



AIIHPC

All Ireland Institute of
Hospice and Palliative Care

**EVALUATION REPORT FOR ALL IRELAND INSTITUTE OF
HOSPICE AND PALLIATIVE CARE
'VOICES 4 CARE' INITIATIVE**

November 2015

*'Meaningful involvement of users, carers and
communities in the development and delivery of
palliative care'*



CONTENTS

1.	Introduction	6
1.1	What is Voices4Care	6
1.2	Methodology	7
2.	Review of the Literature	8
2.1	Definition: What is User Involvement?	8
2.2	Benefits and Challenges of User Involvement	9
2.3	Policy Context.....	10
2.4	User Involvement in Palliative Care	12
2.5	Exemplars of User Involvement within Palliative & End of Life Care Practice	13
2.6	Future Considerations	15
2.7	Conclusion	16
3.	Secondary Analysis of Data	17
3.1	Setting Up – Implementation and Development	17
3.2	Selection and Recruitment of Members	19
3.3	Description of Membership and Ways of Working.....	21
3.4	Activities and Participation	25
3.5	Conclusion	27
4.	Key Stakeholder Interviews	28
4.1	Method.....	28
4.2	Key Findings.....	28
4.2.1	Role of Voices4Care	29
4.2.2	Pereived Impact of Voices4Care	29
4.2.3	Barriers to Voices4Care Achieving its Full Impact.....	31
4.3	Stakeholder Recommendations	34
4.4	Conclusion	36
5.	Focus Group Interviews	37
5.1	Method.....	37
5.2	Key Findings.....	37
5.3	Recruitment and Motivation.....	38
5.4	Membership Role	39
5.5	Level of Support	40
5.6	Palliative Care Impact.....	41
5.7	Personal Impact.....	43

5.8	Future Development	45
5.9	Conclusion	46

6.	Conclusions	47
-----------	--------------------------	-----------

7.	Recommendations.....	48
-----------	-----------------------------	-----------

8.	References.....	49
-----------	------------------------	-----------

LIST OF APPENDICES

Appendix 1: Voices4Care Stakeholder Invitation Letter	56
Appendix 2: Voices4Care Stakeholder Participant Information Sheet.....	58
Appendix 3: Voices4Care Stakeholder Consent Form	61
Appendix 4: Voices4Care Stakeholder Interview Schedule	62
Appendix 5: Voices4Care Focus Group Invitation Letter	63
Appendix 6: Voices4Care Focus Group Participant Information Sheet.....	65
Appendix 7: Voices4Care Focus Group Consent Form	69
Appendix 8: Voices4Care Focus Group Interview Schedule	70

TABLES

Table 1: Examples illustrating User Involvement Approaches	14
Table 2: Guiding Principles for Forum.....	18
Table 3: Examples of Advertisement Strands	20
Table 4: Criteria relating to balanced Membership.....	20
Table 5: Demographics of Confirmed Members of Voices4Care	21
Table 6: Key Aspects of Membership.....	23
Table 7: Meeting Format and Purpose	24
Table 8: Key Informants for Stakeholder Interviews	28
Table 9: Demographic characteristics for Voices4Care Focus Group participants.....	38
Table10: Involvement in Education, research, policy and practice.....	41

FIGURES

Figure 1: Stakeholder Benefits of Inclusion	10
Figure 2: Report of Workshop on Draft NICE Guidelines.....	26

ACKNOWLEDGEMENTS

The authors of this report wish to thank Paddie Blaney, Director of AIIHPC and Cathleen Mulholland Programme Manager for Policy and Practice for their assistance in conducting this evaluation. We also extend our thanks to all the participants and key stakeholders who gave of their time for interviews and provided open and honest information.

EVALUATION TEAM

Professor Sonja McIlpatrick, Professor in Nursing, Ulster University

Dr Felicity Hasson, Senior Lecturer, Ulster University

Dr Lisa Hanna-Trainor, Research Associate, Ulster University

Paula Brogan, Research Associate, Ulster University

1.0 Introduction

User involvement is widely promoted within health and social care policy as an effective means of developing patient-centred services as well as ensuring that research programmes address the concerns of patients and carers. This has, however particular challenges for palliative care. Patients, carers and professionals can be uncomfortable discussing palliative and end of life issues and patients are likely to be experiencing poor health and may be approaching end of life, making the task of involvement difficult. Nevertheless according to the National Council of Palliative Care (NCPC) there are clear benefits to ensuring meaningful involvement of users, carers and communities in palliative care (NCPC, 2008). All Ireland Institute for Hospice and Palliative Care (AIHPC) recognised the importance of this, through the inclusion of a key theme seeking to ensure the meaningful involvement of users, carers and communities in the development and delivery of palliative care education, research, policy and practice. Hence this strand of work was developed as a core activity and a cross cutting theme across all the work programmes. A key aspect of realising this work strand was through the establishment of the 'Voices4Care' initiative.

1.1 What is Voices4Care ?

Voices4Care is user/carer forum established by AIHPC, comprised of patients, service users, carers or former carers, and people/citizens from the wider community, with an interest in palliative and end of life care. The overall purpose and remit of Voices4Care is:

- To function within the context of AIHPC's work, with members sharing and discussing issues which will inform how best to care for people with an illness or condition which may limit or shorten their lives.
- To inform and influence AIHPC's work in palliative care education, research, policy and practice, in a collaborative and supportive manner.

Since its inception, the Voices4Care group has engaged with a number of key AIHPC projects and further details of these are provided within the report. To date, however, the impact, process and outcome of this work has not been evaluated. Therefore the overall aim of this project was to evaluate the implementation process and contribution of Voices4Care initiative within the context of the AIHPC framework. Specific objectives were:

1. To undertake a review of the evidence of the role, impact and models of public involvement in health and social care and specifically palliative care education, research, policy and practice.
2. To review the process of establishing, implementing and maintaining user involvement.

3. To explore Voices4Care members perceived role, experiences and views on the level of involvement in general and specific palliative care education, research, policy and practice and seek recommendations for its future development.
4. To seek key stakeholder views on the role and impact of Voices4Care
5. To identify lessons learned from the Voices4Care initiative and provide recommendations for future role and activities.

1.2 Methodology

This proposed project was informed by a “realistic evaluation” approach (Pawson & Tilley, 1997), which sought to answer the question not simply “What works?” but “What works for whom in what circumstances?” This approach is recommended where the causative link between an intervention and its outcomes is multi-factorial. This approach recognised the need to evaluate not just outcomes, but also the processes leading to those outcomes. Therefore the overall approach for the evaluation was both: formative, concerned with process; and summative, concerned with outcomes. A mixed methods approach was adopted, comprised of four various strands of work. These included:

- Strand 1: Review of the literature
- Strand 2: Secondary Data Analysis
- Strand 3: Focus groups with Voices4Care participants
- Strand 4: Key Stakeholder interviews

This report will detail each of these phases of the project and conclude with an overall summary, conclusion and recommendations.

2.0: Review of the Literature

A review of the literature was undertaken focusing on the process, role and models of best practice of public involvement initiatives in research. A range of available databases was searched to collate evidence pertinent to the topic. These included Ovid, Medline, Synergy, Science Direct, and the Cochrane database. All relevant reports and grey literature available were also included. The search was restricted to research articles and reviews in English. Search terms included: user engagement, consumer participation; patient and/or public involvement; advocacy; engagement; consumer-based participatory research; hospice care; palliative care and end of life. The articles included in the search represent research projects, literature reviews, descriptions of particular initiatives and opinion pieces.

2.1 Definition: What is User Involvement?

Over the last number of years, user involvement has increasingly become a part of research, education and policymaking in health and social care (Black, 2008). Although acknowledged as difficult, service user involvement within health and social care is widely promoted as an effective means of developing patient-centred services as well as ensuring that the concerns of patients and carers are addressed (Haarsma et al. 2014). The inclusion of users is underpinned by the following three arguments:

1. It is morally and ethically correct behaviour;
2. It has the potential to lead to improvements and;
3. It is theoretically and practically justified (Collins et al. 2014, p1-2).

According to INVOLVE, a government funded programme supporting active public involvement in research (National NHS Advisory Group), user involvement is “*an active partnership between the public and researchers in the research process*”. This can take many forms including ‘consultation’, ‘collaboration’ and even ‘user control’ (INVOLVE, 2004). In this context therefore, public involvement is defined as “research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them” (University of Oxford, 2015). According to Wilson et al. (2014) user involvement has the potential to lead to greater transparency of health care services through *‘improved quality and impact of research and accountability of researchers’* (Wilson et al., 2014, in INVOLVE, 2014).

According to Payne et al. (2005), in a scoping study examining user involvement in palliative care, user involvement was defined as:

“...the way people, who use public services, are involved in making suggestions and taking decisions about how different services are run and developed. User involvement is about how service users are involved in shaping or building the future of public services” (p.1).

This involvement can be considered as Direct or Indirect

- **Direct involvement** might include a service user group writing an information leaflet about a public service or a health problem.
- **Indirect involvement** might include a professional group asking a service user about what they think of the plans the professionals have already decided are important (Tritter et al. 2004).

Over the last decade, user involvement has become increasingly common, not just in terms of research but throughout policy development, practice and service delivery. Problems however exist with regards to definitions and conceptual factors and whilst there has been increasing acceptance of the term, multiple terminologies and assumptions exist. Moreover there has been little research (Petit-Zeman & Locock 2013), which demonstrates the impact of inclusion especially on practice. In response international mechanisms to assess impact of public involvement have been developed (e.g., Public Involvement Impact Assessment Framework Guidance (Piiaf) (Popay et al. 2014); GRiPP checklist (Staniszewska et al. 2011); yet these to date, have not been widely implemented.

2.2 Benefits & Challenges of User Involvement

Research suggests there are potential widespread benefits for users, commissioners, academics and providers of health services (Simpson et al. 2014; Mockford et al. 2012). Proposers have identified a variety of values to different stakeholders (see figure 1.)

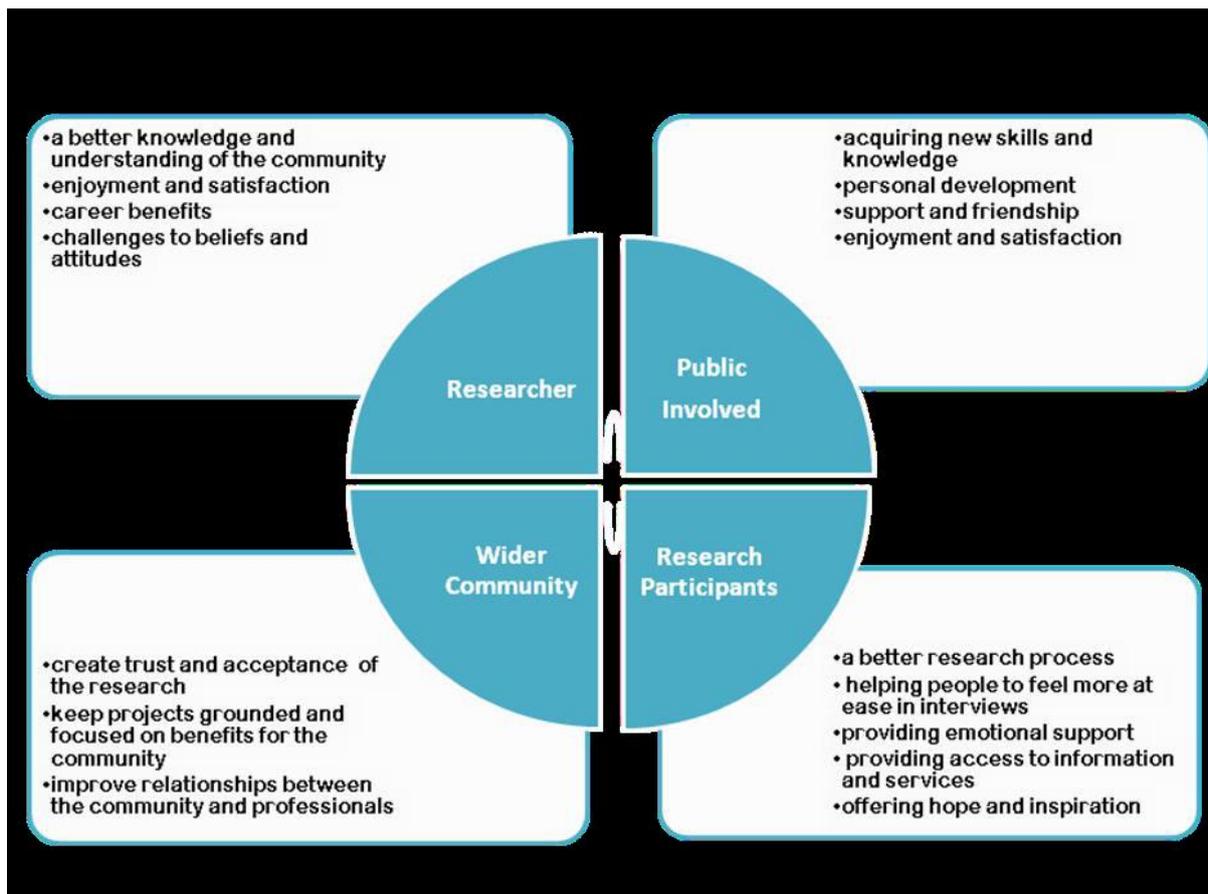


Figure1: Stakeholder benefits of inclusion (Source: Stanley 2009)

As well as opportunities there are practical, professional and personal challenges when creating, establishing and maintaining engagement with users. For example there is no standard protocol available to advise on how best to implement user involvement in any health and social care field, including palliative care. Practically, challenges also exist in relation to resourcing, debate on its purpose and the complexities in sharing power (INVOLVE, 2012; Vale et al. 2012; Boote et al. 2010). Professionally, confusion and uncertainty exists regarding the differences and similarities between the views of users and other key stakeholders (Daveson et al. 2015) and if involvement may in fact worsen outcomes (Khwaja, 2004). Whilst personally, lack of clarification regarding users' roles and their value, whilst coping with academic and clinical language in that role have also been cited as barriers (Buck et al. 2014; Two Can Associates, 2009).

