HSE's Senior Community Worker post, which has been key to the Project.
- With regard to the community consultation methodology, the original model has required adaptation in some settings. The learning for facilitators is that implementing the consultation over three sessions of two hours each is ideal and gives the best results. However, some groups may not be able to give that amount of time to the process and it is important to be able to modify the methodology to meet the groups in terms of where they are at with the overall process.

Appendix 3: Membership of the National Working Group on Community Participation in Primary Care

Mary Culliton, Director of Advocacy, Clinical Quality and Care Directorate, HSE (Chair)

Elaine Houlihan, Social Inclusion Division, DCEGA (Project Coordinator)

Rachel McEvoy, HSE Advocacy Unit (Project Coordinator)

Liz Sullivan, Social Inclusion Division, DECGA (up to February 2010)

Brian Murphy, Primary Care, HSE

Bill Ebbitt, Population Health, HSE

Sheila Marshall, PCCC, HSE

Chris Sheridan, Principal Community Worker, HSE West

Tony Quilty, Social Inclusion, HSE West

Diane Nurse, National Planning Specialist, Social Inclusion, HSE

Maire O' Leary, Social Inclusion Manager, HSE

Veronica Larkin, HSE

Ellen O'Dea, TDO HSE

Ailish Ni Riain, Irish College of General Practitioners

Fiona Reilly, Royal College of Surgeons

Jimmy Duggan, DoHC

Edel Reilly, Fatima Regeneration Board

Fran Keyes, Pavee Point

Helen McAvoy, Institute of Public Health

Tonya Saunders, CAIRDE

Appendix 4: Membership of the Evaluation Sub-Group (Working Group on Community Participation in Primary Care)

Elaine Houlihan, Social Inclusion Division, DECGA (Project Coordinator)

Rachel McEvoy, HSE Advocacy Unit (Project Coordinator)

Veronica Larkin, HSE

Brian Murphy, Primary Care, HSE

Helen McAvoy, Institute of Public Health

Jane Pillinger, Evaluator

Liz Sullivan, Social Inclusion Division, DECGA (up to February 2010)

Appendix 5: Interviews held with key stakeholders and decision makers

In addition to the consultations and interview with HSE and community representatives from the nineteen projects, the following national stakeholders and decision makers were interviewed.

Mary Culliton, Director of Advocacy, Clinical Quality and Care Directorate, HSE

Elaine Houlihan, Social Inclusion Division, DECGA (Project Coordinator)

Liz Sullivan, Social Inclusion Division, DECGA

Rachel McEvoy, HSE Advocacy Unit (Project Coordinator)

Brian Murphy, Primary Care, HSE

Alice O'Flynn, Assistant National Director, Social Inclusion, HSE

Diane Nurse, National Planning Specialist, Social Inclusion, HSE

Bill Ebbitt, Population Health, HSE

Philip Crowley, Deputy Chief Medical Officer, DoHC

Catherine Hazlett, Principal Officer for Social Inclusion, Department of Social and Family Affairs

Helen McAvoy, Institute of Public Health

Bibliography

- Allsop J and Taket A (2003) 'Evaluating user involvement in primary health care', *International Journal of Healthcare Technology and Management*, Vol. 5, No.1/2 pp. 34 - 44
- Arnstein S (1969) 'A ladder of citizen participation in the USA', *Journal of the American Institute of Planners*, 35(4), pp. 216–224
- Balanda K and Wilde J (2001) *Inequalities in Mortality 1989-1998: A Report on All Ireland Mortality Data*, Dublin/Belfast: Institute of Public Health in Ireland
- Berkman L F (1995) "The social relations of health promotion", *Psychosomatic Medicine*, 57: 245-254
- Berkman LF and Syme SL (1979) "Social networks, host resistance and mortality: a nine year follow-up of Alameda County Residents", *American Journal of Epidemiology*, 109: 186-204
- Burke S (2009) *Tackling Poverty: Talking Inequalities in Health*. Combat Poverty Agency: Dublin
- Burke S, Keenaghan C, O'Donovan D, and Quirke B (2004) *Health in Ireland – an unequal state*, Public Health Alliance Ireland
- Burtenshaw Kenny Associates (2008) *A Profile of the Needs of the Tyrrelstown Community*.
- Butcher H et al (1993) *Community and Public Policy*. London: Pluto Press
- Carnegie Trust (2010) *Making good society: Commission of Inquiry into the Future of Civil Society in the UK and Ireland*. Carnegie UK Trust
- Centre For Effective Services (2010) *Framework for the Local Community Development Programme*. Centre for Effective Services: Dublin
- Combat Poverty Agency (2000) *Community Development in Tackling Poverty*. Combat Poverty Agency: Dublin
- Combat Poverty Agency (2005) *Community Participation and Primary Care: learning from the Building Healthy Communities Programme*. Combat Poverty Agency: Dublin
- Combat Poverty Agency (2005) *Tackling Health Inequalities: a community development approach*. Combat Poverty Agency: Dublin
- Combat Poverty Agency (2009a) *People, Poverty and Participation*, Combat Poverty Agency: Dublin
- Combat Poverty Agency (2009b) *Tackling Inequalities Locally*, Combat Poverty Agency: Dublin
- Commission on Social Determinants of Health (2008) *CSDH Final Report: Closing the gap in a generation: Health equity through action on the social determinants of health*. World Health Organisation
- Corduff Health Action Group (2004) *Corduff's Right to Care: The Voice of the Corduff Community. Health Action Plan*, Corduff CDP: Dublin
- Cosgrove S (2004) *Mulhuddart Primary Health Research Report*, Blanchardstown CDP: Dublin

