

A Framework for Implementation of Community Participation in Primary Healthcare

‘Participation is Integral’



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SUMMARY

Involvement of communities in primary healthcare results in more equitable and inclusive services, which are more responsive to the needs of the community. ¹⁻⁷

This Framework is designed to provide you with information about factors that promote community participation in primary healthcare, and about factors that make that work difficult to conduct and to sustain. It is based on national and international research about involving individuals and communities in primary healthcare. It is designed for use by all stakeholders who are involved in community participation in primary healthcare. Stakeholders include paid and unpaid personnel involved in community groups, paid or unpaid community representatives, general practitioners, HSE service planners, and managers and employees working in front-line primary healthcare services. Our research evidence indicates that there are four key issues that impact on the process and outcomes of community participation in primary healthcare – if they are well understood and managed then the chances of sustaining successful, meaningful community participation in primary healthcare increases. Below we present each issue with information about the ideal condition and a recommendation to achieve that ideal.

1: What is Community Participation in Primary Healthcare?

- Ideal – all stakeholders involved in community participation in primary healthcare can develop a shared understanding of this way of working.
- Recommendation – all stakeholders clarify their own understanding of community participation in primary healthcare and, through dialogue with each other, arrive at a shared understanding of community participation in primary healthcare with other stakeholders at the start of a community participation project.

1Kenny A, Hyett N, Sawtell J, Dickson-Swift V, Farmer J, O'Meara P. Community participation in rural health: a scoping review. BMC Health Services Research. 2013;13(64).

2WHO. Primary Health Care. Report of the International Conference on Primary Health Care. Geneva: World Health Organisation. 1978.

3WHO. Community Participation in Local Health and Sustainable Development: Approaches and techniques. Geneva: World Health Organization, Contract No. 4 2002.

4WHO. Primary Health Care: Now more than ever. Geneva: World Health Organization. 2008.

5Crowley P. Community Participation and Primary Care: Learning from the Building Healthy Communities Programme. Dublin: Combat Poverty Agency. 2005.

6Draper AK, Hewitt G, Rifkin S. Chasing the dragon: developing indicators for the assessment of community participation in health programmes. Social Science & Medicine. 2010;71(6):1102–9.

7Houlihan E. Ireland: Building Healthy Communities Programme. In: Koller T, editor. Poverty and Social Exclusion in the WHO European Region: Health systems respond. Copenhagen: World Health Organization. 2010.

2: Why do stakeholders get involved?

Ideal – all relevant stakeholders are engaged and work together to drive forward the implementation of a community participation in primary healthcare project.

Recommendation – stakeholders work together to clarify who needs to be involved and agree to work together to drive the implementation of a community participation in primary care project forward.

3: What is needed to do the work?

Ideal – all relevant stakeholders can participate effectively in community participation and primary healthcare activities.

Recommendation – all stakeholders should have appropriate organisational support, skills and training, trust in the work and the ability to perform all tasks involved in order to make an activity or process take place.

4: What impact does the work have?

Ideal – all stakeholders can see the positive benefits of community participation in primary healthcare.

Recommendation – stakeholders will appraise their work, using formal and informal systems, so that they can learn about what is working well and can modify work practices to maximise community participation in primary healthcare.

Go to Part 1 for information and interactive exercises to help you and other stakeholders to work through these four important issues to progress your work in community participation in primary healthcare together.

Go to Part 2 for detailed information about the research process and how we came to develop the recommendations.

In the spirit of community participation, all stakeholders who are interested in a community participation project in primary healthcare are invited to work together through the activities to develop a shared view and common approach to progressing their work.

If stakeholders cannot physically come together to complete the activities, they could complete them in their own time but ensure that the activities are discussed together regularly.

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FOREWORD

National and international health policies recognise that communities should be involved in shaping primary healthcare to promote shared decision-making and inclusion in the management of all aspects of health and illness.

This philosophy of involvement reflects a vision for user-led or user-centred services rather than service-led systems, and there is evidence of positive impacts in national and international settings.¹⁻³

A plethora of terms is used to describe and study this process. In the Irish setting, 'service user involvement' was used in the Health Service Executive's 2008 national strategy¹ as a general description of a range of individual- and community-level activities.

Community participation is one form of involvement and is a term used to describe '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'.² This Framework has community participation as its focus.

Following the publication of the *Strategy for Service User Involvement in the Irish Health Service 2008-2013* (2008)¹ and *Primary Care: A New Direction* (2001),³ the Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs (DCEGA) and the then HSE Office of Consumer Affairs jointly developed and funded the Community Participation in Primary Care Initiative (hereafter the Joint Initiative), which was designed to support disadvantaged communities and local health service providers to work together and plan for the participation of excluded communities and groups in local Primary Care Teams (PCTs) and networks, and in the implementation of *Primary Care: A New Direction*.³ The Initiative supported 19 demonstration projects in rural and urban locations across Ireland (Appendix 1A).

A research collaboration was formed in 2009 between the University of Limerick Graduate Entry Medical School (GEMS), the Health Service Executive (HSE) National Advocacy Unit in the Directorate of Quality and Patient Safety, community partners from national settings, and academic partners from national and international settings. The research collaboration was funded by the Health Research Board Research Award 2010 HRA-HSP-2010-2, the HSE and the GEMS.

The purpose of the research collaboration was to learn **what factors promoted or inhibited community participation activities in the sites involved in the HSE Combat Poverty Joint Initiative**. Our overall research aim was to synthesise these influences in order to produce a framework to support the implementation of community participation in primary care projects funded and initiated by the State. Given that the Framework is the result of *theoretically* informed research, some elements may be transferable to other kinds of individual- and community-level involvement activities.

During the research, participants emphasised that they regarded their work as being about primary healthcare in a broad sense rather than primary care services only. Therefore, the focus shifted and we have produced a **Framework to support the implementation of Community Participation in Primary Healthcare**.

The Framework is designed for use by all stakeholders who are involved in community participation in primary healthcare. Stakeholders include paid and unpaid personnel involved in community groups, paid or unpaid community representatives, general practitioners,

HSE service planners, and managers and employees working in front-line primary care services. We focus on the network of stakeholders that could or should work together on a project, which may be a one-off event such as a community health fair day or a longer process such as supporting a community garden, drug and alcohol awareness programmes, stress management programmes or supporting community representatives to work with Primary Care Teams.

The Framework is underpinned by an awareness that not all stakeholders have the same power and that it is easy, and all too common, to involve community members in a tokenistic rather than a meaningful way. However, every stakeholder has knowledge and expertise that is valuable and necessary for community participation in primary healthcare. Therefore, the Framework includes a series of interactive exercises designed to stimulate thinking among all stakeholders about the influences on community participation, and to encourage stakeholders to *share their knowledge and expertise* with each other and to *learn from each other* (Part 1).

Full details of the research – a critical review of the national and international literature about 'service user involvement' in primary care research and development projects, and a comprehensive theoretically informed case study analysis of four sites involved in the 'Joint Initiative' that informed the development of this Framework – are provided in Part 2.

We invite people to use this Framework to enhance their understanding of community participation in primary healthcare projects and to develop collaborative working and partnerships to realise this way of working in an equitable fashion.



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¹ HSE, DoHC. *Strategy for Service User Involvement in the Irish health service 2008-2013*. Dublin: Health Service Executive and Department of Health and Children, 2008.