2.3 Policy Context

Internationally, the concept of user involvement is not new. In 1978, the World Health Organisation conference on health care in USSR, recognized through the Declaration of Alma-Ata that;

‘..people have the right and duty to participate individually and collectively in the planning and implementation of their health care’ (WHO, 1978, p.1).

Sargeant et al. (2004) argued that the emergence of a user voice in health decision making in the UK, can be traced to organisational changes within the health system, alongside new conceptualisations of citizenship. For example, as early as 1990, UK legislation was established to ensure that users were consulted in service planning. The act required local authorities to prepare community care plans and consult with user groups and was the first of a number of pieces of legislation developed to promote the concept of ‘the state as an enabler rather than a provider’ (NHS and Community Care Act, 1990; Human Rights Act, 1998; PPI in the New NHS, 1999; Health and Social Care Act, 2001, 2007; The Care Act, 2014; NSUN, 2015). Government guidelines (DoH 2006; DoH, 2008a; DoH, 2008b; Healthcare Commission, 2008) clearly acknowledged that;

‘...the views of patients, their carers and others must be sought and taken into account in designing, planning, delivering and improving healthcare services’ (Healthcare Commission, 2008, p.15).

In 2006, INVOLVE and the NHS Centre for Involvement published a document ‘Health Democracy: The Future of Involvement in Health and Social Care’, outlining the role of user involvement throughout health and social care and involving patients as ‘active partners in their own healthcare’. They highlighted some of the key challenges in the current evidence-base of effective methods of involvement and noted good examples of how these challenges were overcome; most notably the importance of ‘involving people as citizens’ and empowering them to make decisions about their own care. They acknowledged the ever-increasing role of web technology and how it could provide citizens with new tools to influence health services, thus creating a truly responsive NHS (Anderson et al. 2006).

Building upon this earlier work, the commitment in the UK is also reflected in various research policies with many funding organisations only supporting applications that demonstrate user involvement such as the National Institute for Health (NIHR, 2013: 2015). Inclusion is also reflected in practice for example, Nursing and Midwifery Council (2015) in ‘The Code: Standards of Conduct, Performance and Ethics for Nurses and Midwives’; stated that staff must acknowledge and respect the views of patients regarding their own care and wellbeing, as well as uphold patient’s rights to be ‘fully involved in decisions about their care’ (NMC, 2015).

In the Republic of Ireland in 2008, the government published a five-year strategy aimed at improving service user involvement across the Irish Health Service. They highlighted the importance of user involvement across Health and Social Service provision. The Strategy outlined seven goals with key deliverables across planning, development, delivery and evaluation of the health service. They acknowledged that involvement should be based on

'inclusion, diversity and equity' on three levels of involvement; individual service users, the community and at a national level. It noted the importance of the systematic evaluation of service user involvement initiatives with any learning/outcomes being disseminated across health and social services in Ireland (HSE and DoHC, 2008). The strategy recommendations have fed into further policy and research reports (i.e. Commission for Patient Safety and Quality Assurance, 2008: Task Force on the Public Service, 2008) strengthening patient and public involvement. More recently, research commissioned by the Medical Research Charities Group (MTCG) of Ireland (Hannigan, 2014), called for greater focus on the development of public involvement and the Irish Health Research Forum (2015) repeated such calls.

Within Northern Ireland, the DHSSPS published its user involvement consultation scheme in January of 2015. It stated that;

'...patients, clients carers and communities must be put at the centre of decision-making in health and social care'; acknowledging that they must be 'properly involved in the planning, delivery and evaluation of their services' (p. 3).

2.4 User Involvement in Palliative Care

Over the last few years there has been a real drive for improving the palliative care services for all people with life-threatening and life-limiting conditions and their carers. According to the World Health Organisation, palliative care should be considered as a basic human right and a recent WHO Resolution (2015), highlighted the need to ensure good integration of palliative care across the health care system. Palliative care policies across the UK and the Republic of Ireland have highlighted the need for greater consistency of services and greater choice for those at the end of their life, through better commissioning and co-ordination of care (DoH, 2006; DHSSPS, 2010; HSE, 2008). One way to address this is to ensure appropriate user involvement in the commissioning and planning for services. This was acknowledged in the Palliative Care Strategy for Northern Ireland, 'Living Matters: Dying Matters' (DHSSPS, 2010), which stated that;

'...palliative and end of life care services should be planned and developed with meaningful patient, family and carer involvement, facilitated and supported as appropriate and provided in a flexible manner to meet individual and changing needs' (p. 10).

It is acknowledged however that this has particular challenges for palliative care. Patients, carers and professionals can be uncomfortable discussing palliative and end of life issues and patients may be experiencing poor health that makes the task of appropriate involvement difficult (NCPC, 2008). Therefore the implementation and role of user involvement in palliative and end of life care has been a little inconsistent, with the greatest advances being seen in the field of cancer research (Collins et al. 2015). For example, a report published by University of Nottingham for Macmillan Cancer (2011) focused on the

role of older carers and their involvement in research. The report noted that involvement in research can take many forms (consultative, collaborative or user-led/controlled). The carers who participated in the research viewed their involvement very positively. The report highlighted a number of benefits of involving users/carers in research. These included: benefits for the carers as research partners, for example, shared experiences and increased confidence, alongside benefits for the research project itself such as making the research more relevant and informing the wider dissemination of accessible findings (Kennedy, 2011, p.9).

In 2008, The National Council for Palliative Care commissioned 'A Guide to Involving patients, carers and the public in palliative care and end of life services'. Although the document acknowledged the limited involvement of the public to date, raising public awareness of death, bereavement and end of life care was highlighted as a key area of future development. The guide outlined eight key parts of the development of user involvement illustrating the fundamental process within palliative and end of life care. This includes;

- Mapping existing activity
- Defining the aims/goals of new activity
- Identifying existing information
- Identifying available resources
- Identifying people
- Identifying methods
- Working out how to evaluate activity
- Identifying how feedback will be provided (NCPC, 2008)

The visual depiction of the process within a wheel, acknowledges the importance of organisation's viewing user involvement as a continuous process with expanding methods, robust evaluation and feedback to inform future research and practice.

2.5 Exemplars of User Involvement within Palliative and End of Life Care Practice

A review of the literature reveals varying models and approaches being adopted to integrate service users (Boote et al. 2010) with no gold standard approach (Daveson et al. 2015), although guidance for specific fields are expanding (i.e., health technology assessment Walsh, 2014). There are various examples of user involvement in health, palliative and end of life care internationally, nationally and regionally (see table 1).

Table 1: Examples illustrating user involvement approaches internationally, nationally & regionally

Location	Title	Scope
Canada	Strategy for Patient-Oriented Research (SPOR), Canadian Institutes of Health Research	Key stakeholders (Patients, academics, researchers, health care providers and decision-makers) actively collaborate, to build a sustainable, accessible and equitable health care system to bring positive changes in the health of people living in Canada.
European Union (EU)	INTEGRATE-EU, re palliative care across the EU	Aims to identify key issues in palliative care that will inform the project; plans involved user involvement across six European counties.
UK	C-CHANGE (King's College London Cicely Saunders Institute)	User group, which aims to shape research, share views, offer advice and ensure that palliative care is improved for patients and families from all walks of life.
ROI	National Centre for Pharmacoeconomics NCPE Ireland	Enhancing the nature of patient/public involvement in health technology assessment in Ireland

Internationally, the Canadian Institute of Health Research, (SPOR) has developed a Value Model for Patient Engagement as a model of best practice illustrating how various stakeholders work together to enhance practice and treatment. For example in research patients have a role in the identification of research priorities, design and completion of projects and the translation and uptake of new practices. In the UK, one of the first to be established at a local level was the North Trent Cancer Research Network Consumer Research Panel – NTCRN CRP. This model of user involvement has been replicated throughout the UK and is recognized as a model of good practice by INVOLVE (Collins et al., 2015). Although a number of challenges have been identified from the model, these can be addressed, according to Collins et al. through a number of simple steps including: a 'clear outline' of service users' involvement and contribution to the research; 'on-going support and guidance' and 'an environment of mutual respect' (p. 3). A finding echoed by an expert consultation on involvement in palliative care research carried out by Daveson et al. (2015); who concluded;

'For involvement in palliative care research to succeed, early and flexible involvement is required. Researchers should advertise opportunities for involvement and promote impact of involvement via dissemination plans. Users should prioritise adding value to research through enhancing productivity, quality and relevance' (p. 1).

Daveson noted that further research was needed to inform the implementation of involvement and ensure its effectiveness, as well as 'to investigate the cost-effectiveness of involvement in palliative care research' (Daveson et al. 2015).

One such example of a piece of research carried out to evaluate the involvement of service users in palliative care was the work of Cotterell et al. (2004). The 'Influencing Palliative Care Project' brought together service users and researchers to look at what palliative care support is available for people with life-limiting conditions and the experiences those service users had regarding the services they received. A participatory research methodology was used and service users, who formed a research user advisory group, were involved in research design, data collection and analysis and dissemination of findings. Although the advisory group acknowledged that there were challenges associated with being involved in the research, they concluded that it was an 'empowering and worthwhile experience' (p. 9).

2.6 Future Considerations

One of the major limitations of research to date on user involvement within palliative and end-of-life care is the systematic measuring of impact and the benefits of involvement. Payne et al. (2005) acknowledged that the majority of research on user involvement focused on descriptive accounts of initiatives, projects, conferences and other practical activities; with little evaluation beyond simple satisfaction surveys (Payne, 2005). This report outlined a number of key recommendations to improve the role and impact of user involvement in palliative care. The report acknowledged that;

- 'User involvement should be part of a new notion of citizenship';
- That we have a responsibility to find 'creative and novel ways' to involve service users, including practical initiatives and the use of information technology;
- That the culture within organisations has to be more supportive of user involvement and show willingness to respond to service user needs; and
- That further research is needed to investigate the effectiveness, cost and benefits of user involvement from the perspectives of patients, carers, professionals and organisations (p. 52).

Similarly, Croft and colleagues in 2012, undertook a piece of research 'Getting it Right: End of Life and User Involvement in palliative Care Social Work'. The survey, carried out with social workers, aimed to provide a baseline of user involvement, what practitioners considered being the benefits and barriers and ideas for improvement. The survey was issued to all 225 members of the Association of Palliative Care Social Workers and gained 45 responses. Findings revealed that whilst practitioners welcomed user involvement;

engagement varied with clear gaps in education, planning, evaluation and research. They recommended that:

- It was important that the concept of user involvement was not lost or negated.
- Further understanding of the meaning of user-involvement and more education and training about user involvement for staff across social care and social work services was required.
- Finally they highlighted a number of practical steps to be implemented to encourage and enhance user involvement across disciplines. These included; 'identifying and establishing champions for user involvement at national level and in specific local services'; 'setting up service user groups' and creating links to maintain and support such groups; and finally 'building links and alliances more broadly with service users and their user-led organisations', as well as service users from palliative care services specifically (Croft et al. 2012).

