Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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Service User Involvement and Primary Care

Framework Document

2011

Regional SUI Implementation Group

April 2011

To be reviewed April 2012

Contents Page

Service User Involvement Framework Document

1. Background and Context

What is Service User Involvement?

Service user involvement is simply '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 polices, in planning, developing and delivering services and in taking action to achieve change' (HeBE 2002). The service user should be central to their own care and to the design and delivery of health and personal social services. Facilitating such a process, will invariably result in more appropriate services of a higher quality with increased service user compliance and satisfaction.

Key principles for bridging the divide between the community and the services it needs and active participation of its community members are:

- Respect for their values
- Close attention to their level of knowledge about HSE matters and appropriately tailored development and team building opportunities
- Adequate mentoring and supervision
- Clearly defined channels for information exchange
- Participatory opportunities at every level of the organisation.

2. Definition of Key Terms

Service User: The term 'service user' is used to include:

- People who use health and social care services as patients
- Carers, parents and guardians
- Organisations and communities that represent the interests of people who use health and social care services
- Members of the public and communities who are potential users of health services and social care interventions.

The term service user also takes account of the rich diversity of people in our society whether defined by age, colour, race, ethnicity or nationality, religion, disability, gender or sexual orientation, and may have different needs and concerns (HSE * DoHC 2008).

In general the term service user is used, but occasionally the term patient is used where it is considered most appropriate.

Involvement:

Involvement is '*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 polices, in planning, developing and delivering services and in taking action to achieve change…'* (HeBE 2002).

A role for service users in monitoring health service performance is also envisaged.

Community Participation:

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'* (Pillinger 2010).

Community Representative:

Community representatives may be recognised as:

- Individuals who are 'representing', 'representative', and/or 'consultative' of one or more populations or affinity groups,
- Stakeholders, opinion leaders, organisers and advocates
- Committed, passionate, present, vocal, honest, offering outside perspectives, and experienced in, and guided by, community-based priorities and needs, and
- Those who serve as a platform and channel for information and voices of community, who communicate ideas and concepts **between** community and health and social services, and who hold people and processes accountable.

3. Why do we need Service User Involvement in the HSE?

Aside from its iteration in various national policy and strategic documents (e.g. Recommendation 19 of the Primary Care Strategy), the literature in this area clearly states that promoting greater service user involvement will result in advantages at **Individual, Community and National Level.**

3.1 Individual

On a patient-clinician level:

- Better health and treatment outcomes
- Increased patient satisfaction with care
- Increased sense of dignity and self-worth
- Empowerment of the patient, leading to greater responsibility for care
- Improvements in staff and patient relationships and increased trust
- Reduced level of complaints and safer care.

3.2 Community

On a community level:

- Improved policies to address inequalities in health
- Joined up approaches to working on improvements in public health
- Services that respond better to the needs of the community
- More equitable and inclusive services that help to address social exclusion
- Reduced complaints and increased trust.

3.3 National

On an organisational level:

- Ensures policies and service plans are informed, relevant, appropriate and targeted
- Cost-effectiveness promoted by delivering better service outcomes
- Improved public perception and confidence in the health services
- Greater understanding of the links between health, lifestyle and the circumstances in which people live their lives.

4. Where do we start with Service Users Involvement in the HSE?

4.1 Strategy Development

The HSE & DoHC developed a National Strategy for Service User Involvement to ensure a systematic and consistent approach to service user involvement across the health and social services. It builds upon the current good practice in involving service users across the country and incorporates consultation with key internal and external stakeholders at various stages of the implementation process.

The Strategy is available for download at: www.hse.ie/eng/services/ysys/Documentation/

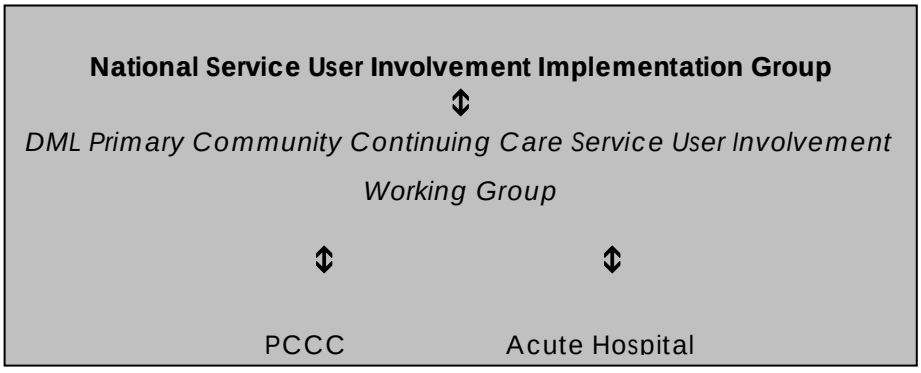
Since its development, the significance and commitment to service user involvement at both an individual and collective level has been further credited through such documents as:

- Charter: You and Your Health Service (HSE 2010)
- HIQA draft standards for safer better healthcare (HIQA 2010)
- Building a Culture of Patient Safety (DoHC 2010)
- Achieving Excellence in Clinical Governance (HSE 2010).

All of the above are available on the HSE Website.

4.2 Strategy Implementation

The HSE National Advocacy Unit has been tasked with leading and managing the overall implementation of the Strategy document. This has involved the appointment of a National Lead for Service User Involvement (June Boulger) and the development of a national implementation plan with an appropriate Governance Structure to help co-ordinate and manage the implementation process. The National Implementation Plan of the Service User Involvement Strategy has taken the following Governance Structure:



A detailed outline of the personnel involved in these various groups is outlined in Appendix 1.