² Pillinger, J. *Formative Evaluation of the Joint Community Participation in Primary Care Initiative*. Dublin: Department of Community, Equality & Gaeltacht Affairs and Health Service Executive, 2010.

³ DoHC. *Primary Care: A New Direction*. Dublin: Department of Health and Children, 2001.

PART 1

INTRODUCTION

Introducing key terms

This Framework is designed to support the implementation of community participation in primary healthcare projects funded and initiated by the State.

Community Participation in Primary Healthcare can be a specific project for a short period of time for example, organising a community needs assessment or a longer process, for example supporting a community garden, drug and alcohol awareness programmes,

stress management programmes or community representatives to work with Primary Care Teams. We recommend that each person and group using this Framework takes time to clarify which kind of project they are focusing on.

Community Participation in Primary Healthcare refers to 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’.¹

Primary healthcare refers to a wide variety of activities, some of which involve medical or clinical services and some of which do not. The range of activities could include a community garden project designed to promote health and well-being, drug and alcohol awareness programmes, stress management programmes and community representatives working with Primary Care Teams.

This Framework is based on evidence from a major research project involving:

- A critical review of the research literature from Ireland and abroad.

- Qualitative research with stakeholders involved in community participation in primary healthcare projects around Ireland that were funded through the Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs (DCEGA) and the HSE Office of Consumer Affairs Community Participation in Primary Care Initiative – known as **the Joint Initiative**.

The research process is described in full in Part 2.

The evidence from this research is that meaningful community participation based on partnerships across agencies can achieve tangible, specific outcomes for all key stakeholders. **Stakeholders** include paid and unpaid personnel involved in community groups, paid or unpaid community representatives, general practitioners, and HSE service planners, managers and employees working in front-line primary care services.



¹ Pillinger J. Formative Evaluation of the Joint Community Participation in Primary Care Initiative. Dublin: Department of Community, Equality & Gaeltacht Affairs and Health Service Executive, 2010.

All stakeholders have relevant expertise but do not necessarily have the same power as each other. Once stakeholders start working together from across agencies and organisations, it is good to ask: who decided on the necessity for the project?

Who decides on scope of project? Who has power over financing? Who has power to make ultimate decisions? Clarify how power dynamics will be managed – how will decisions be made in an inter-stakeholder group?

The following quotes are from a variety of stakeholders who participated in our research study and talked about the impact of community participation in primary healthcare projects that they were involved with.[^]

... this process [through the Joint initiative] has allowed for the communities within the specific primary care team regions that never would have worked together, to actually network together and share resources. And that's quite key, that's been an impact. (Bree, Community Support Worker)

... it [the Joint Initiative] did serve to create a huge amount of awareness about the primary care team and especially the information directory [i.e. local services available] ... And the relationships that were built up were definitely very valuable as well. (John, HSE employee)

They [community representatives] co-ordinate some of the voluntary bodies and the drop-in centres and the men's groups and women's groups around the community ... and those are all very important functions

especially in an area like this which is relatively deprived, with high unemployment rates and a certain amount of social problems. (Tom, GP)

'It [the JI] really was positive. The people who were on it, I don't think they were just being positive with us because we were their GPs, they were positive because when they saw everything they realised that we were providing more or less a lot more than other practices were. (Dock, GP)

... we had huge success within the community ... the gardening and mental health programme, the green prescription, and different aspects of that and that has been obviously through our involvement in the primary care team. (Tess, Community Representative on Primary Care Team)

The evidence is that, to achieve positive impacts and sustain community participation in primary healthcare, stakeholders need to work together in a network and consider four interrelated issues:

1. The meaning of community participation
2. Getting stakeholders involved
3. Getting the work done
4. Evaluation of community participation.

[^] All names are pseudonyms. For further information about the research that led to the development of this Framework, see Part 2.

Our research evidence indicates that if these four issues are well understood and managed then the chances of sustaining successful, meaningful community participation in primary healthcare increases.

The evidence also indicates that these four are *very fluid*. Things can change over time. These four areas are also *interlinked*. For example, a stakeholder's understanding of what community participation means may change over time as they gain experience of getting the work done and see the outcome of evaluations.

In this section, we present:

- **The ideal conditions** for implementing community participation in primary healthcare in Ireland
- Specific **recommendations** to achieve those ideals
- A series of **activities** to stimulate critical thinking about the process and outcomes of community participation in primary healthcare.

The Framework is designed to support new projects or ones that are underway.

Activities involve:



'TASKS' to support the work.



'REMEMBER POINTS' to highlight the fluidity of, and interconnections between, the sections.



'THINK POINTS' to encourage reflection on your work or project and to see if anything has changed or can be changed in order to improve community participation in primary healthcare

In the spirit of community participation, all stakeholders who are interested in community participation in primary healthcare are invited to work together through the activities to develop a shared view and common approach to progressing

their work. If stakeholders cannot physically come together to complete the activities, they could complete them in their own time but ensure that the activities are discussed together regularly.

The meaning of community participation in primary healthcare

Recommendation – all stakeholders clarify their own understanding of community participation in healthcare and, through dialogue with each other, arrive at a shared understanding of community participation in primary healthcare at the start of their work together.



REMEMBER

Stakeholders' understanding of community participation can change *over time* based on their experiences, so it is valuable to *return to this point* occasionally as a group to ensure that there is still a shared understanding.

Community participation in primary healthcare is a ***new way of working*** for many in the Irish context. It is generally regarded as something different from the 'usual' or routine way of working in primary care. This can create interest and energy. However, it can also create uncertainty and fears, including concerns as to how communities can be meaningfully involved, which community members should be involved, who exactly they are representing, what their role will be, whether they will have any real power, whether the emphasis will be on criticising primary care or whether there is scope for meaningful dialogue and exchanges of ideas to improve service provision, health and well-being.

process such as drug and alcohol awareness programmes, stress management programmes or involving community representatives on Primary Care Teams.

- Often used interchangeably even though they are about different (albeit related) kinds of activities – this can cause confusion.
- Used within groups of stakeholders who work together but who have not had an opportunity to clarify their preferred terms and develop a shared understanding of community participation in primary healthcare – this can cause frustration.
- Sometimes used only because they are ‘fashionable’ but without stakeholders having a full understanding of the work involved – this can lead to tokenistic activities.



Here are some examples of terms used in this work to stimulate your thinking... but you may have others to add to this list. What do you think...

1) Service user involvement or
Community participation in
primary health care or
Public and patient community
involvement or

3) How can I explain to others what this term means to me? What examples can I provide of meaningful participation?

After talking about this
with other stakeholders...

5) Stakeholders in this project have the following preferred terms ...

2) My preferred term is...

4) How will I let people know what I feel?

6) Our agreed term for our work together is



1) How is this similar to the way I currently work?

3) What concerns or interest might I have in this way of working?

- What is making me feel interested?
- What is making me feel concerned?

2) How is this different to the way I currently work?

4) How will I let others know what I feel?

Stakeholders with a community development or social inclusion background are usually very familiar with community participation and are clear about its aims, objectives and benefits. However, other stakeholders may be less familiar with this way of working and less clear about its aims, objectives and benefits.

It is also necessary for stakeholders to *form meaningful partnerships* between service providers in primary healthcare and community development organisations. This enables an exchange of expertise and ideas about community participation and its potential benefits.