A systematic review carried out by Conklin et al. (2012) focused on nineteen empirical pieces of evidence of the outcomes of public involvement in healthcare policy. The review criticized the robustness and consistency of the research carried out to date, in terms of defining user involvement and clearly measuring the impact/effect of involvement on policy. Conklin concluded that despite the growing body of literature within the area, robust evidence of the long-term impact of user involvement remained scarce. However, the review highlighted the positive effect user involvement has had on practice, as well as the improvement in patient/public understanding and knowledge (Conklin et al. 2012). Finally Conklin and colleagues called for more robust evaluations in this area, in order to strengthen the evidence base for whether 'public involvement improves processes and/or outcomes of decision-making and policy' (p. 163).

2.7 Conclusion

This brief review has outlined the value and importance user-involvement has, not just within palliative and end of life care, but throughout health and social care research, policy practice and service delivery. The involvement of the 'public' and 'service users' to inform and drive up standards within palliative and end of life care is irrefutable; although work is needed to evaluate the role and understand further the benefits of user involvement, especially within palliative care. Research to date has highlighted the importance of involving service users, families, carers and general public in ensuring high quality, person-centred palliative and end of life care practice.

3.0: Secondary Analysis of Data

A number of documents and reports have been developed in relation to the work of Voices4Care . In order to address the objective seeking to review the process of establishing, implementing and maintaining user involvement, a secondary analysis of data and documentary review was undertaken. Secondary analysis is a process that involves the use of existing data, collected for the purposes of a prior study or project, in order to address a research interest which is distinct from that of the original work; this may be a new research question or an alternative perspective on the original question (Hinds et al. 1997, Szabo & Strang, 1997). This analysis is considered under the following aspects:

1. Implementation and development
2. Selection and recruitment of members
3. Membership and ways of working
4. Activities and participation

3.1 Setting up –Implementation and Development

The process of establishing Voices4Care was initiated by convening a ‘Think Tank’ event, involving 70 organisations and associations with some remit for user/carer involvement from across Ireland, in 2012. Attendees of this event were asked to consider four key areas of interest in relation to setting up the forum, drawing on their experience of what went well from previous experience and how things could have been developed differently. The areas of focus included:

- Advertising and Marketing
- Recruitment and Selection
- Training and Development
- Appointment and Support

Advertising and Marketing

In terms of advertising and marketing, some of the following key aspects were identified for consideration:

1. The need to provide feedback in a variety of methods, giving careful consideration to the type of language used;
2. The need for a clear and precise communication strategy;
3. The importance of local media alongside direct communication combining word of mouth activities with the need to listen to user views and balancing their expectations;
4. The importance of building rapport/trust and allowing time for all voices to be heard, as well as tailoring media usage to suit the audience;

5. The centrality of the message in terms of content/target audience; groups need to work on understanding and reaching ‘the unreached’ in terms of audience;
6. The importance of the name of the user group clearly establishing the identity and reducing confusion with other organisational forums.

Recruitment and Selection

A number of key issues were identified: including the importance of a clear rationale and purpose for the forum; aims and objectives; clearly defined parameters (as a way to manage expectations); terms of reference and better understanding amongst forum members as to their representative role (whether they are representative ‘of’ or ‘for’ themselves or an organisation). The participants also identified a number of guiding principles for the Forum to consider (Table 2):

Table 2: Guiding Principles for Forum

- | |
|--|
| <ul style="list-style-type: none">• A collaborative foundation, ensuring meaningful and relevant participation;• Striking a balance in terms of structure and flexibility;• Developing a culture of listening and learning;• Creating opportunities for a virtual forum for ease of access. |
|--|

Different forum models were discussed, including both larger forums with structured agendas, and smaller more virtual forums, alongside potential challenges such as managing agendas, levels of participation, training issues; ‘professionalising’ user involvement, and the risk that strategies/processes linked to recruitment could ‘close’ rather than ‘open’ involvement.

A number of key aspects were identified in relation to recruitment strategies:

1. The need for multiple recruitment methods;
2. Duration of membership;
3. The need for a ‘strong chair’;
4. Building a review process and opportunities for feedback;

Finally the participants noted a few important considerations including:

- The challenges of travelling to meetings (location);
- The need to capture the voice of those with ‘no service’ / ‘lone voice’ (type of user involved);

- The need for flexibility of groups (clarification of role, level of engagement and managing expectations);
- The importance of including younger people to raise awareness and build a foundation for the future.

Training and Development

Some key aspects were identified for consideration:

- The importance of clear purpose, role and principles for the group.
- An induction process for new members.
- The need for trained/informed facilitators.

Training and development was dependent on the skills/experience of forum members, and how they can be facilitated to contribute effectively to the work of AIHPC. Participants acknowledged that the forum should impact ‘on lives’ not just on organisations. They also discussed having a dedicated space on the Institute’s website to support forum induction, information dissemination and discussion.

Appointment and Support

Key aspects relating to the appointment and support of forum members were considered. This included terms of reference, membership, methods of working, participants’ requirements, managing expectations, individual/representative voice and resources (people and financial) and a ‘Code of Conduct’ for members, providing clear guidelines on the term of office (with members’ involvement not exceeding three years) and regular accessible meeting (approximately four times per year) ensuring that members’ expectations are managed.

A clear message was that the forum needed to remain flexible and adopt multiple approaches to consulting with wider groups to ascertain key information and feedback and to disseminate outcomes.

3.2 Selection and Recruitment of Members

The Think Tank event provided clear guidance that was subsequently taken forward in the process of selection and recruitment for the Voices4Care . This resulted in the development of guidance information and recruitment information clearly outlining the role and format of the forum, what membership of the Forum would involve as well as the support that would be available to members to enable them to undertake this role.

Marketing and Advertisement

In terms of marketing and advertising a recruitment plan was devised that included direct communication (adverts) with newspapers and other organisations throughout Ireland (North and South) over a sustained 6 month period (see Table 3)

Table 3: Examples of Advertisement Strands

ActiveLink.ie (online network for Irish non-profit organisations); AgeNI; An Bord Altranais (Irish Nursing Board); Archdiocese of Dublin website; CARE at End of Life website; Citizens Information Board (Ireland); Volunteer Centres; Online Community/Parish noticeboards; Multiple Sclerosis Society Ireland; Volunteer Ireland and Volunteer Now (N. Ireland); TV coverage; Local newspapers; Links were also posted on a number of organisations' Facebook pages, including; Carers Association; Volunteer Centres across Ireland.
--

Selection Process

The selection process was enabled through the development of Expression of Interest forms that collated key criteria on each potential member including: basic demographic information (name, address, contact information, age and gender); whether the individual was a patient, carer or interested citizen and their experience and interest areas; their motivation for joining; their previous experience and skills; their availability to engage and a character reference. A formalised selection process using a selection panel was established and the key criteria for selection included:

1. Motivation
2. Experience and Skills
3. Availability and Engagement

Additional criteria were also developed in terms of seeking to gain a 'balanced' membership (see Table 4).

Table 4: Criteria relating to 'balanced' membership

- | |
|--|
| <ul style="list-style-type: none">• Balance of service users, carers and wider community members,• Geographical spread of members - across Northern Ireland and the Republic of Ireland,• Balance across potential members' experience of illnesses/diseases, and• Balance of representation from the diversity of society. |
|--|

3.3 Description of Membership and Ways of Working

In terms of the original applicants, it was noted that there were 40 applicants who applied to become members of the Vocies4Care initiative. Following the selection process 20 members were confirmed and joined the Voices4Care forum (see Table 5).

Table 5: Demographics of Confirmed Members of Voices4Care

	Category	Number (Percentage)
Gender	Male	2 (10%)
	Female	18 (90%)
Age	25-34	1 (5%)
	35-44	1 (5%)
	45-54	9 (45%)
	55-64	4 (20%)
	65+	4 (20%)
	Age not given	1 (5%)
Geographical Area	ROI	16 (80%)
	NI	4 (20%)
Category	Service User	2 (10%)
	Carer / Former Carer	15 (75%)
	Interested Citizen	3 (15%)
Reason for Involvement	Service User Reduce Fear	1 (5%)
	Carer/Former Carer Former Carer of Parent	9 (45%)
	Former Carer of Spouse	3 (15%)
	Former Carer Other Family Member	2 (10%)
	Carer of parent	1 (5%)
	Interested Citizen Works in Healthcare	2 (10%)
	Keen to develop public understanding	1 (5%)

From Table 5 (above), it was clear that the majority, 90% (n=18) of the members of the Voices4Care initiative were female; the remaining two were male (10%). Members' ages ranged from 25yrs old to 68yrs of age, with one member not disclosing their age. Almost half of the members, 40% (n=8) were aged over 55yrs old. Nine members (45%) were aged 55yrs-64yrs old, with only two members (10%) aged under 44yrs old. In terms of geographical spread, sixteen members lived in the Republic of Ireland (80%), with the remaining members residing in Northern Ireland (20%, n=4). Of the confirmed members of Voices4Care, three quarters (n=15) described themselves as either a carer or a former carer. Two (10%) were service users and the remaining three (15%) were described as interested citizens.

The members were also asked to outline their reason for involvement in the Voices4Care initiative. One service user didn't comment, but the other acknowledged a desire to 'reduce [the] fear' that exists surrounding the role of palliative care. Of the 15 members (75%), who described themselves as carers/former carers; almost half (45%, n=9) had cared for a parent who had died. Three (15%) had cared for a spouse. One member (5%) was a current carer for a parent. Of the three members (15%) that were described as interested citizens, two (10%) worked in the area of healthcare, whilst the other reported a keen interest in 'raising public awareness and understanding' of palliative care issues. From the Expression of Interest sheets that members completed, it was noted that many of the members had previous experience as Board members on different charitable/advocacy organisations and had previous experience working with/supporting marginalized groups and those with life-limiting/chronic conditions.

Terms of Reference

The members of the Voices4Care initiative were asked to agree and sign up to abide by a number of Terms of Reference, established for the group. The Terms of Reference document outlined key aspects of membership including the purpose and remit of the group; membership role; meetings and correspondence; guidance for members and AIHPC; Expenses and ground rules for all members to follow. Some of the key aspects are outlined in Table 6.

Table 6: Key Aspects of Membership

Purpose and Remit

Members were advised that they would function within the context of AllHPC's work, with members sharing and discussing issues which would inform how best to care for people with an illness or condition which may limit or shorten their lives. Their perspectives would inform and influence AllHPC's work in palliative care education, research, policy and practice, in a collaborative and supportive manner.

Membership

Voices4Care would be made up of approximately 30 members, recruited by AllHPC, from both Northern Ireland and the Republic of Ireland and members would include patients/service users, carers and former carers and people from the wider community interested in palliative care. Membership was voluntary, and initially would last two years.

Meetings and Correspondence

Members were advised that they must meet approximately three times per year, face-to-face. Some members of Voices4Care would be involved in AllHPC's Management Committee and various Steering Committees/groups; whilst others were to be involved in specific initiatives/working groups, where it was considered the member could make a particular contribution.

Membership Role

Members role included;

- bringing their views and skills to provide comment on AllHPC's work in palliative care education, research, policy and practice, where appropriate this may be informed by members' personal experience;
- being involved through attendance and participation in Voices4Care meetings, discussions, and through other committee meetings, where required;
- being willing to comment on written material, for example, reports;
- preparing for meetings by reading papers received beforehand;
- being prepared to think beyond personal and local experience in order to consider the needs of the wider population;
- not acting as a spokesperson or make comment publicly on behalf of or about Voices4Care . This included not commenting on social media (Facebook, Twitter etc.) about Voices4Care meetings or business;
- protecting and promoting the reputation of Voices4Care and AllHPC;
- taking part in training to support involvement in Voices4Care ;
- taking part in any evaluation of Voices4Care .

All members agreed to the Terms of Reference outlined above and signed an agreement, which was co-signed by the AIIHPC Director, in support of the effective working of Voices4Care .

3.4 Activities and Involvement

From the secondary analysis of data it was noted that the members attended a total of 7 meetings, from June 2013 to October 2015. Each of these meetings had a different function and purpose and a number of meetings were used as a platform to develop and evaluate different initiatives and tools (see Table 7).

Table 7: Meeting Format and Purpose

- | |
|---|
| <ul style="list-style-type: none">• SenseMaker – survey tool used to gather ‘stories’ of the experience of people living with an illness for which there is little or no prospect of cure and for whom the primary treatment goal is quality of life• Online introductory education programme on palliative care for the public• Palliative Care Information – review media materials (website, adverts (posters, radio) and communication toolkits for use as part of palliative care week• Development of Adult and Public Palliative Hub – updating Voices4Care materials, expanding membership and highlighting key issues/areas for further development• Develop resource for Palliative Care Senior Nurse Network (PCSNN) |
|---|

Feedback and evaluations were collected at the end of each meeting/event. Members reported ‘feeling privileged’ in being involved in the ‘interesting’, ‘fun and informative’ events and enjoyed the ‘interactive’ nature of workshop events.