Due to the numbers of stakeholders in each region, the project is divided into two distinct areas allowing for integration on service user involvement across areas at every level possible; PCCC and Acute Hospital.

5. Integrating Service User Involvement into the Business of the HSE

There are three levels at which service users should be integrated into the business of the HSE; these are best reflected in the figure below:

(Source HSE & DoHC 2008)

At each level various different mediums/structures for service user involvement should be put in place. These structures vary in terms of there placement within the 'continuum of participation'. Some of the structures/mediums most familiar to health service providers and users will include the following:

Structures/Mediums	Placement of Structure on the 'Continuum of Participation'
▪ Regional Health Fora	Partnership
▪ Public enquiries	Delegation
▪ Advocacy Groups	Partnership
▪ Service User Panels	Partnership
▪ Community Participation and PCTs	Partnership
▪ Your Service Your Say	Information
▪ HSE Information Line	Information
▪ Patient experience surveys	Information

Through such structures issues pertaining to the following may be addressed:

- Health literacy
- Shared decision making
- Self care
- Safety
- Access
- Care experience
- Service development.

Sample interventions to address such issues are presented in Appendix 2, and expanded further in appendix 4b with practical suggestions from a primary care setting in Dublin South City. It is important to note that whatever methods are applied, at whatever level, through whatever structures, in terms of ensuring service user involvement, **the key message is to understand that service user involvement is *everyone's* responsibility.**

6. Community Participation & Primary Care

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

Learning from the 'Building Health Communities Project', and the more recent 'Joint Initiative on Community Participation in Primary Health Care', highlight that in order to ensure the successful participation of communities and groups the following key activities have proved essential (Pillinger 2010):

- Developing and supporting community representative infrastructure
- Conducting community needs assessments and local services mapping exercises;
- Building on existing community structures and recognising previous community experience. Working in this way proved to be an efficient way of engaging local communities. The only caveat to this is that one must still ensure that the community project leading the process is not working with a limited number of local groups and effectively excluding others.
- Developing joint plans between the HSE and community groups to support community participation in PCTs and Primary Care Networks using participative methodologies and focusing on the **wider determinants of health** (see Appendix 7). Sample actions are provided in Appendix 4b.
  These are merely suggestions that were drawn from Dublin South City, and relevant actions will be specific to local needs and priorities;

- Joint training and support for PCTs and local community representatives on community participation.

Further information on each of the 19 projects who engaged in the Joint Initiative on Community Participation in Primary health Care, and various supporting resources, is available at www.hse.ie/eng/services/ysys/SUI/Library/participation/ The main activities undertaken by the projects is also summarised in Appendix4.

7. Ensuring 'True Representation' of Service Users Views

It is understood that it is nearly an impossible task to get true representation of service user issues. Each service user has a unique experience, perspective and agenda which can shape their perceptions and their experiences. To avoid this happening different involvement processes usually combine several service user engagement methods to achieve true engagement. The shape, use and results of involvement methods are usually determined by who is using them as well as by the nature of the methods themselves and the context, purpose etc.

In adopting different involvement methodologies, it is important to note that guaranteeing 'true representation' can be an impossible task. Service user involvement is perhaps more about a way of thinking that is able to progress beyond personal experience and apply such knowledge to broader healthcare issues. These different methods are explained later in the document.

However, a degree of representatives can be assured by *'combining several methods to achieve an aim'*. This includes the systematic gathering of feedback from all service users, seeking permission to discuss issues and getting to the core of what matters to the patient/client and using that information to continuously improve services, whilst being ever mindful of those whose voices are seldom heard.

In deciding upon various methods of involvement the 'HSE Resource Guide for Service User Involvement Methods' and the supporting webpage www.hse.ie/eng/services/ysys/SUI/Library/ will be of assistance.

8. Model for Service User Involvement in PCCC through Primary Care

The following model has been developed to aid the implementation of service user involvement through Primary Care Team's and Networks (see Appendix 5). This model has been developed through:

- The learning's from the 'Building Healthy Communities Programme', and the 'Joint Initiative on Community Participation in Primary Health Care',
- Consultation with representatives of lead regional personnel on the DML Working Group. (Membership outlined in appendix 1)
- Consultation workshop with both staff and management tasked with implementing this agenda to further refine the proposed model and to explore the potential strengths and weakness of the model.

The Model is composed of the following three levels:

8.1 LHO/Integrated Services Level

In each of the Local Health Offices a *'LHO SUI Nominee'* has been agreed to lead out on service user involvement. The LHO SUI Lead nominee must be comfortable talking and listening to what people have to say, both service users and providers alike. They must be able to challenge the system where this is needed whilst respecting and appreciating the views different from there own. They must also be able to think of different ways of doing things and be able to take responsibility and follow things through.

The LHO SUI Nominee will be responsible for:

- Supporting the development and implementation of service user involvement within the LHO area
- Seeking expressions of interest from staff for people to take on the role of *Network SUI Lead.*
- Helping in the establishment of *Service User Involvement Network Steering Groups'*
- Monitor progress, promote and report to the LHO SUI Nominee on service improvements and the integration of successful participation measures.
- Linking between the TDO, The Primary Care Implementation Group/Area Senior Management Team and Service User Network Leads.

At this local level the Care Groups will be linked into the Area Senior Management Team/Local Implementation Group and can link in with all levels directly through this mechanism.

During regular intervals throughout the year the *LHO SUI Steering Group* will meet to share information and to highlight service development needs across the network areas which will then be prioritised at LHO/ISA level.

From across all the Network SUI Steering Groups, a HSE Representative and SUI Community Representative will be nominated to become members of the Primary Care Local Implementation Group or other Area Senior Management Team to represent all service users for the LHO/ISA. The nominated persons however may change after an agreed time in post.