THINK!

Stakeholders should ask themselves – *what benefits do I think community participation may have to offer (me and/or my organisation/ community)? How will I know whether this is a meaningful partnership or not?*



TASK!

Clarifying People Involved

Looking at the visual below and the list of potential stakeholders, make a list of the people or types of people who you could or should try to form a meaningful partnership with.



WHERE POSSIBLE, LIST NAMES AND CONTACT NUMBERS FOR EACH STAKEHOLDER GROUP

2

3

4

5

6



THINK!

NOTES PAGE

SECTION II

Getting involved

Ideal – all relevant stakeholders are interested and willing to work together to drive forward the implementation of community participation in primary healthcare.

Recommendation – stakeholders work together to clarify who needs to be involved and agree to work together to drive the implementation of community participation in primary healthcare forward.

The purpose of this recommendation is to ensure that stakeholders from relevant organisations and with relevant responsibilities and relevant expertise are involved and are working together to implement a project.

Opportunities and challenges

When any new way of working is proposed it is important that there are champions to drive it forward and encourage others to become involved. There are many positive examples of champions for community participation in primary healthcare in the Irish context.

At the same time, there are many personnel changes due to HSE restructuring and the effects of budget cuts in the HSE and community sector. Certain champions of community participation in primary healthcare may no longer be available. These personnel changes impact on continuity and progress of relationships, partnerships and projects.



REMEMBER!

It is important to *clarify the meaning* of community participation for different stakeholders at the outset of the project so that everyone is driving the implementation of *the same kind of project*.



TASK!

Identifying champions to drive community participation in primary healthcare forward.

This is a good activity for stakeholders who have experience of community participation in primary healthcare – drawing on this experience, complete this table about champions:

Names of key champions	What did they do?	Are they still available?	Who else in my network can I discuss this with?	Names of possible alternative champions?

A key role of champions is to encourage others to get involved and to ‘buy into’ community participation in primary healthcare. There are many examples of individuals from the community and the HSE who get involved simply because they were asked to do so by an enthusiastic and persuasive champion. On the other hand, some individuals from the HSE get involved because they have to as part of their professional role. This means that

some stakeholders may be involved without having a clear understanding of the work and what is required of them. Some individuals from community settings are involved because it is part of their paid role for a community organisation and others are volunteers or representatives of a local community group who aim to speak for their wider community.



TASK!

Thinking about why you got involved.

Think of the following questions in terms of you as an individual first and then share your thoughts with others involved with you in community participation in primary healthcare.

Why did/would I get involved in community participation in primary healthcare?

If not, is there a manager/ colleague/peer that I could discuss my experiences and concerns with?

Do I believe it is right for me to be involved in this work?

Who else in my network do I think has responsibility and/ or expertise for this work?



THINK!

*Can you identify a key person in the HSE or community who could take on a role as champion?
Can you initiate a meeting and identify a date for speaking together?
Can you be a champion?*



REMEMBER!

It is important that all relevant groups and agencies are involved – remember to ask how representative the stakeholder group is. Is any important stakeholder missing from the network? Do the individuals from various groups

and agencies represent their wider network or community? Be mindful of the stakeholders that are not always so vocal or visible within the community and may require a voice!

SECTION III


Getting the work done

Ideal - Community participation in primary healthcare activities and processes take place.

Recommendation – stakeholders have appropriate resources, skills and training, trust and confidence in each other’s work and the ability to perform all tasks involved in order to make an activity or process take place.

The purpose of this recommendation is to ensure that efforts to conduct community participation in primary healthcare are supported appropriately so that stakeholders, as individuals and as a group, can carry out their roles and responsibilities for their project.

- 4. Champions in community organisations with protected time to drive forward and co-ordinate community participation in primary healthcare activities.
- 5. A named and dedicated champion at primary care team level to drive the work.
- 6. Protected time for HSE service planners and front-line providers for community participation in primary healthcare activities.
- 7. Protected time for personnel from community organisations to attend relevant meetings and activities in order to represent the views of the specific community group that they are working with.
- 8. Expenses, e.g. travel expenses, childcare costs to enable people living in the community to become involved in an activity or process.
- 9. Resources for GPs to support and endorse the work, and to work with PCT members and community representatives.
- 10. Pooling of HSE and community resources, e.g. sharing of suitable venues in communities to carry out the work or combining training events.
- 11. Partnerships with good working relationships between all participants based on equality and respect for individual roles and expertise.
- 12. Resources for regular, interim evaluations of activities to explore impact and the scope to modify practice and improve impact.



Sometimes people’s understanding of community participation changes when they see a specific activity or process in action. Remember to check in with each other at regular intervals to clarify understanding! Has anything changed for any stakeholder?


Opportunities and challenges

Resources for projects

Community participation in primary healthcare relies on resources. It cannot and should not rely on goodwill of, or ad hoc arrangements between, HSE or community personnel.

There are a number of resources that need to be available in an organised way:

- 1. A clear policy in favour of community participation in primary healthcare in the HSE and community organisations.
- 2. Managers or leaders in senior positions in the HSE who can make sense of community participation and are keen to support colleagues’ engagement with projects.
- 3. A champion at a senior level in the HSE to drive the work forward.



What other resources would you add based on your context or experience?



Think about your context – your role at present. What resources are available and which ones are missing? Are there actions you or someone in your network can take to address missing resources?

Available resources	Missing resources	Actions to address missing resources



Different stakeholders have different power. Think about stakeholders who are involved or who could be involved who have power to make decisions about resources.

Skills to do the work

Community participation in primary healthcare can take on many different forms (see APPENDIX 1A, Part 1) and, therefore, the skills required will vary depending on the specific activity or process involved. However, there is a core set of skills that are required for all kinds of community participation in primary healthcare. Skills in facilitation, chairing, energising and LISTENING are really important for formal and informal

interactions, all of which influence the quality of stakeholder relationships.

The work is also strengthened if stakeholders have basic and clear knowledge about the principles of community participation.



TASK!

Think about the focus of your activities for community participation in primary healthcare. Reflect individually and with others in your network about the skills and training you will need. Complete this table and analyse strengths, gaps and training opportunities.

Person's name	Skills we have	Skills we need	Training opportunity



REMEMBER!

A gap in training can be addressed by inviting a new stakeholder to join the partnership – look back at the previous section about ‘getting involved’ and think again about the network of stakeholders. Are there new people with important skills that can be identified and invited to join the existing network?

Working styles

Community participation benefits from good relationships and a strong sense of trust in the expertise of individuals involved. Given that community participation in primary healthcare requires working in partnership across agencies and sectors, different stakeholders involved will often have different working styles. It is important that those involved are willing to get used to different working styles and respect each other’s backgrounds and skills. This can mean initially

trusting a process that may feel unusual and sometimes a little uncomfortable. General practitioners are used to having to make decisions in short periods of time, and find long meetings with lots of discussion unusual or unworkable. Community development workers are used to long meetings with time for social interaction and debate. Neither way of working is right or wrong; each is a function of professional training and organisational set-up!



TASK!

What is your own background, context and usual working style for meetings?

What is the mix of working styles in the stakeholder group involved in the project?

What can be done to manage the different working styles involved?



TASK!