Types of Activities included

It is noteworthy that the members of Voices4Care have contributed to a number of many varied and distinct activities across the various work strands for AIIHPC. These include:

- Representation on Management Committee and all three Steering Committees
- Let’s Talk About survey: design, engagement and analysis
- Involved in Filming (Education) awareness
- Focus group as part of Dignity Care initiative
- Involved in selection panels for commissioned work
- NI Transforming your Palliative and End of Life Care
- Participation in Public Awareness campaign
- Helping inform The Palliative Hub: Adult & Public website
- Input to helping identify research priorities

Figure 2 (overleaf) provides evidence of a key activity that Voices4Care members were involved in where their input resulted in various recommendations for commissioners and policy makers with regards to a consultation on NICE Guidelines on Care of the Dying Adult with Users and Carers.

Figure 2: Report of Workshop on Draft NICE Guidelines on Care of the Dying Adult with Users and Carers

Overview of Event

AllHPC facilitated a workshop to discuss matters related to the draft NICE Guidelines on Care of the Dying Adult. Seventeen users and carers took part. Four participants were members of AllHPC's user/carer panel Voices4Care with the remaining being members of the Patient Client Council in Northern Ireland. Two observers attended one from the Patient Client Council and the Public Health Agency.

Feedback from the day was provided to Northern Ireland's Living Matters Dying Matters Implementation Board. This feedback also helped inform AllHPC's Palliative Hub's End of Life stage on the Palliative Hub – Adult website.

During the day, participants were asked firstly to reflect on what they felt were the most important issues for the last days of life. Good communication was a significant theme to emerge, encompassing the importance of ensuring that families, friends and carers are included and supported in last days of someone's life

The main aspects of the draft NICE guidelines were presented to participants, and a discussion was held pertaining to the content and clarity of the 6 key areas covered in the guidelines. The participants agreed that the key areas from the guidelines, directly related to the issues that they had discussed in the morning in terms of communication surrounding last days.

A number of recommendations were put forward by the participants to the Living Matters Dying Matters Implementation Board for their consideration.

- Develop and deliver adequate guidance and training to health and social care professionals on content of guidelines.
- Roll out training programme to improve communication skills tailored to care of the dying for all health and social care professionals.
- Bereavement should be included in final version of the Guidelines or supplementary guidance should be produced.
- Guidelines should be considered as guiding principles underpinning a tailored and personalised approach to care of each person as an individual informed by clinical judgement.

3.5 Conclusion

The secondary analysis of data provides an analysis and description of both the process of what was adopted in terms of the implementation and development of the Forum; selection and recruitment of members; ways of working and key activities and participation. What is clearly evident is the learning that was achieved through some of the consultative, think tank events that helped to inform the subsequent ways of working and the diversity of activities that the Voices4Care members have contributed and participated in.

4.0: Key Stakeholder Interviews

This phase of the evaluation consisted of a series of individual semi-structured interviews with a purposive sample of key stakeholders. These individuals were selected in consultation with AllHPC, because they had either direct experience with the project at different stages, or could offer a broader view of the Voices4Care initiative in a wider palliative and health and social care context across different regions of the island of Ireland.

4.1 Method

Individuals were contacted via email initially with a letter of invitation (see Appendix 1), participant information (see Appendix 2) and a consent form (Appendix 3). Upon receipt of consent, a series of individual semi-structured telephone interviews were conducted (n=7) (see Appendix 4). These lasted approximately 20 minutes, were audio-recorded with permission, transcribed verbatim and subjected to thematic analysis (Burnard et al, 1991). Stakeholders represented all regions of Ireland, North, South, East and West and included participants from a variety of backgrounds (see Table 8).

Table 8: Key informants for stakeholder interviews

Clinical leads in palliative medicine	N=1
Senior researchers and commissioners of research	N=2
Representatives from patient advocacy and PPI organisations	N=2
Policy commissioner	N=1
Current and past members of Voices4Care (not involved in the focus groups)	N=1

4.2 Key findings

Findings from stakeholder interviews reflected three key areas:

1. Role of Voices4Care.
2. Perceived impact of the Voice4care initiative.
3. Barriers to Voices4Care achieving full impact.

In addition, participants made recommendations to develop and build on current progress, which are also outlined.

4.2.1. Role of Voices4Care:

Stakeholders described several key elements, which they perceived to be central to the role of Voices4Care . These were:

- **Providing a supportive context** in which the voices of users and carers could be heard and valued and where members could benefit from mutual sharing of information and experiences in relation to palliative care.
- **Bringing the voices of users and carers specifically into the work of the AIIHPC** by informing specific projects, such as “let’s talk.”
- **Embedding user and carer experience in the culture of palliative care delivery** and as a key driver in palliative care education, research, policy and practice development activity at every stage and across all of Ireland. One participant noted:
- *“We can no longer assume that we know what patients, carers and the general public think. We actually have to have their voices there – present in the research process every bit as in the education process...”* (Participant 2)
- **Providing a model of how this embedding process may be achieved.**
- It was important to participants that the role of service users and carers was equal, meaningful, and not ‘tokenistic’ (Participant 7).
- **Providing a resource of user and carer experience, which may be consulted by healthcare professionals and organisations to inform their own practice developments.** Although having a consultative role within the AIIHPC and engagement in various projects, the potential for Voices4Care to be active and influential in a larger palliative healthcare arena was a recurrent theme.

4.2.2. Perceived Impact of Voices4Care:

There was widespread acknowledgement among stakeholders that the AIIHPC had provided an important and useful initial platform for the service user and carer voice. Participant 2 noted: *“Voices4Care has provided a megaphone for people who previously could only whisper”*.

Without exception, stakeholders described real and potential positive impacts at personal, practice, and policy levels. Participant 4 reflected this sentiment, when remarking about Voices4Care: *“The value of something like this is tremendous”*.

At a personal level, stakeholders indicated satisfaction with the process of engagement by AIIHPC which demonstrated value and respect for members’ voices and adequately recruited, prepared and supported them to share experiences with each other and in a wider healthcare context. As Participant 1 explained:

“The Institute has been a real champion of the user/carer voices and particularly in terms of listening to the awful stories...They’ve been very encouraging with getting all the experiences out there and not sort of dismissing or hierarchizing different experiences.”

At an education, research and practice level; satisfaction with key initiatives was illustrated by several participants, who provided examples of where they thought Voices4Care had had most impact. These included:

- **Influencing and challenging professional complacency:** Participant 7 stated: *“They bring a common sense perspective to the meeting...no matter how long people have been involved in palliative care, that professionals just wouldn’t think about – even the language...they challenge that.”*
- **Triggering discussion:** Several participants described practice development activity after results from the ‘Lets talk about’ survey. For example, one participant outlined an organisational review of the language used to describe carers, since findings from the survey challenged this labelling.
- **Developing the research agenda:** Work identifying the top 10 research priorities was widely described as important and timely, providing a focus for palliative care research going forward across the island of Ireland.
- **Influencing approach to practice:** One clinical lead described significant changes to practice: Participant 2 explained: *“We have been influenced by Voices4Care . We now have a bank of service users who are going to be, or are involved in all new research projects and on any new research committee there will be an end-service user.”*

At a policy level, all participants identified the *potential* for Voices4Care to inform national and regional strategy for palliative care provision by aligning with national work programmes north and south. For some stakeholders, the Voices4Care initiative went to the heart of legislated requirements for user involvement in the UK and they highlighted direct benefits from having the user voice inform specific strategic projects, such as the recent NICE guidance for care at the end of life (DH, 2014).

It was clear that some stakeholder organisations had been working closely with the AIIHPC in relation to Voices4Care and this was a source of satisfaction for these participants:

“If you’re asking me am I satisfied with the impact of Voices4Care , I would say that I am more than satisfied – I am highly satisfied”

(Participant 6)

Yet this was not a universal experience. Based in the Republic of Ireland, one participant described frustration that without “*pro-active engagement coming from the Institute, to communicate what’s the perspective of Voices4Care ,*” (Participant 4). Without a joined up approach which might enable Voices4Care to influence the wider healthcare agenda, opportunities were being missed to exert influence at a national policy level, such as in the evolving National Cancer Strategy. More generally, when asked if Voices4Care had, in the opinion of participants, *achieved its potential*, responses were less positive:

“I have to say that I don’t think the potential [of Voices4Care] has been actualised in the working of the Institute this far...”

(Participant 5)

4.2.3. Barriers to Voices4Care achieving its Full Impact

Findings suggested that several barriers existed, which were perceived to have undermined the potential impact of the Voices4Care initiative. These were firstly described in relation to the initiative’s early stage of development and secondly, to the interface between Voices4Care and the wider healthcare community:

1. Barriers relating to early stage of development: The Voices4Care initiative was emerging from an initial exploratory stage of development, which had several inherent limitations.

- **Time taken to form the group:**

Responses indicated that the time required for this initial phase had been underestimated, with implications for what could realistically be achieved to date. One participant reflected:

“Framing, developing and supporting the group was much more labour intensive than we anticipated...and the building, growing part was not factored in.”

(Participant 5)

Participants directly involved with Voices4Care described an exploratory process, from which their role and its potential impact was just beginning to emerge. One person commented that early expectations may have been unrealistic:

“I think everyone would have gone into Voices4Care hoping to see improvements, but it’s too early – you wouldn’t expect overnight improvements...”

(Participant 1)

- **Group membership:**

Concerns were expressed that group membership may not be fully representative of the range of user experience. Although participants acknowledged the challenges of recruiting people from ‘difficult to access groups,’ it was noted that participants tended to be professionals and female. Representation from other sections of the community, such as travellers, men, people from ethnic communities; people with disabilities and non-

professional people was lacking.

- **Selected model of participation:**

It was universally described that the consultative panel model adopted, had implications for the way in which Voices4Care might inform the work of the AIIHPC and other organisations and stakeholders felt that members may have more to offer.

“It certainly feels that the initial steps have been – ‘here’s some projects, get the user’s input there.’ I think it should be going deeper...into the forums of conversation, rather than just ‘do you like A,B or C?’ More deeply in what should A,B or C be? Or even co-developing research...” (Participant 1)

A ‘ladder of participation’ (Participant 1) was desired by some participants. This would enable Voices4Care to be embedded within all the work of AIIHPC, but integrated at all levels of operation, from planning and design of projects to consultation on existing work. Others considered that additional models needed to be explored, so that creative ways to engage with Voices4Care might achieve a broader range of user and carer experiences.

- **Paternalistic approach:**

Stakeholders pointed to a paternalistic approach to the members of Voices4Care by AIIHPC, which blocked engagement with the wider healthcare community to the extent that was possible. There remained a need to balance respect for people in difficult end of life situations, recognition of their choice to participate and the pragmatic need of palliative care providers and others to maximise the benefit of their shared experience. This view was summarised in the following comment:

“There’s a danger that you end up patronising the service user: ‘You are wonderful to come here today, you know’- but it should be much more meaningful. There should be a way that we are being challenged about what is coming out of Voices4Care and that we [provider organisation] are challenged to respond. That’s how you get change happening.”(Participant 4)

2. Barriers relating to the interface between Voices4Care and the wider healthcare community: Stakeholders perceived that a limited interface existed between Voices4Care and the wider palliative care community, and one participant described that the *“bridge between Voices4Care and stakeholders is just not there....”* (Participant 5). Furthermore, findings suggested that the absence of robust links had several negative impacts on how user voices might be heard within the work of other stakeholder organisations. These included:

- **Poor visibility and lack of awareness of Voices4Care :**

Embedded in AllHPC project work, a common critique from participants was that the work of Voices4Care was not always perceptible to the wider palliative and healthcare community. Participant 7 described:

“They may be giving very good inputs into the projects of the AllHPC, but the input has not been fed into the wider sector to enable that wider sectoral change.”

Overall, the statement, *“I know of it, but I don’t know a great deal about it”* (Participants 2, 3 and 4), was a common introductory remark from individuals not directly involved with the establishment of the initiative or with specific projects.

- **Accessibility to user perspectives:**

Participants highlighted the absence of regular opportunities to meet Voices4Care members and the lack of a transparent mechanism through which stakeholders from the wider palliative and healthcare community might access this AllHPC resource:

“there were no meetings where we could access the V4C group... There was no clear pathway to get information from the group... while you can keep trying, in the current climate there’s no time to keep trying, and it deters you from getting the user perspective” (Participant 5)

- **Project specific links:**

Findings suggested that the establishment of links between Voices4Care and the wider palliative and healthcare sectors were largely project specific (Participant 3), with implications for how the experience of Voices4Care members might be heard. For example, linked to value for money considerations and a desire to have Voices4Care inform national and regional programmes of work, concerns existed about leadership of Voices4Care and how the project work was selected:

“Who gets to determine what the group spend their time on? I know they [Voices4Care] have contributed to the website and maybe survey design, but how is this influenced from outside?” (Participant 5)

Disappointment was expressed by some that a broader process of engagement with key stakeholders had not materialised as expected:

“The process and engagement of stakeholders around the development of this – well there isn’t a sense at the end of projects of any ownership of the Voices4Care .”
(Participant 4)

Other stakeholders considered that a different approach was required to integrate the user perspective more deeply in organisations as part of *their* infrastructure:

“What I’d really like to see is that user/carer panels in hospices and the sort of places that actually implements and delivers packages of care.”

