



Voices4Care

Terms of Reference & Agreement

Member:



AIIHPC

All Ireland Institute of
Hospice and Palliative Care

Voices4Care is an initiative of All Ireland Institute of Hospice and Palliative Care (AllHPC) - an all-island organisation working to improve palliative and end-of-life care for patients and their families. This document is provided to clarify expectations in relationship to your membership of Voices4Care and sets out AllHPC's commitment to supporting you. We appreciate your contribution to our work and want to ensure that your involvement with us is both productive and rewarding.

1. Purpose and remit

Voices4Care will function to encourage and provide service user, carer and community engagement within the context of AllHPC's work and the work of the wider palliative care community across both jurisdictions on the island of Ireland, with Voices4Care 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.

The perspectives of Voices4Care members will inform and influence palliative care education, research, policy and practice, in a collaborative and supportive manner, with the aim of improving the palliative and end of life care experience of people on the island of Ireland with life limiting illnesses, and their families.

Voices4Care will consider palliative care for adults (but will share all relevant information and ideas with any AllHPC partner, health and social care organisation or charity on the island of Ireland that addresses palliative care for children).

2. Membership

2.1 Voices4Care will be made up of approximately 50 members.

2.2 Members will be recruited by AllHPC.

2.3 Members will be from Northern Ireland and the Republic of Ireland. The Health and Social Care Board and Public Health Agency in Northern Ireland have initiated *Palliative Care in Partnership* - a dedicated programme to improve palliative and end of life care services. The Service User and Carer Reference Group in this structure - 'Palliative Care in Partnership Voices4Care' - will be made up of members of Voices4Care in Northern Ireland. (See Appendix A for group in NI structure – a copy of the programme mandate will be shared with members from Northern Ireland).

2.4 Membership will consist of a selection of: patients/service users receiving palliative care; carers or former carers of adults with palliative care needs; people from the wider community interested in palliative care.

2.5 Members join on a voluntary basis and participate as individuals, not representing any particular organisation.

- 2.6 The initial term of membership is two years; rolling membership may be facilitated by one year extensions. Membership will be reviewed on an annual basis.
- 2.7 Members may resign at any stage by contacting the Programme Manager.
- 2.8 In the unlikely event of a member acting outside of these Terms of Reference & Agreement, AllHPC will suspend their membership or remove them from membership. A decision to take such action will involve the AllHPC Director and the Chair of AllHPC Council of Partners.
- 2.9 If a member fails to respond to correspondence, the Programme Manager will make follow up contact with the member. Where a member fails to respond to three correspondences, the Programme Manager will write asking if the member wishes to remain on Voices4Care. If no response is received it will be assumed that membership will be discontinued.

3. Meetings and Correspondence

- 3.1 There may be face to face meetings of Voices4Care up to three times per year at venues across the island of Ireland. Contact and engagement will not be limited to face to face meetings. AllHPC will continue to explore methods with members on how best to engage and involve them, including the use of new technology such as videoconferencing.
- 3.2 Other potential involvement will include providing comment by correspondence; by telephone contact, and by electronic communication, where practical.
- 3.3 Some members of Voices4Care may be involved in AllHPC's Governance Structures and in palliative care structures in the Republic of Ireland and Northern Ireland. Northern Ireland members will be engaged in 'Palliative Care in Partnership Voices4Care' in the *Palliative Care in Partnership Programme* (Appendix A). There will be occasions where it will be appropriate to involve only members from the respective jurisdictions in pieces of work, for example, where the application of any topic being discussed only applies to Northern Ireland or the Republic of Ireland.
- 3.4 AllHPC may involve individual members of Voices4Care in specific initiatives/working groups, where it is considered the member could make a particular contribution.
- 3.5 AllHPC may establish smaller working groups of Voices4Care for particular projects/pieces of work or to consider particular issues, which members may join if invited to do so, and which will report back on work undertaken from time to time to the wider group.