Crowley P (2003) *Community Development and Primary Care in Northern Ireland and England*. Combat Poverty Agency: Dublin

Crowley P (2005) *Community Participation and Primary Care: Learning from the Building Healthy Communities Programme*. CPA: Dublin

Dahlgren G and Whitehead M (1991) *Policies and Strategies to Promote Equity in Health*. Stockholm: Institute for Future Studies

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

Department of Health and Children (2000) *National Health Promotion Strategy 2000-2005*, Dublin: Government Publications

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

Department of Health and Children (2001b) *Quality and Fairness: A Health System For You*. Stationary Office: Dublin

Department of Health and Children (2002) *Traveller Health: A National Strategy 2002-2005*. Stationary Office: Dublin

Department of Health and Children (2004a) *Guidelines for Community Involvement in Health*, Position Paper of the National Primary Care Steering Group. Stationary Office: Dublin

Department of Health and Children (2004b) *National Health Promotion Strategy*. DoHC: Dublin

Department of Health and Children (2008) *Building a Culture of Patient Safety*. Report of the Commission on Patient Safety and Quality Assurance. DoHC: Dublin

Farrell C, McAvoy H, Wilde J and Combat Poverty Agency (2008) *Tackling Health Inequalities An All-Ireland Approach to Social Determinants*. Dublin: Combat Poverty Agency/Institute of Public Health in Ireland

Fatima Regeneration Board (2009) *Community health: community wealth. Rialto's health and wellbeing: local needs and community solutions. A Participatory Research and Action Programme*, Fatima Regeneration Board: Dublin

Fisher B, Neve H, Heritage Z (1999) "Community development, user involvement and primary health care". *British Medical Journal*, 318:749-750

Government of Ireland (2000) *Supporting Voluntary Activity: A White Paper on a Framework for Supporting Voluntary Activity and for developing the Relationship between the State and the Community and Voluntary Sector*. Government Publications Office: Dublin

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

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

Government of Ireland (2007) *National Development Plan 2007 – 2013; Transforming Ireland; A Better Quality of Life For All*, Government Publications: Dublin

Graham H (2004) *Closing the Gap: Strategies for Action to Tackle Health Inequalities*. Presentation at the 1st Business Meeting of the EU Project 'Closing the Gap' on 27/28 October 2004, Cologne

Health Services Executive (2004) *A Model for Community Participation in Primary Care: Lifford / Castlefinn Primary Care Project*, HSE

Health Services Executive (2006) *Transformation Programme 2007 – 2010*. Health Services Executive

Health Services Executive (2007) *National Intercultural Strategy in Health 2007-2012*. Health Services Executive

Health Services Executive (2008a) *Improving Our Services: A Users' Guide to Managing Change in the Health Service Executive*. Health Services Executive

Health Services Executive (2008b) *Population Health Strategy*. Health Services Executive

Health Services Executive (2009) *HSE Community Development Work Service: A Position Paper*. HSE PCCC Social Inclusion Governance Group

Health Services Executive (2010a) *Primary Care Team Status Report, January 2010*. Health Services Executive

Health Services Executive (2010b) *HSE Service Plan 2010*. Health Services Executive

Health Services Executive (forthcoming) *National Health Inequalities Framework (2009-2012)*. Health Services Executive

HEBE (2002) *Guidelines on Community Participation*. HEBE: Dublin

Institute of Public Health (2008) *Tackling health inequalities. An All-Ireland approach to the social determinants*. IPH: Dublin and Belfast

Institute of Public Health in Ireland (2001) *Report of the Working Group on the National Anti Poverty Strategy and Health*. Dublin: Institute of Public Health in Ireland