Roles and responsibilities

In community participation in primary healthcare, things run smoothly when stakeholders are clear and happy about their roles and responsibilities. It is important to spend time discussing and clarifying a 'division of labour' that is workable.

What are the roles and responsibilities involved in our work/my area?

What roles and responsibilities do I think others can take on?

What roles and responsibilities can I take on?

When can I meet others in my network and discuss this to see if we are all on the same page?

The skill of listening is very important in all relationships. Community participation in primary healthcare relies on active listening to demonstrate meaningful involvement.

Below are five core principles of active listening. ^^

1. Physical attention: face the person who is talking, notice the speaker's body language, match the speaker's body language and try not to do anything else while you are listening.
else, reflect the speaker's feelings by saying things like 'Are you saying that you're angry/disappointed/glad, because...?' 'It sounds like you feel....'
2. Paraphrasing: show you are listening and understanding what is being said, check the meaning and your interpretation, restate basic ideas and facts, check to make sure your understanding is accurate.
3. Reflecting: show that you understand how the person feels, help the person evaluate his or her feelings after hearing them expressed by someone
4. Clarifying: help clarify what is said, get more information, help the speaker see other points of view, use a tone of voice that conveys interest; ask open-ended questions, as opposed to yes/no questions, to elicit more information.
5. Encouraging: show interest by saying things like 'Can you tell me more about that?' 'Really?' 'Is that so?'

Ideally, resources, strong skill-sets, clear divisions of labour and good working relationships characterised by trust lead to interactions between community and HSE personnel that are

meaningful rather than tokenistic. A final task in this section is to take time to reflect on your experiences and views about meaningful involvement.

^^ Available from: <http://www.buildingpeace.org/sites/usip.qorvisdev.com/files/Core%20Principles%20of%20Active%20Listening%20Handout.pdf>



What is meaningful involvement? Consider the following questions...

When do you know you have been listened to at a meeting?

When do you feel involved?

How do you know if a meeting has been meaningful and not tokenistic?

How do your views on this compare with others from the stakeholder group?

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SECTION IV

Evaluating community participation in primary healthcare

Ideal – all stakeholders have clear information to determine the impacts of community participation in primary healthcare.
Recommendation – stakeholders use formal and informal methods to learn about what is working well and what can be modified to maximise the positive impacts of community participation in primary healthcare.

People working in community and healthcare settings are often tired of evaluations. However, understanding the impact of community participation in primary healthcare is really crucial, because knowing about impact means that stakeholders can:

- See whether their efforts are worthwhile,
- Make informed decisions about their involvement in this work, and
- Develop appropriate mechanisms to demonstrate outcomes from community participation in primary healthcare.

Therefore, the purpose of this recommendation is to ensure that there is clear information about the impact of community participation in primary healthcare.



REMEMBER!

There will be different ways to learn about the impact of community participation in primary healthcare depending on the kind of project that you are working on – a one-off event like a community needs assessment or health fair day compared with a process of delivering drug and alcohol awareness programmes, stress management programmes or supporting community representatives to work with Primary Care Teams.

Here are some key issues to consider when thinking about evaluating the impact of community participation in primary healthcare.

When to evaluate? *Formative* evaluations, which take place during the course of a community participation activity, are helpful because they can be used to provide feedback to all involved *during the course of the work*. This can alert stakeholders to modify their ways of working if need be. *Summative* evaluations take place at the end of an activity or process and aim to capture the overall experience or outcomes.

Opportunities and challenges

‘Impact’ may relate to some feature of the process or to some end result or product. Evaluations produce evidence of many different kinds of outcomes for different stakeholders. For example, there is scope for:

- Better understanding about the social determinants of health among clinicians in PCTs.
- People in the community to become more aware of how they can influence health outcomes in their own community setting and what health and social care services are available.
- Improved communication and referrals between HSE and community organisations.
- Stronger relationships between and across HSE and community settings.

These outcomes do not happen overnight and are hard to see and to measure in traditional ways. However, overall, stakeholders rightly expect that the lessons they learn about and from community participation will shape the way services are organised and structured. Lessons from the ‘grass roots’ community settings should be used to inform HSE service planning and Irish health policy. This is an important sign of HSE support for community participation in primary healthcare. It will keep the momentum going rather than having projects that are short term and unsustainable.

How to evaluate? Formal evaluations using surveys or interviews can be helpful, but it is important to remember that stakeholders’ informal appraisals of their experiences are extremely influential as well – what are people *saying to each other* about community participation in primary healthcare?



TASK!

Formal appraisals include:

- Surveys
- Focus groups
- Interviews

Informal evaluations include:

- Briefings
- Conversations
- Staff meeting discussions

What methods do I think are relevant?



TASK!

Think about the impact of community participation in primary healthcare and answer the following questions. Discuss your answers with others in your network.



Finally, remember that the process and outcomes of your work will be influenced by the extent to which everyone involved has had a shared understanding of the aims and objectives of the work and whether there were strong champions in place and appropriate resources, skills and relationships for stakeholders to work together. ‘Success’, seeing positive outcomes from evaluations, is dependent

on all of the factors presented in this Framework. Take this into account when developing evaluations of impact, because **it is necessary to know if the project did not work because these factors were not in place or not well-developed or whether the project had the necessary conditions but still did not reach the required goals.**

FINAL SECTION

Bringing it all together

When you think about your project overall, how you would rate the work of your team/project at this point in time? Is there room for improvement?

Use this checklist as an opportunity to develop your project and work further, and discuss with your colleagues and all stakeholders.

Where are you on the chart? Are you emerging, or have you attained excellence in delivering community participation in primary healthcare?

		Emerging improvement	Continuous improvement	Sustained improvement	Excellence
The meaning of community participation in primary healthcare	Do all stakeholders have a shared understanding of community participation in primary healthcare?				
Getting involved	Have stakeholders clarified who needs to be involved and agreed to work together to drive the implementation of a community participation project in primary healthcare?				
Getting the work done	Do stakeholders have appropriate organisational support, skills and training, trust in the work and the ability to perform the tasks involved?				
Evaluating community participation in primary healthcare	Can stakeholders appraise their work, using formal and informal systems? Can they modify work practices to maximise community participation in primary care?				

Key:²

- Emerging Improvement: a strong recognition of the need to further develop and improve community participation in primary healthcare projects.
- Continuous improvement: there is significant progress in the development, implementation and monitoring of community participation in primary healthcare projects.
- Excellence: the team develops an identity as an innovative leader in consistently delivering good experience, excellent quality and a high level of community participation in primary healthcare.

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² Health Service Executive (2013) A Practical Guide: Supporting services to delivery quality healthcare. Quality and Patient Safety Directorate, HSE.