It is important that representative structures are put in place to support the development of a collective agenda for the representative, to facilitate feed-in and feedback and to ensure accountability.

8.2 Network Level

At network level, a *'SUI Network Lead'* will be sought through expressions of interest from within each LHO. The Network Lead must be comfortable talking and listening to what people have to say, both those who work for us and those who use our services. They must be able to challenge the system where this is need and respect and appreciate views different from there own. They must also be able to think of different ways of doing things and be able to take responsibility and follow things through.

The Network Lead will work in Partnership with the LHO SUI Nominee, and will be responsible for:

- Fostering the development of service user involvement and community participation at Network level
- Seeking a HSE Representative and Community Service User Representative from each PCT in the Network.
- Helping in the establishment and development of the Service User Involvement Network Steering Group
- Monitor progress, promote and report to the LHO SUI Nominee on service improvements and the integration of successful participation measures.

All of the Networks Primary Care Team's HSE Reps and SUI Reps will form a *'Service User Involvement Network Steering Group'* which will be co-ordinated under the direction of the SUI Network Lead.

These Network Steering Groups will have support from Health Promotion, Community Workers, Social Inclusion, and other care groups etc. as appropriate. The committees can develop at Network or PCT level at the discretion of local management.

8.3 PCT Level

For each PCT, a HSE representative and Community representative will be sought. The process by which reps will be sought from the PCT and the Community will be decided locally. Guidance may be sought from the learning from the 19 national projects and supporting resource documents and literature. There will be flexibility to mould community participation at local team level accordingly (See appendix 4). Further ideas, supports and resources can be drawn from the Joint Funding Initiative (Pillinger 2010) www.hse.ie/eng/services/ysys/SUI/Library/ It is envisaged that the community representative would attend the Business Meeting of the PCT.

Table: Steps in Service User Involvement in each LHO area

Step	Target	Timeline	Completed
Step 1	Appoint a *'LHO SUI Nominated Person'*	Q1	
Step 2:	Expressions of Interest for *'SUI (Network) Leads'* across LHO/ISA: ▪ Clarify Rationale, Mandate, Governance, Roles and Responsibilities ▪ Outline Plan for SUI in LHO/Networks and PCT's.	Q1	
Step 3:	Expressions of Interest for *PCT's HSE SUI Rep and Community SUI Rep* ▪ Clarify Rationale, Mandate, Governance, Roles and Responsibilities ▪ Outline Plan for SUI in LHO/Networks and PCT's (see appendix 2)	Q1	
Step 4:	Identifying gaps in resources & training needs	Q2	
Step 5:	Implement service user involvement methodologies at each level. ▪ See appendix 3 &4b for suggestions ▪ See resource materials and case study examples from Joint Initiative on Community Participation in Primary Care	Q2- Q4	
Step 6:	Continuously reviews, ▪ See terms of reference for frequency of meetings and review dates/ updates	Q1-Q4	

9. HSE Resources & Support Mechanisms to Local Health Office Areas:

Various different levels of support, resources and guidance are available from internal HSE departments and personnel. The level and extent of this support will depend on the outcome of local consultation based on the needs and capacity within the area.

Possible Areas of HSE Support:

- Community Development Officers
- Consumer Affairs
- Health Promotion
- National Advocacy Unit
- Organisation Development & Design
- Performance & Development
- Social Inclusion
- Transformation Development Officers
- 19 Projects nationally**.**

Appendix 1: Membership of the National and Regional Governance of Service User Involvement Strategy Implementation.

National Service User Involvement Implementation: Sub-Group on PCCC

- June Boulger, Lead for Service User Involvement, National Advocacy Unit
- Rachel McEvoy, Research Officer, National Advocacy Unit
- Denise Keoghan, Organisation Development & Design, DML
- Jennifer Garry, Organisation Development & Design, DML
- Service User Representative (Rotation).

Regional: DML Primary Community Continuing Care Service User Involvement Working Group

- Helen Deely, Regional Specialist Primary Care, DML
- Ellen O'Dea, TDO, Dublin South City
- Rachel McEvoy, Research Officer, National Advocacy Unit
- Eileen Dunphy, Research Officer, Clinical Audit & Research
- Deborah Keyes, General Manager, Consumer Affairs, DML
- Denise Keoghan, Organisation Development & Design, DML
- Jennifer Garry, Organisation Development & Design, DML
- Key stakeholders: Health Promotion, Social Inclusion, CDW, etc.
- Service User Representation (Rotation).