(Participant 1)

- **Communication and dissemination of outputs:**

A comment from Participant 7, *“I don’t fully understand what Voices4Care is involved in?”* reflected a general lack of knowledge about Voices4Care activities and outputs.

It was commented by several participants that outputs of Voices4Care were not clearly identified or measured (Participants 6 and 7). Without valid indicators of contribution being established, there was no way in which the benefits and value of Voices4Care might be demonstrated to stakeholders. Participants offered suggestions, one of which was that the impact of the user voice on research design might be demonstrated in studies examining of patient and family recruitment.

Furthermore, some respondents highlighted the absence of a coherent communication strategy for known outputs, such as information on patients and family experience, which undermined full engagement by partnering organisations and had negative implications for how these might embed user information and influence change in their own organisations.

“What the Institute should be doing better is communicating...[and] I don’t think there has been a proper dissemination strategy to say ‘this is what Voices4Care are saying’ – I don’t see it as a product that we’re all clear about.”

(Participant 4)

Instead, one participant described that the strategy relied on *“just hoping that what Voices4Care is doing in the different projects and reports will filter through [to the wider community]”* (Participant 1).

4.3 Stakeholder Recommendations

Stakeholder recommendations to support the progress of Voice4care, related to structure, accountability and sustainability of the initiative.

Need to review structure of Voices4Care : Suggestions for how Voices4Care might build on existing structure included:

- Expansion of group membership to include hard to access groups.
- Development of a ‘ladder of participation,’ of service user and carer involvement.

Suggestions for how Voices4Care might build on existing processes of engagement between with AllHPC and the wider healthcare community included:

- Exploration of additional models other than consultative panel.
- Embedding of Voices4Care within all work of AllHPC – integrated at all levels of operation.
- Transparent processes through which the groups' experiences might be accessed by stakeholders in the broader palliative and healthcare community.
- Regular opportunities for feedback from Voices4Care to AllHPC and other organisations.
- Education and training development for healthcare professionals to enable them to maximise user participation, for example training for chairs about how to work effectively with users in meetings.

Accountability and sustainability: Suggestions for how the Voices4Care initiative might be more widely accountable included:

- Reflection on the scope and remit of the initiative to set realistic and transparent future goals.
- Wider ownership of the Voices initiative among stakeholder groups outside AllHPC – evidenced in greater involvement with and by these stakeholders.
- Regular opportunities where Voices, management committee and stakeholders interface.
- Identification of clear outputs and a mechanism to measure improvements over time in order to determine value for money.
- Increased efforts to disseminate outputs from Voices4Care to the wider palliative care community, for example in published reports and research papers.

A key issue, voiced universally by stakeholders, was the sustainability of the initiative and the need for succession planning. Suggestions for how the Voices4Care initiative might be more sustainable included:

- Efforts to promote a greater profile of Voices4Care among public and wider healthcare organisations, to attract participation from a wider group of service users and carers.
- Improving the profile of Voices4Care initiatives via social media and other forms of advertising to raise public awareness around the initiative, its achievements and important areas of further work – to galvanise on-going commitment from group members and to attract new members.
- To expand the focus and potential impact of Voices4Care by linking to other existing user groups north and south.
- To develop a succession plan to include refreshment of group membership and on-going management as well as practical and financial support of the group.

4.4 Conclusion

Following the establishment the Voices4Care initiative, there was a general sense from stakeholders that the initiative was important and necessary. However findings suggested that developmental issues limited its potential impact on palliative care research, education, policy and practice with group membership, structure and the process of engagement with the wider health and palliative care community via the AIIHPC. Project specific links and the lack of a transparent way to access Voices4Care and identify their outputs created inconsistency in the experience of stakeholders and undermined their understanding of its value, since that was not clearly visible to all nor easily measured. With the commencement of another phase, stakeholders identified the need to move from early *“developmental stages to being more structured and accountable”* (Participant 5). Stakeholders offered a variety of recommendations to achieve this, which are included in the final section of this report.

5.0: Focus Group Interviews

This chapter provides a brief overview of the research approach and presents the findings from a focus group discussion held with members of Voices4Care . A focus group schedule was designed to explore members' perceived role, experiences and views on the level of involvement in general and specific palliative care education, research, policy and practice and seek recommendations for its future development.

5.1 Method

This phase of the evaluation consisted of focus groups with a purposive sample of Voices4Care members. All focus groups took place during a Voices4Care workshop. Prior to the event all attending Voices4Care members were sent a letter of invitation (see Appendix 5), participant information sheet (see Appendix 6), and a consent form (S.A.E.) (see Appendix 7) from the AllHPC. Once written informed consent was obtained participants were allocated to a focus group.

In total two focus groups were conducted as part of the evaluation that explored Voices4Care members perceived role, experiences and views. Each focus group was comprised of 6-8 participants and lasted between 40-60 minutes; both were audio recorded, transcribed and subject to content analysis (Burnard & Newall 2006). An interview schedule based on the evaluation objectives and review of the literature was employed (see Appendix 8). Participants demographic characteristics were captured using a tick box questionnaire.

5.2 Key Findings

In total 13, Voices4Care members (1 male and 12 females) participated; the majority (77% n=10) were aged over 55 years of age (see table 9). The duration of membership ranged between less than one year to three years; the majority (77% n=10) had been a member for over two and a half years. Most participants were located in the Republic of Ireland and identified themselves as being a former carer.

Table 9: Demographic characteristics for Voices4Care Focus Group Participants

	Category	No%
Gender	Male	1 (8%)
	Female	12 (92%)
Age	35-44	1 (8%)
	45-54	2 (15%)
	55-65	5 (38.5%)
	65 plus	5 (38.5%)
Membership timeframe	Less than 1 year	2 (15%)
	Two years	1 (8%)
	Two and a half years	5 (38.5%)
	Three years	5 (38.5%)
Location	Northern Ireland	4 (31%)
	Republic of Ireland	9 (69%)
Membership	Patient/Service user	1 (8%)
	Former carer	7 (54%)
	Person from wider community	1 (8%)
	Current and former carer	1(8%)
	Former carer and person from wider community	3 (23%)

The following six key themes emerged from analysis: (1) recruitment and motivation, (2) membership role, (3) level of support, (4) palliative care impact, (5) personal impact and (6) future development. Excerpts from the transcribed focus group discussions that exemplify these themes are outlined below.

5.3 Recruitment & Motivation

In order to understand member's reasons to join the Voices4Care initiative participants were individually asked about their recruitment experience and why they became a member. The process of becoming a member of the initiative was varied with the majority stating that they were asked to become a member based on their involvement with existing hospice and palliative care services in their local area (n=6) and five responded to adverts placed in the press or on radio. The remaining two members however revealed that they came upon the Voices4Care initiative by chance via a web search.

Underpinning each member's reason for becoming a member was linked to a personal bereavement they had experienced of a close family member and their experience of interacting with health, social and palliative care services. Whilst a few highlighted the positive experiences they had interacting with such services the majority voiced their own individual story of the barriers and challenges they faced caring for someone at the end of life. Overwhelmingly the desire to use their personal knowledge and experience to inform and make a difference to services delivering palliative care to patients, carers and families

was a primary reason for becoming a member. Other reasons included a desire to increase public's awareness of palliative care and to try and learn more about the palliative care process and services. As stated:

"I came as a carer and the positive and the negative experiences we've had a family – ... Wouldn't that be nice to make a difference to somebody else's experience and maybe had more positive than negative" (FG2 Participant 2)

"So I suppose I was left very confused and a lot of questions and wanting ... clarity, so when I saw the ad for the Voices4Care, I thought this might be the place where I could learn and try and understand, and also to bring something what I had been through and maybe it would, you know, inform services for other people who go through the same thing". (FG2 Participant 4)

"My reason for being involved is like most people, I've had experience of looking after a loved one, to their final days and in addition to all, I am a weekly volunteer in [name] Hospice. I felt Voices4Care was a terrific opportunity to feed into the overall care of patients, or people, who have a life limiting illness". (FG1 Participant 1)

5.4 Membership Role

Before joining the initiative, most said they were informed about what their role was going to be and some recalled discussions about establishing ground rules and a contract between Voices4Care and the wider Institute. This process was deemed beneficial as it helped to develop a sense of ownership, bring people from disparate backgrounds together and also developed boundaries within which members could feel safe. Undertaking this process also helped them to develop a collective sense of what the role would not be a *"tick box exercise"*, a message they feel has been reinforced by the AIHPC.

Participants were then asked to describe their role as a Voices4Care member, and responses revealed a multifunctional, evolving role. Essentially they believed their primary purpose was to inform palliative care education, research, policy and practice; however transferring this to practice underplayed the complexity and width of the role. When asked for examples of what the role constituted responses revealed, to inform policy and practice but also build and create awareness, educate the wider community, work and liaise with other health and social care teams, and overall adopt a holistic approach to connect societies not just individual communities. As commented:

"It is about creative awareness and telling people what the Institute does, what this group is about, how we are working to create change, so it's about awareness raising". (FG 1 Participant 1)

“What I do for Voices4Care is feeding in to the Institute’s policy and practice.it has to do with connecting with societies other than my own immediate one” (FG 1 Participant 5)

“It’s feeding in our experience, I suppose, and trying change policy, work on it, build awareness, educate the wider community and work with other groups. This is what I do anyway”. (FG 1 Participant 3)

Moreover they recognised that their role and contribution was based and informed by their individual experiences, as a patient, former/ current carer and as a person from the wider community. They actively tapped into their own personal and professional experience to enable practice, policy, education and research to be developed. The value of having been a carer enabled them to adopt a holistic approach, with a 24/7 vantage point of the care and services delivered to the patient and carer by the multi-professional team. As stated:

“I think it’s a multifunctional kind of a role. In one way we are not user experienced, we’re recipients of the service directly, but we’re the recipients by one remove, we’re the significant people in the lives of the service user, we’ve experienced the service. You are tapping into a representative group, if you like, of a community, that’s wider than our shared experience may be of a particular illness, or death, or whatever. And then other people are bringing professional backgrounds here as well, that are also useful, so I think it is a kind of a multifunctional thing” (FG 1 Participant 5)

5.5 Level of support

All participants believed they were supported and appreciated by the Institute. Members were able to provide examples of personal support they had received and were aware that they only had to ask if they required assistance. The physical provision of support in the form of overnight stays and social events (dinner) were also appreciated. This they felt symbolised the value placed on their role and consequently it helped to form strong bonds between members of the forum and the wider Institute.

The support and protection that the Institute offered was also discussed. Whilst participants recognised that the forum and their role could be open to abuse and resources spread too thinly if it were not for the protection provided by the Institute; this level of support was welcomed by all the participants, who recognised that they could not do everything. As illustrated:

“She does realise we have other commitments and we are here on a voluntary capacity, so we can’t be swamped under with work. So she’s kind of selective and I suppose it has to be something, if there’s going to be positive change, if we’re going to go on board”. (FG 2 Participant 6)

“She has been so supportive to me, in my whole journey and development, my self-development. They have just been so encouraging”. (FG 1 Participant 4)

However, perceptions regarding the level of support and awareness from external agencies varied. With some believing that agencies still treat their work as a tick box exercise without realising the full potential of their role or influence. Others felt that a lack of connectivity between North and South resulted in many health and social care professionals being unaware of the forum and /or Institutes role or work.

5.6 Palliative Care Impact

Participants identified an array of activities they have been involved with which they felt had contributed to palliative care education, research, policy and practice. Table 10 outlines a list but not exhaustive of the types of activities involved in. All participants believed their involvement had made a difference.