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APPENDIX 1A

Summary Table of activities in the Joint Initiative ¹

Lead community partner	CP steering group	Community consultations	Community Needs Analysis	Joint Training	CP training for PCT members	Training for community reps	Community health forum	Sustainability built into project
HSE West								
Roscommon	*	*		*		*	*	*
Mayo	*	*	*			*	*	*
Leitrim	*	*	*	*		*	*	*
Belmullet	*	*				*	*	*
Limerick	*	*	*	*		*	*	*
Donegal	*	*	*	*	*	*	*	*
HSE South								
Bantry	*	*	*	*		*		*
Wexford	*	*				*		*
Waterford	*	*				*		*
Clonmel	*	*	*	*			*	*
HSE DML								
Westmeath	*	*		*		*	*	*
Tallaght	*	*	*		*			*
Fatima	*	*	*			*	*	*
Offaly	*	*	*		*		*	*
HSE DNE								
Blanchardstown	*	*	*			*		*
Blanchardstown	*	*	*	*			*	*
Monaghan	*	*						*
Finglas	*	*				*		*
Pavee Point	*	*				*		*

PART 2

The Development of the Framework

INTRODUCTION

Development of the Framework

The development of this Framework was informed by a sociological theory called Normalization Process Theory (NPT)¹ (see Table 1 in Appendix 2A). This theory was designed to enhance understanding about factors that promote or inhibit the implementation of innovations or complex interventions in healthcare settings, and has proved useful for studying a wide variety of innovations and interventions.² NPT can be used to raise awareness about the work that stakeholders have to do to implement a new way of working in a healthcare setting.

This Framework is the first application of NPT to community participation in primary healthcare. The benefit of using NPT is that some of the recommendations about community participation in this Framework may be transferrable in to other forms of involvement in other HSE and community settings.

The development of the Framework was undertaken in two parts:

1. **A review of international and national literature.**
The aim of this review was to critically interrogate the conditions for the implementation of 'service user involvement' in both primary care research and health service development projects in order to make recommendations that will enhance chances of its normalisation. We used the term Service User Involvement (SUI) because this is the terminology employed by the Health Service Executive (HSE) in Ireland in its Strategy for Service User Involvement 2008. We focused on a sample of original published empirical work that is reported as service user

involvement in the primary care literature to rigorously examine the way definition, enrolment, enactment and appraisal are reported vis-à-vis each other.³

The review was conducted by a multidisciplinary and inter-agency team, which included community representatives (see Table 4 in Appendix 2B). We searched the international literature for relevant papers from 2007 to 2011. We engaged in an iterative process to identify relevant papers and learn from them, using a critical interpretive synthesis approach⁴ and NPT. From an initial sample of 289 papers, 26 were chosen as a relevant sample of work and were analysed extensively. See Appendix 2C for a detailed academic description of our methodology.

2. **Two complementary theoretically informed qualitative research studies** based on the case of the Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs (DCEGA) and the HSE Office of Consumer Affairs Community Participation in Primary Care Initiative (the Joint Initiative).

The Joint Initiative 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*.⁵ The Initiative supported 19 demonstration projects in rural and urban locations across Ireland. For a description of projects and activities see Appendix 1A in Part 1.

1 May C, Finch T. Implementation, embedding, and integration: An outline of Normalization Process Theory. *Sociology* 2009; 43(3):535–54.
2 McEvoy R, Ballini L, O'Donnell C, Mair F, MacFarlane A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. *Implementation Science* 2014; 9:2.
3 Tierney E, McEvoy R, O'Reilly-de Brún M, de Brún T, Okonkwo E, Dowrick C, Rogers A, MacFarlane A (in press) A critical analysis of the implementation of service user involvement in primary care research and health service development using Normalization Process Theory. *Health Expectations*. doi: 10.1111/hex.12237
4 Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology* 2006;6:35.
5 DoHC. *Primary Care: A New Direction*. Dublin: Department of Health and Children, 2001.



Study 1 was designed to explore the following issues with national and regional drivers of the Joint Initiative:

- Identify the ideal conditions for policy implementation of community participation in primary healthcare.
- Explore the process of implementing the Irish National Strategy for Service User Involvement.
- Make recommendations to maximise opportunities for policy implementation.

Study 2 was designed to explore the following key questions about the Joint Initiative with community and HSE participants:

- What definitions of community participation are being used in community participation projects in primary healthcare?
- How did stakeholders get involved in community participation projects?
- What methods were used to enact community participation in primary healthcare?
- What are the outcomes of community participation in primary healthcare involvement projects?

We received ethical approval for both of these studies from the Irish College of General Practitioners (ICGP).

Data generation and analysis

Based on principles of a participatory research approach, we carried out semi-structured interviews (studies 1 and 2) and focus groups (study 2) with a purposeful sample ($n = 72$) of community representatives ($n = 43$), GPs ($n = 3$), HSE personnel ($n = 25$) and a project evaluator ($n = 1$). We also utilised documentary evidence (study 1). We developed a topic guide for generating data with stakeholders. The topic guide was developed based on study aims and objectives and NPT.

Questions were changed or rephrased as the study progressed, based on feedback and learning during interviews and focus groups. All data were analysed using NPT to explore the findings and enhance interpretation of the data.

In study 2 we used interactive techniques during focus groups to stimulate data generation, e.g. participatory research techniques such as flexible brainstorming⁶ to enhance group participation.

Stakeholder involvement

The *research team* for developing this Framework comprised academics, health authority personnel, clinicians and community organisation representatives (see Appendix 2B).

A *steering group* oversaw each study (see Tables 2 and 5 in Appendix 2B) and review meetings were held with

the steering groups to discuss progress and any arising issues. Steering group members included experts from international universities, members of community organisations, the HSE and an independent research consultant.

For the *fieldwork*, we involved stakeholders representing different perspectives of the Joint Initiative:

- Principal applicants to the Joint Initiative from HSE and community settings.
- Community representatives (paid and unpaid) who have been involved in community health projects, primary care teams (PCTs) and/or community health fora.
- HSE staff or service providers who are working in PCTs.
- HSE service planners and policy makers who oversee the development of PCTs and ongoing community participation projects.
- General practitioners.

In terms of sample size, study 1 participants ($n = 32$) consisted of the principal applicants (PAs) i.e. those who applied to the Joint Initiative from both the HSE ($n = 11$) and community ($n = 14$) from across 15 of the 19 project sites. Seven of the 18 members of the national Joint Initiative steering group also participated.

In study 2, participants ($n = 39$) were identified via gatekeepers at four sites involved in the Joint Initiative. These gatekeepers had responsibility for recruiting participants and for identifying who may be suitable for participation in study 2. These gatekeepers liaised with the researcher regarding initial contact with participants, as well as communication during and after the fieldwork. Four case study sites were chosen to represent different geographical areas, different levels of experience with community participation and indigenous and migrant communities in study 2.

In terms of methods for data generation, in studies 1 and 2 we interviewed the principal applicants, HSE personnel, GPs and HSE policy personnel. In study 2, focus groups were used with community representatives and were beneficial to elicit shared and differential views about community participation projects.

In keeping with good practice in qualitative research, all case study sites were coded for anonymity, and in study 2 research participants chose their own pseudonyms to preserve their anonymity. These research participants had the opportunity to comment on emerging findings and to make suggestions for the content of the Framework.

Finally, to *involve community members and other stakeholders* we organised the following.

- A **welcome event** was held in March 2010 to raise awareness of the project and its objectives. Stakeholders representing a variety of perspectives attended this event.
- A **research newsletter** was circulated to all stakeholders by e-mail in June 2013 to provide an update about our progress.
- **Involvement of research participants from community and HSE settings** in the launch and dissemination of the Framework in 2014.

⁶ O'Reilly-de Brún M, de Brún T. Participatory Learning and Action (PLA) Training Manual – internal document, Centre for Participatory Strategies, Galway, Ireland, 2011.