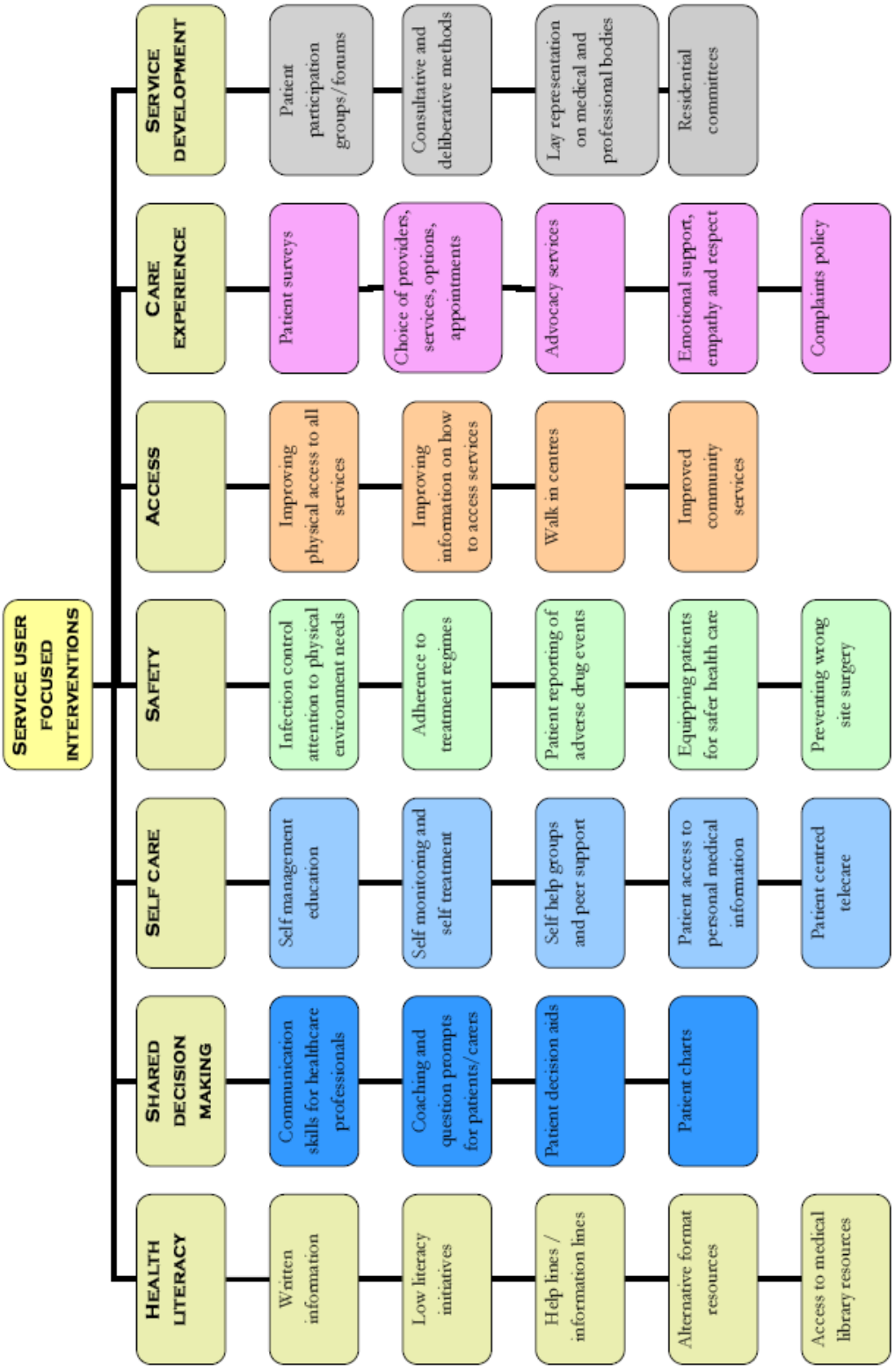
The membership of the group may evolve as work progresses.

Regional: DML Acute Hospital Service User Involvement Working Group

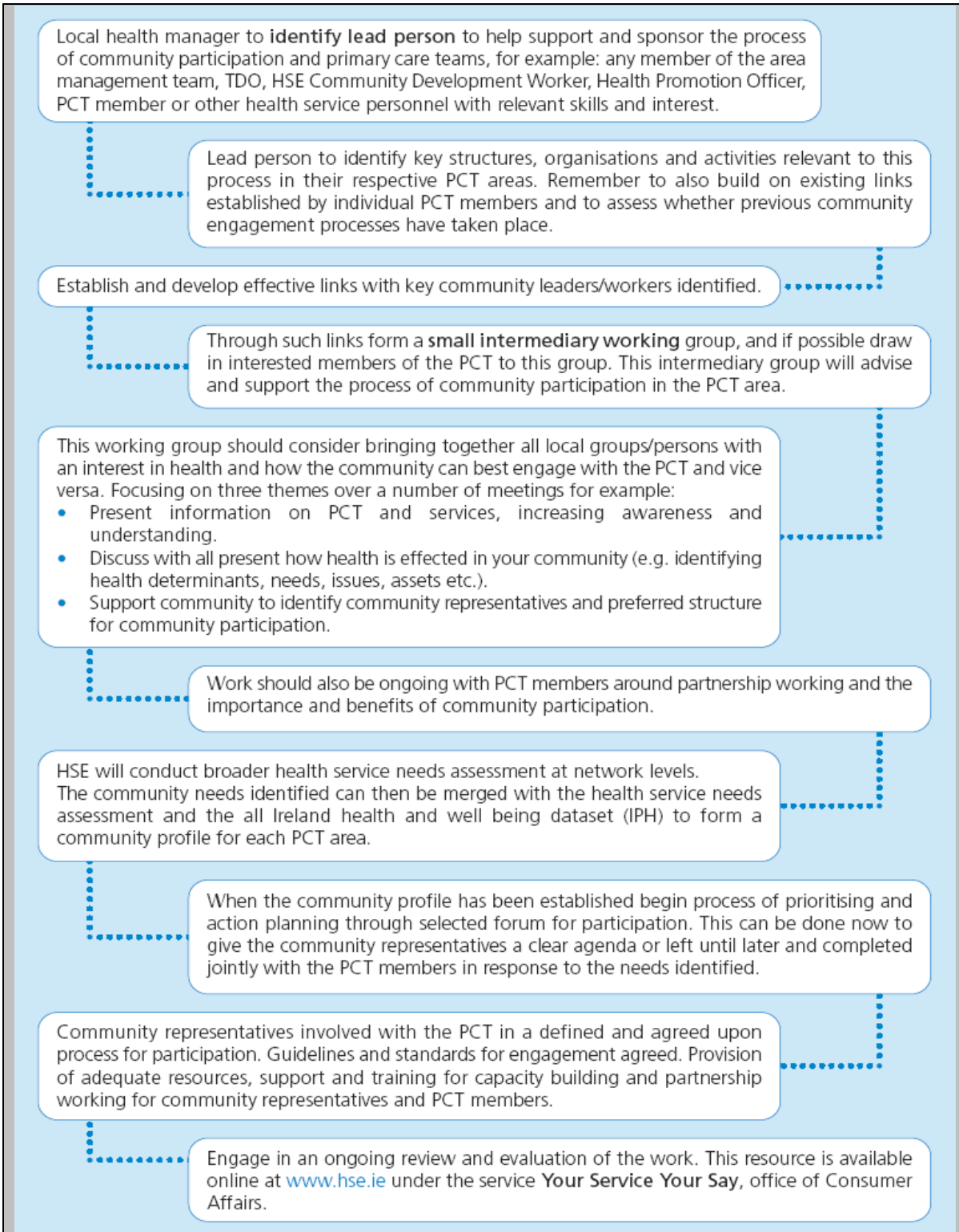
- June Boulger, Lead for Service User Involvement, National Advocacy Unit
- Deborah Keyes, General Manager, Consumer Affairs, DML
- Denise Keoghan, Organisation Development & Design, DML
- Jennifer Garry, Organisation Development & Design, DML.
- Key stakeholders: Health Promotion, Social Inclusion, CDW, Primary Care
- Service User Representation (Rotation).