Table 10: Involvement in Education, research, policy and practice

Area	Examples of initiatives
Education	Palliative Care Awareness Week Informing Palliative Care HUB Adult & Public website ‘Let’s Talk’ survey, design, engagement and analysis Palliative Care Hub for Children Education of the Institute Education of local communities Involved in Filming (Education) awareness
Research	Consulted about research questions/ topics Involved in the recruitment of research staff Informed the design of research proposals Identification of Research priorities for Palliative care Involved in individual research projects committee groups Involved in selection panels for commissioned work
Policy	HSC Strategic plan for next 5 years NICE Guidelines Palliative care international framework the local colloquium Representation on Management committees/ steering committees i.e. Heads of Profession Meeting HSC
Practice	Constipation guidelines Review of Palliative care Practice in Nursing and Residential Homes

Focus Group participants also spoke of other types of impact they felt they had offered such as:

- Asking questions
- Keeping discussions grounded and holistic to consider the patient, carer and family
- Promoting issues or questions which members believe would be important to patients and/or to the public.
- Bringing in knowledge from their own experience as a carer, bereavement and other related experiences (i.e., jobs)
- Advocating and promoting the use of plain English
- Contributing to practical decisions
- Being involved in and informing the development of publicity material
- Liaising with key stakeholders
- Being a voice in and for communities.

As a consequence of being a member of Voices4Care and being involved in a range of initiatives and projects, the members were able to identify a number of partnerships the group had formed, regionally, nationally, and internationally. For example national links had been formed with Marie Curie UK in the development of palliative care research. National examples included the guidance participants provided into the development of constipation guidelines for the Palliative Care Senior Nurses Network. Regionally, members provided examples where they have helped to inform local hospices, and health services about the AIHPC and Voices4Care role and work. Being involved also helped them to be aware of other service user partnerships such as Patient and Client Council in Northern Ireland.

Whilst the members were able to articulate a range of initiatives and committees they had input to, they were aware that they did not have any authority or expertise to direct how those ideas would be implemented. They all recognised that their role was to deliver a voice. Whether their views were listened to was dependent on the audience. However they were able to provide examples of when they felt their voice was listened to. Some commented:

“...it was the senior palliative care nurses network, and they were presenting a piece of work and we were critiquing it and I suppose what really struck me from that one, was the language, that we’re coming with the ordinary. ... and we were able to say “actually, if you just said something like, used the toilet, instead of whatever,” you know”! (FG 2 Participant 1)

“I mean, to hear the presentation this morning, reading out a piece in a document that he is from the Health Service Executive, that we had informed, it is good to see

that actually, the voice has been heard, and that maybe that might impact in terms of service, delivery or policy to them to whatever". (FG 2 Participant 3)

There have also been factors, which have initially limited the impact of the Voices4Care role for example the time required to learn medical / academic jargon, build confidence and establish their role on a community and/or initiative. However being able to draw upon the support of individual members and accept that they play a vital role, helped to develop these skills.

"I think we've come through the chase of it because of our experiences. Our language we use is based on our real life. They say lay-man's language, as opposed to the academic language, which can be disconnected". (FG 2 Participant 5)

"...the first year or two, and I found it quite difficult to know where I would fit, in terms of the outside work and I wasn't sure how it worked, how it was allocated, how some people were on committees and some weren't. I joined a committee, and I mean, I didn't feel, to be honest, inducted into them, I really hadn't a clue in what they were talking about, it took a while". (FG 2 Participant 5)

"You also have to remember that you're at the heart of it, because everybody round that table, everybody in the room is a potential patient. And you're the only one with their voice. You know, your role is vital and sometimes they need to be reminded". (FG 2 Participant 4)

Another barrier mentioned by some participants was the need for the Voices4Care to integrate and learn more about the Northern Ireland's Health and Social Care Services, to enable the forum to be truly All-Ireland. At present some stated that they had gained an insight into the different health systems from other members and suggested that additional resources could supplement this.

5.7 Personal impact

Involvement had an impact on Voices4Care members. One positive impact that was identified was the sense of pride they felt at being involved in an all-Ireland initiative, which they felt helped the forum to stand out from others and be recognised on a national level. Other examples of impact included in some cases members becoming involved in other activities, which they would not have done otherwise such as speaking up on behalf of families or others in need. There were also reports of a more personal impact with two participants referring that Voices4Care membership had given them a new lifeline and the majority revealing that it had increased their confidence, feelings of empowerment and a belief that they are actively making a difference. The process also helped some to think

more about palliative care and take responsibility for planning ahead for their own death. Sharing similar past caring experiences has enabled friendships to be formed within and outside of the group setting providing some with a sense of purpose. Participants also felt they have been valued and their skills and experience have been recognised both within and out with the Institute. As stated:

“I found it a very empowering experience. If when you leave these meetings, you know you have actually done some work” (FG 1 Participant 1)

“But it is actually – I’m not afraid of death. It has made me think about it. It’s also made me think about, and take responsibility for my future and what I want or myself and that I’m not just going to leave it, you know for chance”. (FG 1 Participant 2)

“It just gives you the confidence and it’s amazing. I suppose, in my own personal journey, it has just given me a whole new lifeline. I think, from this and the confidence I got from the Group. So it has definitely changed my whole life”. (FG 1 Participant 6)

“So it is just a whole – you said it has changed your life. I just find it has educated me in a way I never thought I could be. That it has informed me that I can now have the courage to go out and do something about it”. (FG 1 Participant 5)

For others, the main personal impact had been demands on their time – membership proved very demanding with one participant describing their experience as *“exhausting”* and for others this had consequences for other aspects of their life. Participants also referred to the psychological challenges (thoughts, emotions and actions) they associated with being a member of the group, especially when they had to relive their past caring and bereavement experience in a public arena. Whilst they recognised that including past carers is complex and challenging within the context of palliative care the need for ethical and sensitive approaches to cater to these needs was required. As commented:

“Well one of the biggest difficulties was that every time we meet, we have to get over this emotional hurdle and I find the meetings very emotionally draining...that needs looking at, in terms of just how that would be managed” (FG 2 Participant 1).

“... it takes out of me, and it takes me two to three days to recover after these meetings” (FG 2 Participant 2)

“You do have to go through – you reach deep inside, that sense of the pain that was there....so there’s always that behind it. But that leads to the passion or the

perseverance, or the urgency that I feel about this issue. If that pain hadn't of been there in the first place, well I wouldn't be here". (FG 2 Participant 5)

5.8 Future Development

When questioned about the future of Voices4Care, overwhelmingly there was support for the continuation of the forum alongside the maintenance of support. The provision of social events and accommodation was considered important by most members as it helped to encourage collegiality.

There was recognition of the need to capitalise on the expertise and knowledge that has been gained and use the learning to plan and inform future palliative care initiatives. For example; use the model to inform the development of other similar initiatives, such as a little Voices4Care forum for children. Furthermore whilst the need to bring in new users to sit on the forum was recommended, recognition that this required careful and sensitive management to ensure the equilibrium was maintained was required.

Consideration regarding the future role and position of Voices4Care was also discussed. Participants identified areas where improvement was needed these included, greater links to other organisations, exploration of greater diversity amongst new members (in terms of gender), consideration of name change of the Institute, and greater equality in the location of meetings to enable wider voice to be heard. Emphasis was also placed upon the need to raise awareness of the forum and its role among the general public. As stated:

"...whether we could occasionally, or just especially on a one-off, move to somewhere like the community room in a community hospital, if any of the people who are, either using our services in the hospice, or even families would like to come along to contribute, without being specifically members and being committed to having to come to these meetings, or whatever. You know, for us to go to them". (FG 1 Participant 2)

"Could we not even go round the country, to have a meeting in a different part, and just maybe for an hour of it, invite in people and give them a presentation on what we do?" (FG 1 Participant 6)

On an individual level the need for psychological support for members was raised as a future improvement of the group with a qualified member of staff available if and when a Voices4Care member needed it.

"... we should have somebody with specific qualification in listening and understanding and hearing. Not telling us we need it, but to let us know that it's

there, for us to decide whether we need it or not. It can be heavy going". (FG 1 Participant 5)

5.9 Conclusion

The Voices4Care Forum was viewed by its members as a sustainable, inclusive and effective way of the voice of the user being interwoven into palliative care policy, practice, education and research. Members were however clear that the success of the Voices4Care forum was based on the acceptance that it was not an add-on, tick box exercise but instead at the core business of palliative care. Participants provided examples of opportunities in which collaboration with professionals had led to an influence of the palliative care agenda. However, user involvement within this context provides a number of unique challenges, particularly because of the potential vulnerability of the individual members themselves.

6.0: Conclusions

User involvement is viewed as an essential element for all stages of high-quality research, service delivery, policy formulation and practice development (Daveson et al. 2015, Collins et al. 2014). This necessity and value is increasingly reflected in national and international legislation and policy. Whilst the notion of user involvement, considered as the way in which *‘service users are involved in shaping or building the future of public services’* (Payne et al. 2005), is widely supported questions around implementation and evaluation remain. Questions exist with regards to agreement on definitions and conceptual factors; consensus on models of implementation and an overall lack of robust evidence clearly articulating the value and impact of user involvement. Despite this, various user involvement initiatives have taken place across several health and social care domains including palliative care, yet evaluations and the experiences of individuals involved are not well reported. This report adds to the knowledge base of service user involvement, the implementation process and the contribution of the Voices4Care initiative within the context of palliative care.

The findings of the study suggest that the Voices4Care Forum has become an inclusive and effective way of implementing user involvement within the palliative care context, enabling the user to be given a voice across different aspects of palliative care policy, practice, research and education. In order to support the sustainability of involvement, the process of establishing the Forum was noted to be a resource intensive (time, monetary and human) activity. Whilst the process of recruitment and selection helped to enlist members with a range of experience, skills and geographical spread, the need for a more diverse voice from hard to reach audiences and genders was recognised.

Members reported feeling well supported practically, personally and professionally, however they also considered that their involvement was at times complex and personally challenging. Specific features in palliative care (such as bereavement needs and deteriorating health) suggested the need to provide psychological support for members to help to ensure well-being. It was also found that resourcing of user involvement is important, taking cognizance of the subsequent costs and need for support.

The review of the literature and analysis of secondary data highlighted various exemplars and models of user involvement exist, suggesting that one size does not fit all and that a degree of flexibility in approach is required. In terms of activities it was noted that the Voices4Care forum tended to adopt a mainly consultative process and that this selected model of participation had the potential to be restrictive. Rather a ladder of participation approach was required, enabling more creative and innovative approaches of involving service users.

Whilst the members considered that their input was valued and examples of involvement in specific projects was outlined from all perspectives, it was considered that the full potential of the Forum was restricted in some ways by the terms of reference; purpose of the Forum, the model adopted and the lack of transparency regarding access and usability. This is noteworthy given that the need for clear guidance and terms of reference were outlined as key aspects of consideration from the initial Think Tank event that led to the subsequent development of the Forum. Perhaps these aspects have less significance following the establishment and initiation of the Forum, reflecting a change in needs and requirements over time.

It was found that Voices4Care contribution was not always made clear to some key stakeholders, resulting in confusion regarding some practical implications of involvement. Whilst a balance is required to ensure that members were not overstretched, tensions regarding access to and utilization of the forum into the wider palliative care community exist. Therefore, ensuring ongoing clarity about their activities, roles and goals, is crucial to the continued success of Voices4Care. This suggests the need to work with stakeholders to incorporate user involvement at various levels and develop an ongoing culture that is both receptive and willing to respond and accept user involvement and participation.

Overall, it was found that Voices4Care provided opportunities for patients, caregivers (active and bereaved) and members of the general public to work collaboratively with health and social care professionals, educators, researchers and policy makers to influence the palliative care agenda. Evidence from this study confirms that the contribution of Voices4Care to these strands and projects proved to be an integral element of the overall process. This evaluation clearly demonstrated that there is much to be gained from the Voices4Care initiative and that further development is warranted. There is however also the need to undertake research and evaluation that clearly articulates the benefits and impact of user involvement from varying perspectives.

7.0: Recommendations

The following key recommendations are outlined:

1. Continuation of Voices4Care alongside the maintenance of support to enable the forum to evolve.
2. Work with key stakeholders in the sector to seek to ensure that user involvement is incorporated at various levels and within the overall culture of an organisation.
3. Capitalise on the expertise, knowledge and skills gained to date and use the learning to inform future user initiatives and plan for the future.
4. Promote the Voices4Care's role and outputs regionally and nationally
5. Ensure greater diversity amongst new patient / public members especially from 'hard to reach audiences'.
6. Identify and agree on consistent and robust ways to assess the impact of involvement.
7. Consider the need for on-going resourcing of user involvement and subsequent costs.