Quality and rigour in the research process

To ensure quality and rigour in the research process we employed a number of strategies known to enhance critical thinking and interpretation of data:

- We held regular research team meetings and data analysis clinics throughout the project to discuss the research process and emerging findings.
- We used reflective notes to capture researchers' thoughts and critical thinking.
- We met with the steering groups of both projects to get their input and reflections on the work and emerging findings.
- Feedback sessions took place with research participants at the four case study sites of study 2 to validate and check emerging research findings.
- Transcripts were sent to all research participants following interviews and focus groups. Any edits or comments were included for data analysis.

Developing the recommendations

Taken together, the critical review of the research literature of service user involvement and the fieldwork about community participation from studies 1 and 2 provided important data about involvement in practice in Ireland and abroad. We explored the meanings of involvement, why stakeholders get involved, what methods are used in projects and how the work is appraised. We compared these data about the practice of involvement and the ideas in NPT to enhance our understanding of the complex interplay between individual, organisational and social factors, and to clarify the *ideal* conditions for implementing community participation in primary healthcare. This exercise enabled us to develop specific *recommendations* across a number of key areas.

Finally, for this Framework we devised a series of *activities* designed to influence stakeholders' work in relation to community participation in primary healthcare. This involves:

- 'thinking work' – thinking about what the term 'community participation' means and who needs to be involved to drive a project forward, and
- 'doing work' – activities to enact community participation in real space and time, and to appraise the value and impact of the project.

We shared the draft Framework with research

participants from studies 1 and 2. We asked participants about this content and what information they felt would be important to include in a framework for implementation of community participation in primary care. We also asked them to suggest exercises or questions which they felt would be useful as workbook-like exercises for individuals or teams implementing community participation in primary healthcare settings.

All feedback was recorded and returned to participants via e-mail to check understanding, informing them that this information would be used in the development of the Framework document.

There were no major disagreements or contentions regarding the content of the Framework. Some clarity was sought about specific issues, e.g. who the Framework was intended for and what our working definitions were for key concepts such as community participation and primary healthcare. We edited the Framework accordingly.

Therefore, each recommendation in Part 2 of this Framework has been devised with a specific link to the data formulated during the fieldwork and to feedback from stakeholders involved in the research.

The recommendations were also developed in accordance with international guidance from the AGREE II Guidelines for quality guideline development.⁷

7 Brouwers M, Kho ME, Browman GP, Burgers JS, Cluzeau F, Feder G, Fervers B, Graham ID, Grimshaw J, Hanna S, Littlejohns P, Makarski J, Zitzelsberger L for the AGREE Next Steps Consortium. AGREE II: Advancing guideline development, reporting and evaluation in healthcare. Canadian Medical Association Journal 2010; 182:E839-842; doi:10.1503/090449

External review of the Framework

This Framework has also been reviewed by an external panel of experts. This panel was independent and its members were not involved at any stage of the research.

We chose the expert panel because they represent different expertise and perspectives on community participation in primary healthcare, and they are currently working in a variety of primary healthcare settings.

The expert panel included community representatives, health professionals working in primary care teams and public health, HSE social inclusion staff, academics and

GPs (see Table 6 in Appendix 2B).

The purpose of the external review was to test the content of the Framework and its applicability to real life settings, and to assess its accessibility for a range of audiences.

When we had completed a draft of the Framework, we e-mailed it to the expert panel and asked them to review the content and layout. We then asked them for their comments and feedback, and incorporated this feedback in the final version of the Framework presented here.

Updating the Framework

This Framework was developed from the results of the literature review and fieldwork carried out and completed in 2013. We are aware that policy and practice change, and our recommendation is that this Framework be reviewed in three years, ideally as an academic, community and HSE partnership project.

This Framework has been developed as an interactive tool for all stakeholders. This is not available online, and we acknowledge that an interactive online tool would be a good next step.

This would enable us to update the Framework regularly

with online interactive feedback on tool content also.

We acknowledge that this Framework was developed in a particular context, i.e. based on findings from two studies which explored community participation in State-funded projects within the context of the Joint Initiative. However, we believe that the recommendations in this Framework, which are based on a relevant sociological theory, may have a transferability and relevance across a variety of contexts for many activities and projects that have meaningful individual and community involvement as the core objective.

Resources

We are aware that implementing this Framework is resource dependent.

By its very nature meaningful community participation in primary healthcare takes time, and this must be built into the work and planning for resources.

Below we have outlined the resources that emerged in the fieldwork as being vital for community participation in primary healthcare to happen.

The resources that are crucial in the implementation of this Framework are:

1. A clear policy in favour of community participation in primary health healthcare in the HSE and community organisations; managers or leaders in senior positions in the HSE who can make sense of community participation and are keen to support colleagues’ engagement with projects.
2. A champion at a senior level in the HSE to drive the work forward.
3. Champions in community organisations with protected time to drive forward and co-ordinate community participation in primary healthcare activities.
4. A named and dedicated champion at primary care team level to drive the work.
5. Protected time for HSE service planners and front-line providers for community participation

in primary healthcare activities.

6. Protected time for personnel from community organisations to attend relevant meetings and activities in order to represent the views of the specific community group that they are working with.
7. Expenses, e.g. travel expenses, childcare costs to enable people living in the community to become involved in an activity or process.
8. Resources for GPs to support and endorse the work, and to work with PCT members and community representatives.
9. Pooling of HSE and community resources, e.g. sharing of suitable venues in communities to carry out the work or combining training events.
10. Partnerships with good working relationships between all participants based on equality and respect for individual roles and expertise.
11. Resources for regular, interim evaluations of activities to explore impact and scope to modify practice and improve impact.

Costs should be built into the development of each primary care team when setting up and negotiating membership of the primary care team.

Editorial independence

The views of the funding body HRB have not influenced the content of this Framework.

APPENDIX 2A

Table 1: Community Participation in Primary Healthcare and Normalization Process Theory (NPT) ³

Question re community participation in primary healthcare	Problems in the practice of community participation in primary healthcare	NPT construct
How is service user involvement defined?	Definition: Multiple terms are in use. People use the same terms to mean different things. There is a lack of shared understanding about what the work involves across stakeholders.	Coherence
Why do stakeholders get involved?	Enrolment: There is a lack of clarity about why different stakeholders get involved. People get involved for different reasons and there is a lack of understanding about the roles that people play.	Cognitive Participation
What methods are used?	Enactment: Involvement can be tokenistic. There is often a lack of adequate resources and skills to do the work meaningfully. Stakeholders are not clear about their individual roles.	Collective Action
What are the outcomes?	Appraisal: It is difficult to evaluate the impact of community participation in primary health care. Evaluation is often ad hoc and/or anecdotal.	Reflexive Monitoring

APPENDIX 2B

Table 1: Research Team Membership Study 1

People involved
This work has been supported by a large number of people, some of whom had multiple roles in the research. The tables below specify contributions to the research team and steering group for Study 1 and Study 2, the literature review group for Study 1 and the Expert Advisory Group for this Framework document.

Prof. Anne MacFarlane	Professor of Primary Health Care Research	Graduate Entry Medical School, University of Limerick, Ireland.
Ms. Rachel McEvoy	Senior Researcher PhD Student (2010-2014)	National Advocacy Unit (2011-2013), Health Service Executive, Ireland. Graduate Entry Medical School, University of Limerick, Ireland.
Prof. Catherine O' Donnell	Professor of Primary Health Care Research and Development PG Convenor	Institute of Health and Wellbeing, University of Glasgow, Scotland.