The membership of the group may evolve as work progresses.

Appendix 2: Service User Focused Interventions



Appendix 3: Community Participation & Primary Care (Joint Funded Initiative 2010).



Details for each of these stages are further expanded upon at

www.hse.ie/eng/services/ysys/SUI/Library/

Appendix 4: Summary of Joint Funded Project Activities (Pillinger 2010)

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

Appendix 4b: Achieving Service User Involvement in Primary Care Settings: Practical Suggestions

- **Health Literacy** – Being able to find, understand and use health information to make sound decisions.

	Yes	No	Suggested Action	Action by whom	Target Date
Is there written/oral/aural information available?			▪ Is written/oral/aural information available about primary care team services? ▪ Is written information available about health promoting groups in the local area? (e.g Exercise classes, mother and baby groups, healthy eating classes?) ▪ Are there local opportunities to update people about health events, changes in HSE or community health initiatives (e.g local newsletter that could have a health section, local paper, church newsletters, drop in centre etc.) ▪ Have local pharmacists been contacted re this?		
Are details of helplines or individuals that can assist with form filling available?			▪ Are there lists available of people who can assist with form filling (e.g citizens advice, local community workers, local health volunteers) ▪ Is the HSE information line number clearly		

			displayed in all health centres, GP centres, and local Pharmacies?		
Are there initiatives in place for patients with low literacy levels?			▪ Do HSE and community services automatically ask if a person would like assistance in form filling? ▪ Have links been made through NALA with local adult literacy trainers so new literature can be proofed? ▪ Do you have a local literacy committee for proofing of patient/service user information?		
Training			▪ Have local HSE staff and community workers had training in health literacy? Opportunities available through NALA.		

➢ **Shared Decision Making** – Actively engage service users in the decision-making process about their treatment or care

	Yes	No	Comment / Action	Action by whom	Target Date
Have medical professionals and other frontline staff undertaken communication skills training?			▪ Are frontline staff aware of the patients charter? ▪ Are frontline staff aware of Your Service Your Say? ▪ Cultural awareness training available ▪ Training also managed locally by area Performance & Development Departments (P&D) ▪ Training modules also available through HSEland.ie		
Are people given sufficient time, privacy and encouragement to ask questions?			▪ Is a leaflet available about questions a person might want to ask health professionals? ▪ Is the patients charter clearly displayed in all local health service areas, local pharmacy, GP office?		
Are decision aids available? For example: Let's Talk Medication Safety Let's Talk Medication Safety: Medication List (ISQSH)			▪ Link with local health promotion unit, social inclusion, local Traveller PCW,		

➢ Self Care – Day to day management of long term and chronic illness

	Yes	No	Comment / Action	Action by whom	Target Date
Are service users provided with written information about their illness? If given written information, are we sure that the service user understands it?			If so, has it been proofed for health literacy and by the service user group?		
Are service users with long-term / chronic illness provided with regular reviews about their illness?			▪ Are there care plans in place? ▪ Are service users aware if a 'Care Plan' has been developed for them by their local 'Primary Care Team'? ▪ Are service users made aware if their case is discussed at a clinical team meeting? ▪ If their case is discussed, are service users told of any decisions made by their 'Primary Care Team' to ensure the best approach to their health care was taken? ▪ Can service users request that their case is		

			discussed at a clinical team meeting? ▪ Do service users get a copy of their care plan? ▪ Are service users involved in decisions made about their care and treatment as much as they would have liked?		
Are self-management education programmes provided to patients?			▪ Identify what's available and run locally? ▪ Are they advertised to the local community? ▪ Are carers welcome? ▪ Have local pharmacists been contacted re this?		
Are patients informed about different self help groups both locally, regionally and nationally.			▪ Contact with Local Pharmacy, Citizens information Bureau ▪ Online directory of services and self help groups ▪ Magnetic business card available to all patients with key support groups & contact numbers		
Are exercise referral pathways in place?			▪ Have exercise referral pathways/reduced rates been agreed with local gyms/sports centres/ yoga groups etc? ▪ Have potential links been made with the Local Sports Partnership Forum?		

Are library prescription pathways in place?			▪ Can clinicians prescribe a book from a local library to assist someone manage their disease/condition?		
Have patients access to personal medical information?					

➢ **Safety** – What can be done to improve patient involvement in patient safety?