8.0: References

- Anderson, E., Tritter, J. and Wilson, R. (2006) (eds.) *Healthy Democracy: The future of involvement in health and social care*. Involve and the NHS Centre for Involvement. Available at: <http://www.involve.org.uk/wp-content/uploads/2011/03/Healthy-Democracy.pdf> (Accessed 19th September 2015).
- Black, J. (2008) User involvement in EoLC: how involved can patients/carers be? *End of Life Care*, 2(4), 64-69.
- Boote, J., Baird, W., Beecroft, C. (2010) Public involvement at the design stage of primary health research: a narrative review of case examples. *Health Policy* 2010; 95. pp.10–23.
- Buck, D., Gamble, C., Dudley, L., Preston, J., Janley, B., Williamson, P., Young, B. & The EPIC Patient Advisory group (2014) From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials. *BMJ Open* 2014; 4, (12) doi:10.1136/bmjopen-2014-006400
- Collins, K., Boote, J., Ardron, D., Gath, J. & Green, T. (2015) Making Public and Patient Involvement in Cancer and Palliative Research a Reality. *BMJ Supportive and Palliative Care*, 5, (2), 203-206
- Conklin, A., Morris, Z. & Nolte, E. (2012) What is the Evidence Base for Public Involvement in Health-care Policy: Results of a Systematic Scoping Review. *Health Expectations*, 18, 153-65.
- Cotterell, P., Cowdrey, D. & Paine, M. (2004) *Reflections and Projections: Service User Involvement in Palliative Care Research*. Lancaster. Available from: http://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2004/papers/cotterell2004.pdf (Accessed 19th September 2015).
- Croft, S., Chowns, G. & Beresford, P. (2012) *Getting It Right: End of Life Care and User Involvement in Palliative Care Social Work*. Available from: http://www.apcsw.org.uk/uploads/3/0/8/4/3084378/getting_it_right.pdf (Accessed 14th November 2015).
- Daveson, B., de Wolf-Linder, S., Witt, J., Newson, K., Morris, C., Higginson, IJ. And Evans, CJ. (2015) Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative Medicine* 29(10),939-949.

Department of Health (2008a) *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life*. Department of Health, London. Available from: <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life> (Accessed 23rd September 2015).

Department of Health (2008b) *The National Health Service Constitution. A Draft for Consultation*. Department of Health, London
http://systems.hscic.gov.uk/infogov/caldicott/caldresources/consultationresps/consultnhsc_onstit.pdf (Accessed 23rd September 2015).

Department of Health (2006) *Best Research for Best Health: A New National Health Research Strategy*. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136578/dh_4127152.pdf (Accessed 23rd September 2015).

Department of Health and Children (2008). *Commission on Patient Safety and Quality Assurance*, DH&C, Ireland.

DHSSPSNI (2015) *Personal and Public Involvement Consultation Scheme*. Available from: http://www.dhsspsni.gov.uk/final_-_dhssps_ppi_consultation_scheme.pdf (Accessed 23rd September 2015).

DHSSPSNI (2010) *Palliative and End of Life Strategy Northern Ireland*. Available from: http://www.dhsspsni.gov.uk/palliative_and_end_of_life_care_strategy_-_consult.pdf (Accessed 23rd September 2015).

Haarsma, F., Moser, A., Beckers, M., van Rijswijk, H., Stoffers, E. & Beurskens, A. (2014) *The Perceived Impact of Public Involvement in Palliative Care in a Provincial Palliative Care Network in the Netherlands: a qualitative study*. *Health Expectations*, 1-15.

Hannigan, B. (2014) *Health Research Landscape in Ireland: What Researchers Say*. Ulster University, Ireland, Medical Research Charities Group.

HSE & DoHC (2008) *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*. Available from: http://www.hse.ie/eng/services/publications/corporate/Your_Service,_Your_Say_Consumer_Affairs/Strategy/Service_User_Involvement.pdf (Accessed 14th November 2015).

Healthcare Commission (2008) *Criteria for Assessing Core Standards in 2007/2008*. Commission for Healthcare Audit and Inspection, London
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132991.pdf

(Accessed 23rd September 2015).

Hinds, P.S., Vogel, R.J., Clarke-Steffen, L. (1997) 'The possibilities and pitfalls of doing a secondary analysis of a qualitative data set'. *Qualitative Health Research*, 7(3), 408-24.

INVOLVE (2014) Webinair 3: Public Involvement in Adult Social Care Research – End of Life Care. Available from: <http://www.invo.org.uk/wp-content/uploads/2014/06/WebinarEndoflife.pdf> (Accessed 23rd September 2015).

INVOLVE (2012) Public involvement in clinical trials: supplement to the briefing notes for researchers. INVOLVE, Eastleigh.

INVOLVE (2004) User Involvement. Available from: <http://www.invo.org.uk> (Accessed 4th November 2015).

Irish Health Research Forum (2015) Document on: Public and Patient Involvement (PPI) in Research. Ireland, IHRF.

Kennedy, S. (2011) in collaboration with research partners Huteson P, Morris J, Redshaw H, Robertson D, Robinson D, Wood G. Older carers and involvement in research. Why, what and when? University of Nottingham. 2011. Available at: <http://www.nottingham.ac.uk/nmp/documents/srcc-older-carers-and-involvement-in-research.pdf> (Accessed 19th September 2015).

Khwaja, AI. (2004) *Is increasing community participation always a good thing?* *Journal of European Economics Association* 2, 10.

Marie Curie PCRC (2014) Four Nations: Sharing Practice in Public Involvement: A One Day Conference to Share and Build on Public Involvement in Health Research in the UK. Available from: <http://www.wales.nhs.uk/sites3/documents/1023/Four%20Nations%20Conference%20Report%20May%202014%20Final.pdf> (Accessed 3rd October 2015)

Mockford, C., Staniszewska, S., Griffiths, F. & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal of Quality Health Care*. 24, 28–30.

NIHR (2015). Going the extra mile: improving the nation's health and wellbeing through public involvement in research. NIHR, London. Available at: <http://www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf> (Accessed 26th November 2015).

Nilsen ES, Myrhaug HT, Johansen M, Oliver S & Oxman AD (2006) Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database Systematic Review 3:CD004563.

NSUN (2015) Service User Involvement in Health and Social Care Policy and Legislation. Available from: <http://www.nsun.org.uk/assets/downloadableFiles/4Pi-SERVICEUSERINVOLVEMENTINHEALTHANDSOCIALCAREPOLICY.V62.pdf> (Accessed 4th November 2015).

NCPC (2008) A Guide to Involving Patients, Carers and the Public in Palliative Care and End of Life Care Services. Joint document from NHS National Centre for Involvement and The National Council for Palliative Care. Available from: <http://www.ncpc.org.uk/sites/default/files/InvolvingPatientsCarersAndThePublicInPalliativeCareAndEndOfLifeCareServices.pdf> (Accessed 19th September 2015).

NICE (2004) Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. National Institute for Clinical Excellence. Available from: <https://www.nice.org.uk/guidance/csgsp/documents/improving-supportive-and-palliative-care-for-adults-with-cancer-manual.pdf> (Accessed 23rd September 2015).

Nursing and Midwifery Council (2008) The Code: Standards of Conduct, Performance and Ethics for Nurses and Midwives. Nursing and Midwifery Council, London <http://www.nmc.org.uk/standards/code/> (Accessed 23rd September 2015).

Pawson, R. & Tilley, N (1997) Realistic Evaluation. London: Sage.

Payne, S., Gott, M., Small, N. Oliviere, D., Thomas, J., Young, E. & Sergeant, A. (2005) User Involvement in Palliative Care: a scoping study. London, NCPC. Available from: http://www.ncpc.org.uk/sites/default/files/UI_ScopingStudy.pdf (Accessed 23rd September 2015).

Petit-Zeman, S. & Locock, L. (2013) Bring on the evidence. Nature (501), 160-1.

Popay, J and Collins, M (editors) with the PiiAF Study Group (2014) The Public Involvement Impact Assessment Framework Guidance. Universities of Lancaster, Liverpool and Exeter. Available from: <http://piiاف.org.uk/> (Accessed 26th November 2015).

Sargeant, A., Payne, S., Small, N., Gott, M., Oliviere, D. and Young, E. (2004) User Involvement in Palliative Care a Scoping Study. National Council for Palliative Care, London. 30th November.

Simpson, A., Jones, J., Barlow, S., Cox, L. (2014) Service User and Carer Group Advising on Research (SUGAR). *Adding SUGAR: service user and carer collaboration in mental health nursing research*. *J Psychosoc Nursing Mental Health Service* 52, 22–30.

Staley, K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. Eastleigh, INVOLVE.

Staniszewska, S., Brett, J., Mockford, C., & Barber, R. (2011) The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. *International Journal Technol Assess Health Care* 27 (4), 391-9.

Szabo, V. and Strang, V.R. (1997) 'Secondary analysis of qualitative data', *Advances in Nursing Science*, 20(2), 66-74.

Task Force on the Public Service (2008) *Transforming public services: citizen centred-performance*. Report of the Task Force on the Public Service. Dublin: Department of the Taoiseach.

Tritter, J., Daykin, N., Evans, A. and Sandias, M. Eds. (2004) *Improving cancer services through patient involvement*. Abingdon, Radcliff Medical Press.

TwoCan Associates (2009) *An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration*. Final report. London, TwoCan Associates.

University of Oxford (2015) *Health Talk: Patient and Public Involvement in Research*. Available from: <http://www.healthtalk.org/peoples-experiences/improving-health-care/patient-and-public-involvement-research/what-patient-and-public-involvement-and-why-it-important> (Accessed 19th September 2015).

Vale, C.L., Thompson, L.C., Murphy, C., Forcat, S. & Hanley, B. (2012) Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: results of a survey. *Trials* 13, 9.

Walsh, C. (2014) Proposed framework for patient and public involvement in the HTA process in Ireland. *Journal of the International Society for pharmaco-economics and Outcomes research* 17 (7), 452

World Health Organisation (2015) Palliative Care Factsheet, No. 402, July 2015. Available from: <http://www.who.int/mediacentre/factsheets/fs402/en/> (Accessed 23rd November 2015).

World Health Organisation (1978) Declaration of Alma-Ata. International conference on primary healthcare. Available from: http://www.euro.who.int/_data/assets/pdf_file/0009/113877/E93944.pdf (Accessed 23rd September 2015).

Appendices

Appendix 1: Voices4Care Stakeholder Invitation Letter

UU Headed Paper

Dear Sir/Madam,

Study Title: To evaluate the implementation process and contribution of Voices4Care initiative within the context of the AllHPC framework

The Ulster University in partnership with the AllHPC are undertaking an external evaluation of the Voices4Care initiative. The AllHPC have suggested that as a key stakeholder associated with Voices4Care , your views would be valuable for this evaluation. I am therefore writing to invite you to participate in one telephone interview to explore the role and the perceived impact.

The enclosed pack aims to provide you with more information about the nature of the project and includes a participant information sheet and a consent form (with s.a.e.) for you to complete if you are willing to take part. All telephone interviews will take place at a time convenient for you and will last between 20-40 minutes. With your permission they will be audio recorded, otherwise notes will be taken.

It is important that you understand that your participation in this study is entirely voluntary and you can withdraw at any stage without detriment. Any information that you provide will be confidential and when the results of the study are reported, you will not be identifiable in the findings. Your name will not be recorded on tape or on the demographic sheet; instead you will be allocated a unique code that can only be identified by the researcher.

If you would like to take part please return the enclosed consent form with a contacting telephone number to Paula Brogan (Research Associate) email: paula@pbrogan.f2s.com.

Upon receipt of consent, you will be contacted by Paula Brogan to discuss the study and to arrange a convenient time for interview.

Thank you for your time and any help you may be able to offer to this study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S McIlfatrick', followed by a small dash.

Professor Sonja McIlfatrick

Professor of Palliative Care, Ulster University, School of Nursing, Shore Road,
Newtownabbey, Co. Antrim BT37 0QB

Tel: +44 28 90368066

Email: sj.mcilfatrick@ulster.ac.uk

Appendix 2: Voices4Care Stakeholder Participant Information Sheet

Title of Study: To evaluate the implementation process and contribution of Voices4Care initiative within the context of the AIIHPC framework

You are being invited to take part in a research study. Before you decide whether or not to take part it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information carefully and do not hesitate to ask any questions about anything that might not be clear to you. Make sure you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

What is the purpose of the study?

The aim of this study is to evaluate the implementation process and contribution of Voices4Care initiative within the context of the AIIHPC framework. The study is devised of 4 strands, this strand of the study, involves telephone interviews with stakeholder views on the role and the perceived impact of Voices4Care .

Why have I been chosen?

You have been chosen to take part in this study as you are a member of the AIIHPC associated with Voices4Care .

Do I have to take part?

It is up to you whether or not to take part. Your participation is voluntary. If you do decide to take part you will be given this information sheet to keep. You will be asked to sign a consent form. If you choose to take part you can change your mind at any time and withdraw from the study without giving a reason or without any consequence to you or your studies. However, if you do withdraw the researcher would reserve the right to include any information that you had given prior to withdrawing from the study.

What do I have to do?