Table 2: Research Steering Group Study 1

Prof. Anne MacFarlane	Professor of Primary Health Care Research.	Graduate Entry Medical School, University of Limerick, Ireland.
Ms. Rachel McEvoy	Senior Researcher PhD Student (2010-2014)	National Advocacy Unit (2011-2013), Health Service Executive, Ireland. Graduate Entry Medical School, University of Limerick, Ireland.
Ms. Elaine Houlihan,	Social Inclusion Division (2010)	Department of Community, Equality and Gaeltacht Affairs, Ireland.
Ms. Mary Culliton	Assistant National Director	National Advocacy Unit (2010), Health Service Executive Ireland. Independent Advisor (2011-2014)
Dr Jane Pillinger	Independent Social Policy Research Consultant	Independent Researcher and Social Policy Analyst Ireland.
Prof. Anthony Staines	Professor of Nursing and Human Sciences	Dublin City University, Dublin, Ireland.
Ms. June Boulger	National Lead for Service User Involvement	National Advocacy Unit, Health Service Executive, Ireland.

Table 3: Research Team Study 2

Prof. Anne MacFarlane	PI and Professor of Primary Health Care Research	Graduate Entry Medical School, University of Limerick, Ireland.
Ms. Edel Tierney	Senior Researcher	Graduate Entry Medical School, University of Limerick, Limerick, Ireland.
Ms. Mary O'Reilly-de Brún	Co-applicant and Senior Researcher Co-founder	National University of Ireland, Galway, Ireland. Centre for Participatory Strategies, Clonbur, Co Galway, Ireland.
Ms. Rachel McEvoy	Co-applicant and Senior Researcher PhD Candidate (2010–2014)	National Advocacy Unit (2011–2013), Health Service Executive, Ireland. Graduate Entry Medical School, University of Limerick, Ireland.
Prof. Anne Rogers	Collaborator, Professor of Health Systems Implementation	University of Southampton, United Kingdom.
Ms. Katya Okonkwo	Collaborator, Community Representative	Galway Migrant Service, Galway, Ireland.
Mr. Tomas de Brún	Co-applicant and Senior Researcher Co-founder	National University of Ireland, Galway, Ireland. Centre for Participatory Strategies, Clonbur, Co. Galway, Ireland.

Table 4: Literature Review Research Team Study 2

Prof. Anne MacFarlane	PI and Professor of Primary Health Care Research	Graduate Entry Medical School, University of Limerick, Ireland.
Ms. Edel Tierney	Senior Researcher	Graduate Entry Medical School, University of Limerick, Ireland.
Ms. Mary O Reilly-de Brún	Co-applicant and Senior Researcher Co-founder	National University of Ireland, Galway, Ireland. Centre for Participatory Strategies, Clonbur, Co. Galway, Ireland.
Ms. Rachel McEvoy	Co-applicant and Senior Researcher PhD Candidate (2010 – 2014)	National Advocacy Unit (2011-2013), Health Service Executive, Ireland. Graduate Entry Medical School, University of Limerick, Ireland.
Prof. Anne Rogers	Collaborator, Professor of Health Systems Implementation	University of Southampton, United Kingdom.
Ms Katya Okonkwo	Collaborator Community representative	Galway Migrant Service, Galway, Ireland.
Mr Tomas de Brún	Co-applicant and Senior Researcher Co-founder	National University of Ireland, Galway, Ireland. Centre for Participatory Strategies, Clonbur, Co. Galway, Ireland.
Prof. Chris Dowrick	Professor of Primary Medical Care	University of Liverpool, United Kingdom.
Ms Michelle Rooney	Community Project Coordinator	Mayo Intercultural Action, Ballina, Ireland.

Table 5: Steering Group Membership Study 2

Prof. Anne MacFarlane	Professor of Primary Health Care Research	Graduate Entry Medical School, University of Limerick, Limerick, Ireland.
Ms. Edel Tierney	Senior Researcher	Graduate Entry Medical School, University of Limerick, Limerick, Ireland.
Ms. Mary O'Reilly-de Brún	Co-applicant and Senior Researcher Co-founder	National University of Ireland, Galway, Ireland. Centre for Participatory Strategies, Clonbur, Co. Galway, Ireland.
Ms. Rachel McEvoy	Co-applicant and Senior Researcher PhD Student (2010 –2014)	National Advocacy Unit (2011-2013), Health Service Executive, Ireland. Graduate Entry Medical School, University of Limerick, Limerick, Ireland.
Prof. Anne Rogers	Professor of Health Systems Implementation	University of Southampton, United Kingdom
Ms. Katya Okonkwo	Community Migrant Representative	Galway Migrant Service, Galway, Ireland.
Mr. Tomas de Brún	Co-applicant and Senior Researcher Co-founder	National University of Ireland Galway, Ireland. Centre for Participatory Strategies, Clonbur, Co. Galway, Ireland.
Dr. Jane Pillinger	Independent Social Policy Research Consultant	Independent Researcher and Social Policy Advisor, Ireland.
Ms. Michelle Rooney	Community Project Coordinator	Mayo Intercultural Action, Ballina, Co Mayo, Ireland.
Mr. Greg Price	Director of Advocacy, Quality and Risk, and Clinical Care Directorate, HSE	Health Service Executive, Ireland.
Ms. Ellen O'Dea	Occupational Therapy Manager, HSE	Health Service Executive, Ireland.

Table 6: Expert Advisory Group for Framework

Dr Fiona O'Reilly	Senior Researcher, Partnership for Health Equity (UL, North Dublin City GP Training Scheme and HSE Primary Care and Social Inclusion)	Partnership for Health Equity Catherine McAuley Centre, Nelson Street, Dublin, Ireland.
Dr Austin O'Carroll	General Practitioner	Mountjoy Street Practice, Dublin, Ireland.
Dr. Tracy Finch	Senior Lecturer, Institute of Health & Society, Newcastle University.	Newcastle University, Newcastle Upon Tyne, United Kingdom.
Ms Diane Nurse	National Lead, Social Inclusion, Primary Care Directorate, HSE	National Planning Specialist: Social Inclusion at Health Service Executive, Ireland.
Ms Libby Kinneen	Head of Organisation Development and Design	Health Service Executive (West), Ireland
Ms Siobhan O Dowd	Project Co-ordinator, Ballyphehane/Togher CDP	Ballyphehane/Togher CDP, Ballyphehane, Cork City, Ireland.
Dr Rosarie Crowley	Clinical Psychologist, PCT	Primary Care psychology team, Cork, Ireland.
Dr Diarmuid O'Donovan	Senior Lecturer in Social and Preventive Medicine and Director of Public Health	National University of Ireland, Galway, Ireland and Health Service Executive (West), Ireland.