	Yes	**No**	**Comment / Action**	**Action by whom**	**Target Date**
Are patients provided with user-friendly information about medicines?			▪ Have local pharmacists been contacted re this? ▪ Are the following information leaflets available: Let's Talk Medication Safety (ISQSH) Let's Talk Medication Safety: Medication List (ISQSH)		
Are patients made aware of the importance of adherence to treatment regimes?			▪ Engage with local pharmacists? ▪ Establish a feedback mechanism with local pharmacists when patients describe non-compliance.		
Are patients made aware that adverse drug effects should be reported to drug safety agencies?			▪ Engage with local pharmacists?		

- **Access** – availability, utilisation, relevance and acceptability and equity of health services

	Yes	No	Comment / Action	Action by whom	Target Date
Are local premises physically and culturally accessible to all service users?			▪ Get occupational therapy students/transition year (with support) to do an access audit of local footpaths/businesses/community buildings. ▪ Ask for feedback re local access issues from local disability groups, IWA etc. ▪ Work with access officer from local council: award businesses/premises who make improvements ▪ Agree actions with local businesses. ▪ Liaise with Traveller PC workers, HSE social inclusion specialist, age and opportunity representative etc. in respect to cultural accessibility. ▪ Liaise with the National Specialist for Accessibility Caoimhe.Gleeson@hse.ie		

Is there a 24 hour advice and phone service available			▪ Compile list of 24 hours advice and phone services available and make it freely available and widely distributed		
Is there information available on how to access the services?			▪ Is information in a range of formats, web, audio paper?		
Are there feedback mechanisms on how accessible services are?			▪ Is Your Service Your Say clearly visible and promoted ▪ Are other feedback mechanisms promoted		

- **Care Experience** – what patients say about services

	Yes	**No**	**Comment / Action**	**Action by whom**	**Target Date**
Are forms available to patients to provide feedback on the services provided?			▪ Ensure all staff and service users are aware and understand 'your service your say' the HSE feedback policy. ▪ Where comments/complaints are made ensure evidence of changes made: 'You Said, We Did'.		
Are patient satisfaction surveys carried out?			▪ Student project ▪ Set an objective that they happen routinely.		

Are there incentives for providers to improve their service?			▪ Work with access officer from local council: award businesses/premises who make accessibility improvements (staff training/physical environment/accessible website/ delivery service etc.)		

- **Service Development** – where individuals can participate in decisions about the development, planning and provision of health services.

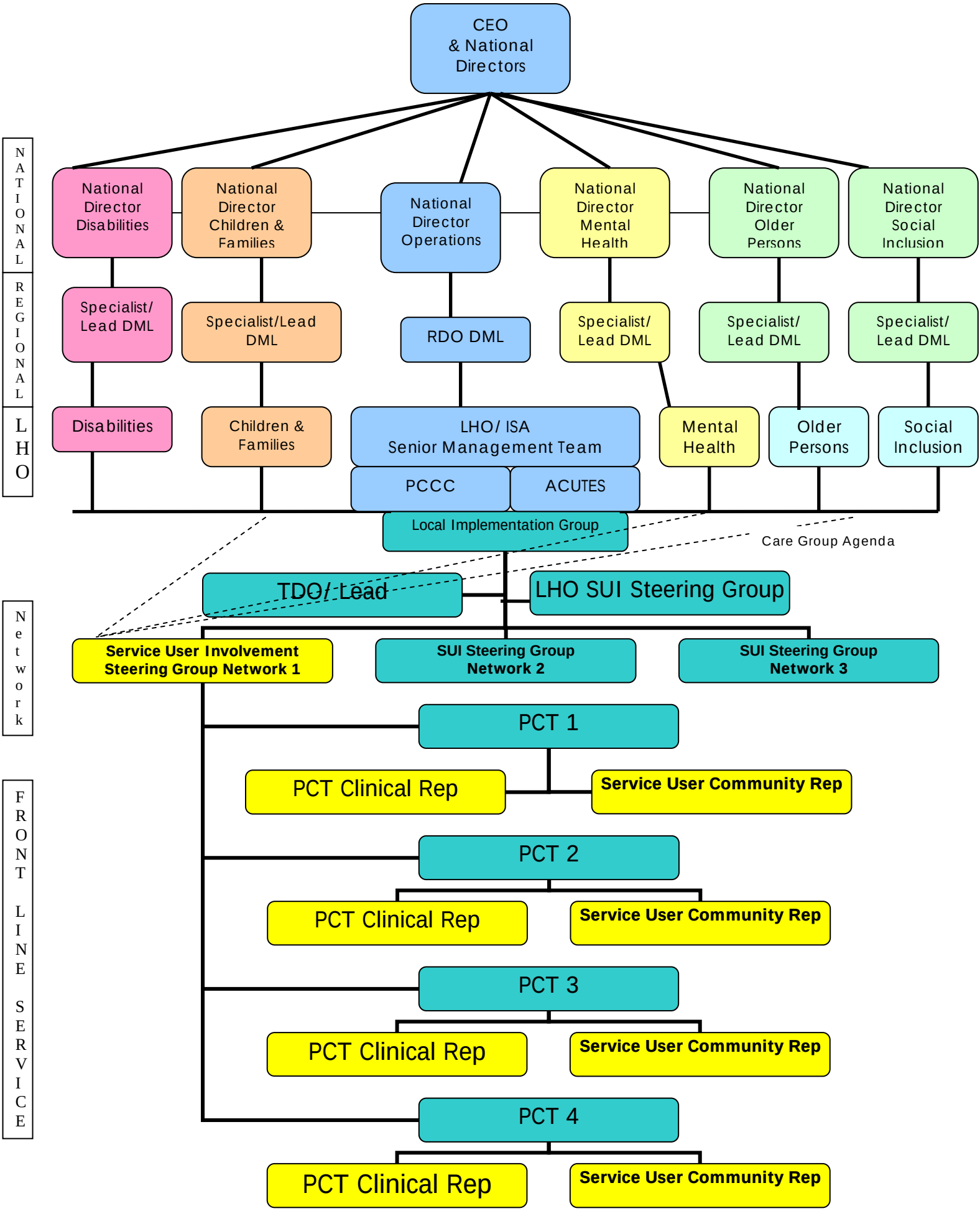
	Yes	No	Comment / Action	Action by whom	Target Date
Are there processes in place to allow for patient participation in service development (i.e. patient participation groups and forums)?			▪ When local team based PCT planning happens each year are community reps involved? Community can also plan how they will deliver health related programmes for the year at his forum. ▪ Other options are the PCT supporting health promotion/health related groups run by the community. ▪ See reference to self care. ▪ Focus on participation at all levels: Each level will adopt different mechanism and methods.		