Judge K, Platt S, Costongs C and Jurczak K (2006) *Health Inequalities a Challenge for Europe*. Paper commissioned as part of the European project "Tackling Health Inequalities: Governing for Health" commissioned under the 2005 UK Presidency of the EU

Kawachi I, Kennedy BP (1997) "Health and social cohesion: why care about income inequality?" *British Medical Journal*, 314: 1037-1040

Layte R, Nolan A, and Nolan B (2007) *Poor Prescriptions: Poverty, Health and Access to Community Health Services*. Combat Poverty Agency: Dublin

Macaulay A C, Commanda L E, Freeman W L, Gibson N, McCabe M L, Robbins C M, Twohig P L (1999) "Participatory research maximises community and lay involvement". *British Medical Journal*, 319: 774-778

Marmot (2010) *Fair Society, Healthy Lives*. The Marmot Review. Strategic review of Health Inequalities in England Post-2010

Marmot M (2004) 'Social Causes of Social Inequalities in Health' in Anand S, Fabienne P and Sen A (Eds.) *Public health, ethics, and equity*. Oxford: Oxford University Press

McAvoy H, Sturley J, Burke S, and Balanda K (2006) *Unequal at Birth: Inequalities in the occurrence of low birthweight babies in Ireland*, Institute of Public Health in Ireland: Dublin

McEvoy H, Keenghan C and Murray A (2008) *Service User Involvement in the Irish Health Service: A Review of Evidence*. DoHC & HSE: Dublin

McInerney C & Adshead M (2010) *The Challenge of Community Participation in the Delivery of Public Services*. NESF: Dublin

- NESC (2009) *Well-being Matters: A Social Report for Ireland*. NESC: Dublin
- OECD (2001) *Engaging Citizens in Policy Making: Information, Consultation and Public Participation*. PUMA Policy Brief No 2. OECD: Paris
- Pillinger J (2001) *Quality in Social Public Services*. European Foundation for the Improvement of Living and Working Conditions. Office for Official Publications of the European Communities: Luxembourg
- Pillinger J (2005) *Social Inclusion in Health: Framework of actions for the HSE in the North West*, HSE NW
- West and South Offaly Building Healthy Communities Partnership (2008) *The West Offaly Way: A community development approach to tackling health inequalities in rural areas*. West and South Offaly Building Healthy Communities Partnership
- WHO (2008a) *World Health Report: Primary Health Care: Now More Than Ever*. WHO: Geneva
- WHO (2008b) *Closing the Gap in a Generation, Health Equity Through Action on the Social Determinants of Health*. WHO: Geneva
- WHO European Region (1999) *Health 21. The health for all policy framework for the WHO European Region*. World Health Organization Regional Office for Europe: Copenhagen
- Wilcox D (1994) *The Guide to Effective Participation*. Brighton: Partnership Books
- Wilkinson R and Pickett K (2009) *The Spirit Level: Why More Equal Societies Always Do Better*. Allen Lane
- Wilkinson R G (2005) *The Impact of inequality: how to make sick societies healthier*. New Press, New York, Routledge, London
- Wilkinson, R. (2005) *The impact of inequality: how to make sick societies healthier*, London: Routledge

Reports and publications produced by the nineteen projects during the Initiative

a) Models of community participation

Bookle S (2009) *Report on Proposed Model for Community Participation in Primary Care in the Finglas/Glasnevin Catchment Area*, HSE/ Finglas South CDP/ Tolka Area Partnership: Dublin

McGrory (2009) *A Model for Community Participation in Primary Care for Corduff, Mulhuddart and Tyrrelstown – Final Project Report and Action Plan* (unpublished report)

b) Community health needs assessments

Fatima Regeneration Board / HSE (2009) *What's out there? A profile of health & wellbeing groups and services in the Dublin South Inner city area*. Dublin

Garratt C (2009) *The Economic Benefits of Community Engagement in Health Provision in County Donegal*, HSE West: Letterkenny

Humphreys E and Humphreys S (2010) *Community Participation in Primary Care. Research findings on local health needs*. Partnership of HSE, Paul Partnership, RAPID, Limerick Regeneration Agencies and the communities of Ballynanty, Kileely, Moyross and Thomandgate. Paul Partnership: Limerick

Monaghan Community Forum and HSE (2010) *Community Participation in Primary Health Care in North Monaghan*, HSE: Monaghan

Murphy D and Wexford Community Health Project (2010) Growing Healthy Communities: Community Health needs Analysis (RAPID areas of Wexford Town). Wolfe Tone: Wexford

c) Newsletters / leaflets

Ballina Migrant Community Health Forum: Newsletter (2010)

Paul Partnership Community Participation Newsletter (2009)

Pavee Point (2010) *Proposals for Traveller Inclusion in the Development of Primary Care Teams*. Pavee Point: Dublin