APPENDIX 2C

Methodology. Critical Review of the Literature

This method was based on a critical interpretive synthesis of the literature. ⁴

We identified a purposeful sample of quantitative and qualitative peer-reviewed papers. We searched EBSCOhost – an electronic literature platform – for original primary care papers about research and health service development projects published between 2007 and 2011 (see Figure 1 for a description of search terms we used at this stage). We identified a potential of 289 abstracts at the outset, which resulted in a final sample of 78 papers being identified that matched our sampling parameters (see Table 1). We excluded duplicate papers and conventional qualitative research studies, and finally selected a purposive sample of 26 papers for inclusion in this review (see Figure 1). We conducted a quality appraisal exercise^{8,9}, on these 26 papers with an emphasis on the *relevance* of the paper to our review. All were deemed appropriate for inclusion in the review.

Table 1:

Sample of 26 papers included in the critical review categorised by six sampling parameters

n=8 – Service user involvement (SUI) studies explicitly reporting experience of ‘doing service user involvement’ and/or studies that demonstrate high-level involvement using participatory methodologies.

n=3 - Qualitative and quantitative health services research (HSR) studies that focus on the perspective or experiences of service users, with more of an emphasis than other HSR studies on reporting outcomes or actions taken as a result of their input.

n=5 - Qualitative and quantitative HSR studies on the theme of SUI and/or patient participation.

To extract data from the papers identified, we used a modified version of the Critical Appraisal Tool.¹⁰ Data were extracted in response to 11 key questions, which then formed the first part of our analysis. Data relating to each of these 11 items were analysed using the computer package NVivo 10 to generate seven themes.

Our analysis of the seven initial themes revealed that three themes were most relevant to the questions which we wished to answer about involvement in primary care: (i) partnership and collaboration, (ii) roles and responsibilities and (iii) control and power. We examined data in these themes using Normalization Process Theory (NPT) to guide our thinking and to progress our knowledge about implementation of user involvement. We used NPT to blend emergent findings and draw out key recommendations.

n=2 - Studies with a focus on shared decision-making, including studies that analyse patient/practitioner consultations in which there is shared decision-making.

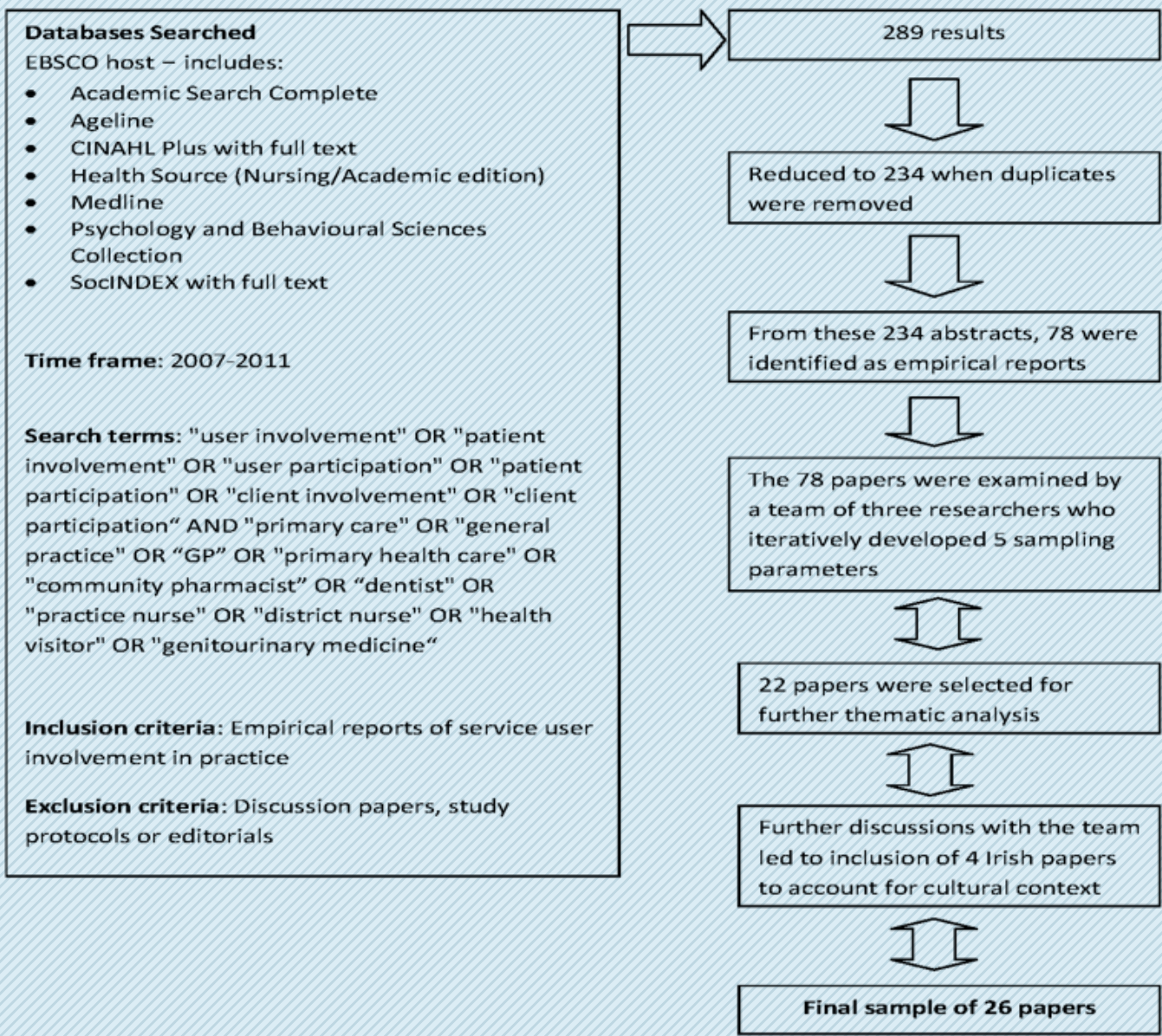
n=4 - Randomised controlled trials where the intervention component has some evidence of patient involvement, e.g. learning skills for self-management, participation in mentoring or coaching.

n=4 - Irish papers (including grey literature) focusing on user involvement in primary care in the Irish context, as recommended by our research team to ensure our review (a) had relevance to the national policy context and (b) was inclusive of studies with participatory methodologies, which were under-represented at one point in the sampling process.

Table 2: Stages of data analysis in literature review

1st order constructs	2nd order constructs	3rd order constructs
First stage of data analysis	2nd stage of data analysis	Final stage of data analysis
<ul style="list-style-type: none">• Socio-political context or drivers• Definition of service user involvement• Level of user involvement• Recruitment strategy• Training• Ethics• Methodological considerations• Dissemination• Impact• Added value of user involvement• Evaluation	<ul style="list-style-type: none">• Dialogue and communication• Ethical practice• Methods• Roles and responsibilities• Control and power• Partnership and collaboration	<ul style="list-style-type: none">• Definition• Engagement• Enactment• Appraisal

Figure 1: Search strategy used in CIS



8 Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: Reviewing disparate data systematically. Qualitative Health Research. 2002;12(9):1284-99.

9 Jadad AR, Moore RA, Carroll D, Jenkinson C, Reynolds DJM, Gavaghan DJ, et al. (1996) Assessing the quality of reports of randomized clinical trials: Is blinding necessary? Controlled Clinical Trials 2002;17(1):1-12.

10 Wright D, Foster C, Amir Z, Elliott J, Wilson R. Critical appraisal guidelines for assessing the quality and impact of user involvement in research. Health Expectations 2010; 13(4):359-68.



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