Joint education initiatives			▪ Are there regular joint training opportunities in health related issues (e.g. literacy, assist training, CPR, domestic violence etc).		
Heath promotion events/weeks			▪ Do the group plan a joint HSE/community groups response to themed weeks throughout the year (e.. men's health week/breastfeeding week/ healthy aging week/ mental health week/ YSYS week etc. Huge scope for joint working here) Themes maybe based around local needs analysis and national promotional weeks.		

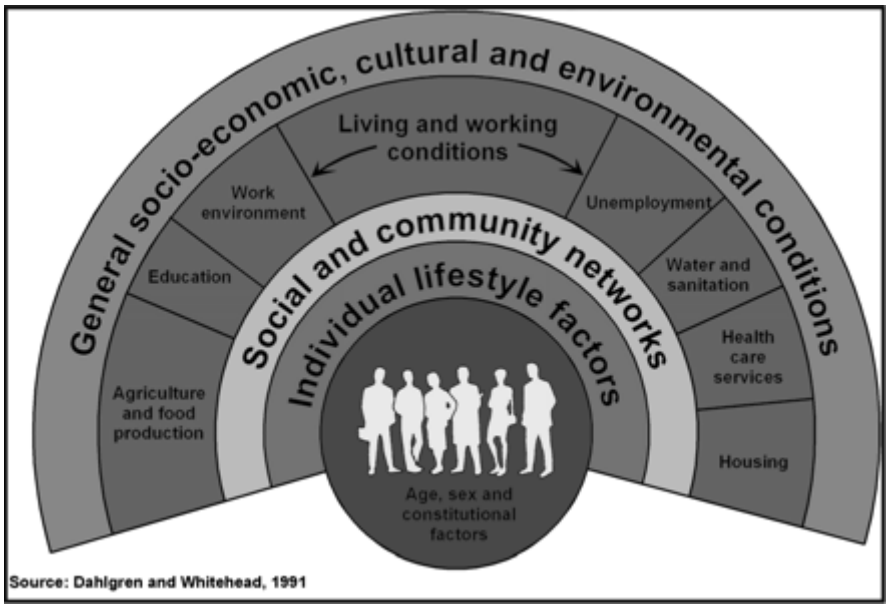
Appendix 5: Stakeholder Analysis

The following are the core internal and external stakeholders for the Implementation of the Service User Involvement Strategy. This is not an exhaustive list and may be added to during the process based on your LHO/ISA's changing structure and processes.

Internal stakeholders	External stakeholders
▪ CEO/ HSE Board/ Regional Directors of Operations	▪ Service Users
▪ Local Health Office Managers	▪ Community Groups
▪ Corporate Stakeholders: Corporate Affairs, Organisation Development & Design, HR, Primary Care Programme Management, Health Promotion, Population Health etc.	▪ Voluntary Bodies/Agencies
▪ General Managers/Senior Area Admin	▪ State Bodies & Departments
▪ TDO's	▪ Professional Bodies
▪ Heads of Service/Heads of Discipline	▪ Advocacy Groups
▪ Network Leads/LHO SUI Nominated persons	
▪ PCT Staff Members & other Network Staff Members	
▪ Local HSE Staff Members especially Community Development Officers, Health Promotion Staff, Social Inclusion Staff.	


NATIONAL
REGIONAL
LHO
Network
FRONT LINE SERVICE
CEO & National Directors
National Director Disabilities
National Director Children & Families
National Director Operations
National Director Mental Health
National Director Older Persons
National Director Social Inclusion
Specialist/ Lead DML
Specialist/Lead DML
RDO DML
Specialist/ Lead DML
Specialist/ Lead DML
Specialist/ Lead DML
Disabilities
Children & Families
LHO/ ISA Senior Management Team
PCCC
ACUTES
Mental Health
Older Persons
Social Inclusion
Local Implementation Group
Care Group Agenda
TDO/ Lead
LHO SUI Steering Group
Service User Involvement Steering Group Network 1
SUI Steering Group Network 2
SUI Steering Group Network 3
PCT 1
PCT Clinical Rep
Service User Community Rep
PCT 2
PCT Clinical Rep
Service User Community Rep
PCT 3
PCT Clinical Rep
Service User Community Rep
PCT 4
PCT Clinical Rep
Service User Community Rep

Appendix 7 Dahlgren and Whitehead's model of the social determinants of health.



Appendix 6 Frequently Asked Questions

Understanding the Challenge?