You will be taking part in one telephone interview lasting between 20-40 minutes.

What are the risks involved in taking part in this study?

There are no known risks associated with this study.

Are there any possible benefits in taking part?

There are no direct benefits; however taking part will help to inform the evaluation of the Voices4Care .

Will my taking part be confidential?

All efforts will be made by the researcher to ensure the confidentiality of that information, [except as might be required by law]. The researcher will ensure that no identifying information is included in the transcripts and that no participant is identified in the final report. Any further reports or publications stemming from this study will not contain any identifying features.

What will happen to the information that I give?

With permission the telephone interview will be audio taped. All data will be stored in accordance with UK Data Protection Legislation (1998). The audiotape of the interview will be stored in a locked filing cabinet in the research teams' office within Ulster University. The transcript of the will be stored on the researchers computer which is password protected. The audiotape and transcript will not be used for any other purpose other than this study. Data will be stored in the research supervisor's office for 10 years and then destroyed.

What if something goes wrong?

In the highly unlikely event that something should go wrong, the Ulster University has procedures in place for reporting, investigating, recording and handling of complaints. Any complaints or concerns will be taken seriously and the Chief Investigator's information details can be found below.

What will happen when the study ends?

The researcher will transcribe the audio tapes from individual interviews and focus groups and carry out an analysis of the data collected.

What will happen to the results of the study?

At the end of evaluation study the findings will be available online from the AIHPC website and the findings will be sent for publication in a peer reviewed journal.

Who is organising and funding the research?

This research is being undertaken by Ulster University and is being funded by the AIHPC.

Who has reviewed this study?

The study has been approved by the University of Ulster Nursing Ethics Filter Committee August 2015.

Further Information

If you wish to contact someone for further information regarding this study you can contact either:

Professor Sonja McIlpatrick (PI) Email: sj.mcilpatrick@ulster.ac.uk Tel: 028 90 36066	Paula Brogan (Research Associate) Email: paula@pbrogan.f2s.com Tel: 07800837636
--	--

If you are unhappy about any aspect of this study please contact Mr. Nick Curry who is an independent member of the University of Ulster not connected with this research study.

Mr. Nick Curry: Telephone: 02890366629 E-mail: n.curry@ulster.ac.uk

Appendix 4: Voices4Care Stakeholder Interview Schedule

Interview schedule

General Warm up

- Welcome and introduction.
- Confirm the participant has completed their Consent Form, no objections to use of audio recorder and wishes to proceed
- Remind participants that there are no right or wrong opinions and they can stop at any time however data recorded to that point will be retained in the study.

Topic themes & questions

Role of Voices4Care

- What do you think Voices4Care role is?
- Do you think the network is targeting the right issues, areas of policy, delivery, need?
- What do you think the Voices4Care role is on a national / regional level and do you think it is achieving its potential?
- Has the Voices4Care developed as expected? (Prompt what more can it do, who else should it engage?)
- Do you think the Voices4Care is proving good value for money?

Perceived impact

- What (if any) impact do you think Voices4Care has had on (please provide examples):
 - a) Education
 - b) Research
 - c) Policy
 - d) Practice
- Do you think the Voices4Care has played a role in facilitating links between palliative care providers and the wider health care system? *(Is yes, please explain and provide examples with your answer)*
- What do you think has been the key impact and why?

Developing & building on progress

- How do you think Voices4Care should develop?
- How do you think Voices4Care should build on its current progress to date?
- Is there anything that you would like to see happen with the Voices4Care in the future?

Warm down

- Reflect on main issues discussed and remind the participant of confidentiality and information and support services available, final thank you

Appendix 5: Voices4Care Focus Group Invitation Letter

UU Headed Paper

Dear Voices4Care Member,

Study Title: To evaluate the implementation process and contribution of Voices4Care initiative within the context of the AIIHPC framework

Ulster University are undertaking an evaluation of the Voices4Care initiative, in partnership with the AIIHPC. As a member of Voices4Care I am writing to invite you to participate in one focus group to explore your perceived role, experiences and views on the level of involvement in general and specific palliative care education, research, policy and practice and seek recommendations for its future development. Participation is voluntary and you can withdraw at any stage at any time for any reason with no consequence to your membership.

This pack aims to provide you with more information about the nature of the project and includes a participant information sheet and a consent form (with s.a.e.) for you to complete if you are willing to take part. All focus groups will take part on the half day workshop organised by the AIIHPC on 18th October 2015, in Dublin. This is not a test and there are no right or wrong answers. In total 3-4 focus groups will be undertaken comprising of 4-8 members of the Vices4care and last between 40-60 minutes. With your permission they will be audio recorded, otherwise notes will be taken. Your demographic details such as gender and age will also be recorded.

It is important that you understand that your participation in this study is entirely voluntary and you can withdraw at any stage with detriment. Any information that you provide will be confidential and when the results of the study are reported, you will not be identifiable in

the findings. Your name will not be recorded on tape or on the demographic sheet; instead you will be allocated a unique code that can only be identified by the researcher.

If you would like to take part please return the consent form to f.hasson@ulster.ac.uk or submit a paper copy to the researchers on the 1st October at the workshop.

Thank you for your time and any help you may be able to offer to this study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. McIlfatrick', followed by a small dash.

Professor Sonja McIlfatrick

Professor of Palliative Care, Ulster University, School of Nursing, Shore Road,
Newtownabbey, Co. Antrim BT37 0QB

Tel: 28 90368066

Email: sj.mcilfatrick@ulster.ac.uk

Appendix 6: Voices4Care Focus Group Participant Information Sheet

Title of Study: To evaluate the implementation process and contribution of Voices4Care initiative within the context of the AllHPC framework

You are being invited to take part in a research study. Before you decide whether or not to take part it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information carefully and do not hesitate to ask any questions about anything that might not be clear to you. Make sure you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

What is the purpose of the study?

The aim of this study is to evaluate the implementation process and contribution of Voices4Care initiative within the context of the AllHPC framework. The study is devised of 4 strands. This strand involves focus groups to explore Voices4Care members' perceived role, experiences and views on the level of involvement in general and specific palliative care education, research, policy and practice. It also aims to seek your recommendations for its future development.

Why have I been chosen?

You have been chosen to take part in this study as you a member of Voices4Care .

Do I have to take part?

It is up to you whether or not to take part. Your participation is voluntary. If you do decide to take part you will be given this information sheet to keep. You will be asked to sign a consent form. If you choose to take part you can change your mind at any time and withdraw from the study without giving a reason or without any consequence to you or your studies. However, if you do withdraw the researcher would reserve the right to include any information that you had given prior to withdrawing from the study.

What do I have to do?

You will be taking part in one focus group discussion (40-60 min) and complete one demographic questionnaire (n= 5 min).

- There will be four to six other participants in the group and the researcher.
- The focus group will be conducted at the AIIHPC workshop in Scheduled to take place in October in Dublin.
- The discussion will focus on your perceived role, experiences and views on the level of involvement in general and specific palliative care education, research, policy and practice and seek recommendations for its future development.
- With permission the focus group will be audio taped.

What are the risks involved in taking part in this study?

There are no known risks associated with this study.

Are there any possible benefits in taking part?

There are no direct benefits; however taking part will help to inform the evaluation of the Voices4Care .

Will my taking part be confidential?

The information you provide will be shared with the other participants in the focus group and the researcher. All efforts will be made by the researcher to ensure the confidentiality of that information, [except as might be required by law]. The researcher will ensure that no identifying information is included in the transcripts and that no participant is identified in the final report. Any further reports or publications stemming from this study will not contain any identifying features. The researcher will ask all participants taking part in the focus group to maintain confidentiality about everything that is discussed within the focus group. A participant agreement to maintain confidentiality is a component of the consent form. The researcher will remind all participants of this agreement again at the beginning of the focus group.

What will happen to the information that I give?

With permission the focus group discussion will be audio taped. All data will be stored in accordance with UK Data Protection Legislation (1998). The audiotape of the focus group will be stored in a locked filing cabinet in the research teams' office within Ulster University. The transcript of the focus group will be stored on the researchers computer which is password protected. The audiotape and transcript will not be used for any other purpose other than this study. Data will be stored in the research supervisor's office for 10 years and then destroyed.

What if something goes wrong?

In the highly unlikely event that something should go wrong, Ulster University has procedures in place for reporting, investigating, recording and handling of complaints. Any complaints or concerns will be taken seriously and the Chief Investigator's information details can be found below.

What will happen when the study ends?

The researcher will transcribe the audio tapes from the focus groups and carry out an analysis of the data collected.

What will happen to the results of the study?

At the end of evaluation study the findings will be available online from the AIHPC website and the findings will be sent for publication in a peer reviewed journal.

Who is organising and funding the research?

This research is being undertaken by Ulster University and is being funded by the AIHPC.

Who has reviewed this study?

The study has been approved by Ulster University Nursing Ethics Filter Committee 26th August 2015.

Further Information

If you wish to contact someone for further information regarding this study you can contact either:

Professor Sonja McIlfatrick (Lead) Email: sj.mcilfatrick@ulster.ac.uk Tel: 044 (0) 28 90 36066	Dr Felicity Hasson Email: f.hasson@ulster.ac.uk Tel: 044 (0) 28 90 36 6895
---	---

If you are unhappy about any aspect of this study please contact Mr. Nick Curry who is an independent member of Ulster University not connected with this research study.

Mr. Nick Curry: Telephone: 02890366629 E-mail: n.curry@ulster.ac.uk

Appendix 7: Voices4Care Focus Group Consent Form

Title of Study: To evaluate the implementation process and contribution of Voices4Care initiative within the context of the AllHPC framework

Name of Investigator: Professor Sonja McIlfatrick (PI) & Felicity Hasson

Please tick

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way
- I understand that if I withdraw during the study the researcher would reserve the right to include any information I have given prior to leaving the group.
- I understand that the researcher will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study [except as might be required by law].
- I understand that the information I give will be shared with the researcher and other participants in the group and that all efforts will be made by the researcher to ensure the confidentiality of that information.
- I will not disclose the experiences and opinions shared by others during the group
- I agree to the focus group being audio recorded
- I agree to take part in the above study

Name of participant

Signature

Date

Please return this consent form to f.hasson@ulster.ac.uk or submit paper copy to one of the researchers on the day of the workshop (1st October 2015)

Appendix 8: Voices4Care Focus Group Interview Schedule

The researcher will ensure that everyone is comfortable and that everyone can see each other before starting. The researcher will read out the following reminder about confidentiality:

Opinions expressed in this group will be treated in confidence by the researcher for the purpose of exploring Voices4Care members' perceived role, experiences and views on the level of involvement in general and specific palliative care education, research, policy and practice and seek recommendations for its future development. All responses will remain confidential, [except where required by law]. Participants are requested to maintain confidentiality about everything that is discussed within the group.

The researcher will check that there are no final objections to the use of the audio recorder before switching it on and commencing the discussion with the following statement: **I'm very grateful to you all for taking time to talk to me, please remember there are no right or wrong opinions.**

Introduction/ Ice breaker

- How did you get involved in Voices4Care
- Why did you get involved in Voices4Care ?

Discussion Questions

Role/Experience

- How would you describe your role?
- What has been your experience of being a member?
- Information: Are Voices4Care members informed about their role/ activities?
- Consultation: Are Voices4Care member clear about their role?
- What level of support do members receive from the institution?
- Do you feel your role is recognised?

Level of involvement

- Deciding together: Does Forum encourage you to provide ideas and options, and to decide with you the best way forward?
- Acting together: Do you feel Voices4Care has formed partnerships with the wider sector (geographic) and across palliative care settings? (please explain)

- Supporting independent community initiatives: Do you think Voices4Care helps palliative and or specialist palliative care members to do what they want? Has it helped you in your role to help you push forward palliative care in north and south Ireland?

Anything you should be involved with?

Anything outside of the institution?

- Education: Do you think Voices4Care has played a role in general / specialist palliative care education? (i.e. educational steering committee, palliative care learning hub). If yes, please provide examples.
- Research: Do you think Voices4Care has played a role in general /specialist palliative care research? (i.e. research priorities in Ireland) If yes please provide examples.
- Policy: Do you think Voices4Care has played a role in general/ specialist palliative care policy? (i.e. feedback on PCN initiatives i.e. constipation guidelines or PC Senior Nurse Care of Dying initiative) If yes please provide examples.
- Practice: Do you think Voices4Care has played a role in general / specialist palliative care practice? (i.e. communication hub) If yes please provide examples.

Recommendations for future development

- What do you think that the future holds for Voices4Care ?
- Is there anything that you would like to see happen with the Voices4Care in the future?
- Is there any other support you think you need or resources required (wish list)?

Ending

Any other questions / points I've missed?

Thank you for your participation.