Undoubtedly in embracing this proposal lies an uncomfortable challenge for some healthcare professionals. Clearly if entering into partnerships involves sharing power, empowerment for one group could mean that somebody else has to relinquish it. It is important to emphasise that at no stage through this cultural change is professional competence being questioned or undermined. Where the confusion has arisen is in differentiating between areas of clinical knowledge and areas of partnership that recognise and value the wisdom of the service user's expertise. Professional knowledge may feel as though it is under siege but this is far from the case.

The challenges are undoubtedly

- the lack of a 'mutually respectful collaboration between the health system and the people it is for'
- the need for open ended dialogue and time to work through and consolidate good ideas
- The need for a coordinated approach that recognises the value of engaging service users, knows how to do it, and use the knowledge that emerges to good effect.

It is the intention that this document and common framework will go someway towards addressing these challenges.

Time.

- **Competing priorities and policies**

Spending time on giving people information or involving them in decision making may appear to create time pressures, although research has demonstrated that this is not necessarily the case.

Training Required.

Type and intensity of training to be determined and subsequently resourced.

Lack of Resources– financial - basic subsistence and personnel.

Today all health and social services report lack of resources, which is even more of a reason to promote and ensure greater service user involvement through community participation. In County Donegal for example €26m per year is being invested by the community and voluntary sector in health related work, over 60% of which comes from non-public sources.

In addition, the payoffs far outweigh the minimal amount of resources initially required to support people in involving service users at an individual and collective level.

There are countless examples within the system of people ensuring greater service user involvement in the design development and delivery of services with little or no additional resources. Sometimes its simply about taking the time to look and reflect at what we are already doing and if it could be improved to better serve the service user, which in turn may actually free up resources in the long run.

Funding: Uncertainty in community groups.

This is a reality and will always be an issue and not necessarily one that we are in a position to control. What we can control however is promoting the concept of patient centered care and working with and alongside community groups to ensure that what resources are available both within the community and in the HSE are maximised and used to best effect.

Culture Change:

- HSE - defensiveness attitude
- GPs – won't like being told what to do.

Yes there needs to be a cultural change and this will take time, but we have to start somewhere and now is an opportune time to do so.

At no stage in the process should a case arise of anyone being told what to do by anyone. Working as part of a Primary Care Team, is about partnership work and if someone feels that they are being dictated to, it's an issue that requires careful facilitation and managing.

This overall process, regardless of who the players are, needs to be facilitated and nurtured and for all team members to feel like equal players in the overall process.

Empowerment:

- **Leadership an issue, ICGP, PCTs and communities**

Senior leadership and commitment is evident, and this process is being driven through various strategic and policy documents which are outlined in this Framework document. In addition:

- Brian Murphy, National Primary Care Office, has signed off on this framework as too has the RDO for DML
- The ICGP were active participants in the national working group for the Joint Funded Initiative
- Community Participation is a Key Performance Indicator, and work has been supported nationally over the past two years to provide relevant case studies and resources to help people drive this agenda on the ground.

Community Representation – Terms of reference, definition.

Community representatives are those who serve as a platform and channel for information and voices of community, who communicate ideas and concepts **between** community and health and social services, and who hold people and processes accountable.

It is important to note that guaranteeing 'true representation' can be an impossible task. Service user involvement is perhaps more about a way of thinking that is able to progress beyond personal experience and apply such knowledge to broader healthcare issues.

If you have specific concerns in relation to the LIG and community representatives, you may initially consider placing interim reps. Such reps may be drawn form Local and Community Development projects (LCDP).
http://www.pobail.ie/en/LocalCommunityDevelopmentProgramme/ContactUs/

There are four key programme goals of the new LCDP programme:

1. Promote awareness, knowledge and uptake of a wide range of statutory, voluntary and community services.
2. Increase access to formal and informal educational, recreational and cultural development activities and resources
3. Increase the work readiness of people to enter the labour market.
4. Promote engagement with policy, practice and decision making processes on matters affecting local communities.

National Attention:

- Structural (org): 'Primary care becomes a box for everything'
- Mandate
- PCT may be seen as 'only' vehicle e.g. legislative issues taking power.

These are issues which will be brought to the attention to the national Primary Care Office to discuss with relevant senior management team members

Managing Expectations, Political agendas, Roles and Responsibilities, Accountability.

A number of key concerns raised (i.e. Managing expectations, political agendas, roles and responsibilities, accountability) are issues that can be managed when appropriate terms of reference and ground rules are established.

Time demands:

- Demand on community representative's time re: lunch or evening meetings
- Clinician time limits re: PHNs

Again there are increasing demands on everyone's time, but it is important to remember that major demands shouldn't need to be placed on community representatives or other team members.

Business team meetings are only held at most quarterly, and times and dates should be set well in advance. Given their infrequency but subsequent importance, they should be prioritised by all team members.

Difficulty identifying community groups in middle class areas.

Again this is an issue related to community 'mapping'. If it is difficult identifying community groups in middle class areas, simply look to other mechanisms/mediums where by you can communicate your message (e.g. Local GAA committee, parish committee, school committee).

Variances Across the System:

- Some areas don't have TDO or Social Network Manage!
- PCTs might not be working well - how will it be operable?
- Challenge of location of PCTs, Population size - 36,000 and 2 PCTs?

Yes there are clear variances across the system, much of which is beyond our control, and as those projects involved in the Joint Funded Initiative clearly demonstrate no two areas are alike. However the proposed Framework allows for enough flexibility to respond to local and regional variances, and the template for achieving service user involvement in primary care setting: practical suggestions allows for plenty of action to be taken regardless of such variances.

In terms of a lead it is important to remember that it need not be a TDO or Social Network Manager that leads out in this process. It does however need to be a 'champion' who is committed to this way of working and has the necessary skill set to engage, work in partnership and to think creatively and in a synergistic manner.