4. Members will:

- 4.1 bring their views and skills to provide comment on AllHPC's and the wider palliative care community's work in palliative care education, research, policy and practice, where appropriate this may be informed by members' personal experience,
- 4.2 be involved through attendance and participation in Voices4Care meetings, discussions, and through other meetings/project groups, where required,
- 4.3 be willing to comment on written material, for example, reports,
- 4.4 prepare for meetings by reading papers received beforehand,
- 4.5 be prepared to think beyond personal and local experience in order to consider the needs of the wider population,
- 4.6 not act as a spokesperson or make comment publicly on behalf of or about Voices4Care. This includes not commenting on social media (Facebook, Twitter etc) about Voices4Care meetings or business,
- 4.7 refer any queries in relation to Voices4Care from third parties to AllHPC Programme Manager,
- 4.8 accept collective responsibility. Once issues have been discussed and a decision or consensus has been reached, the convention of collective responsibility will be applied. This does not mean that all members have to be unanimous on one particular viewpoint, but they will refrain from articulating their own personal reservations outside Voices4Care,
- 4.9 protect and promote the reputation of Voices4Care and AllHPC,
- 4.10 take part in training to support involvement in Voices4Care,
- 4.11 take part in any evaluation of Voices4Care.

5. AllHPC will:

- 5.1 recruit to membership of Voices4Care,
- 5.2 provide training and support for members for their work with Voices4Care,
- 5.3 assign a contact person for Voices4Care members (principally AllHPC Programme Manager),
- 5.4 address on-going information and training needs,

- 5.5 co-ordinate arrangements for Voices4Care meetings and correspondence with members, including facilitating 'Palliative Care in Partnership Voices4Care' in Northern Ireland and facilitating engagement in palliative care structures in the Republic of Ireland,
- 5.6 support and coordinate involvement of those Voices4Care members involved in AllHPC's Governance structures and other relevant structures,
- 5.7 manage and/or co-ordinate requests to consult with Voices4Care, mindful of demands on members' time,
- 5.8 keep Voices4Care members informed of significant AllHPC developments, primarily through the AllHPC monthly newsletter issued electronically, and with other updates by correspondence, where appropriate,
- 5.9 provide regular feedback to members of Voices4Care on how they have informed and influenced AllHPC's work,
- 5.10 manage and facilitate communications and any comment on behalf of Voices4Care within AllHPC and with any other agencies, including acting as or arranging a spokesperson for media, where appropriate,
- 5.11 reimburse reasonable, vouched out of pocket expenses to members in relation to their Voices4Care involvement.

6. Expenses

- 6.1 Expenses will be reimbursed to members in line with established policies - Health Service Executive Guidelines in the Republic of Ireland and Guidelines for Health and Social Care Organisations in Northern Ireland.
- 6.2 Reimbursement will be determined by the jurisdiction in which the member resides, which will also determine the currency in which expenses will be reimbursed (euro or pounds sterling).
- 6.3 Members should reclaim expenses using the expenses form provided by AllHPC.
- 6.4 Actual receipts for expenses, e.g. bus, train, parking, must be attached to the expenses form to ensure payment.
- 6.5** Members should aim to use the most cost effective form of transport available to them, and in the event where taxis need to be used, approval should be sought/granted in advance.

7. Ground rules

Members of Voices4Care and AllHPC staff agree to the following ground rules

- 7.1 Honour time limits.
- 7.2 Interact sensitively and respect the input of all members.
- 7.3 Where a personal story or experience is being articulated, this is listened to sensitively and any issues raised by this experience are discussed in relation to the lessons, implications or applications for the wider community.
- 7.4 Listen and consider the opinions of others.
- 7.5 Use mutually respectful language and behaviour.
- 7.6 Share responsibility for success by speaking up.
- 7.7 Act in the interest of Voices4Care and not on behalf of any conflicting interest, organisation or interest group.
- 7.8 Respect confidentiality of any personal information or matters discussed through Voices4Care activities.
- 7.9 Any discussion of Voices4Care, or the publication of any material related to its work, will not attribute comment to a particular individual. Equally, the identity of any individual in relation to a comment/discussion will not be revealed, either deliberately or by a process of elimination (e.g. with reference to where the individual is from or their gender).
- 7.10 Should AllHPC wish to use a quote or story from a particular individual, in anonymised form, as told by that individual (whether in a publication or media piece), the owner of the quote or story will be informed and their agreement sought.
- 7.11 It is accepted that the outcome of discussions by members of Voices4Care may be summarised for reporting to other fora, such as AllHPC Council of Partners.
- 7.12 No individual member has the mandate to speak publicly on behalf of Voices4Care to other agencies, the media, or in any other forum, unless expressly requested to do so by AllHPC.
- 7.13 Where draft documents are being shared by AllHPC or any other agency for comment by members of Voices4Care, and these are shared on a confidential basis, this confidentiality must be respected.

8. Agreement

I am happy to accept these Terms of Reference & Agreement in support of the effective working of Voices4Care

Name: _____ **(Voices4Care member)**

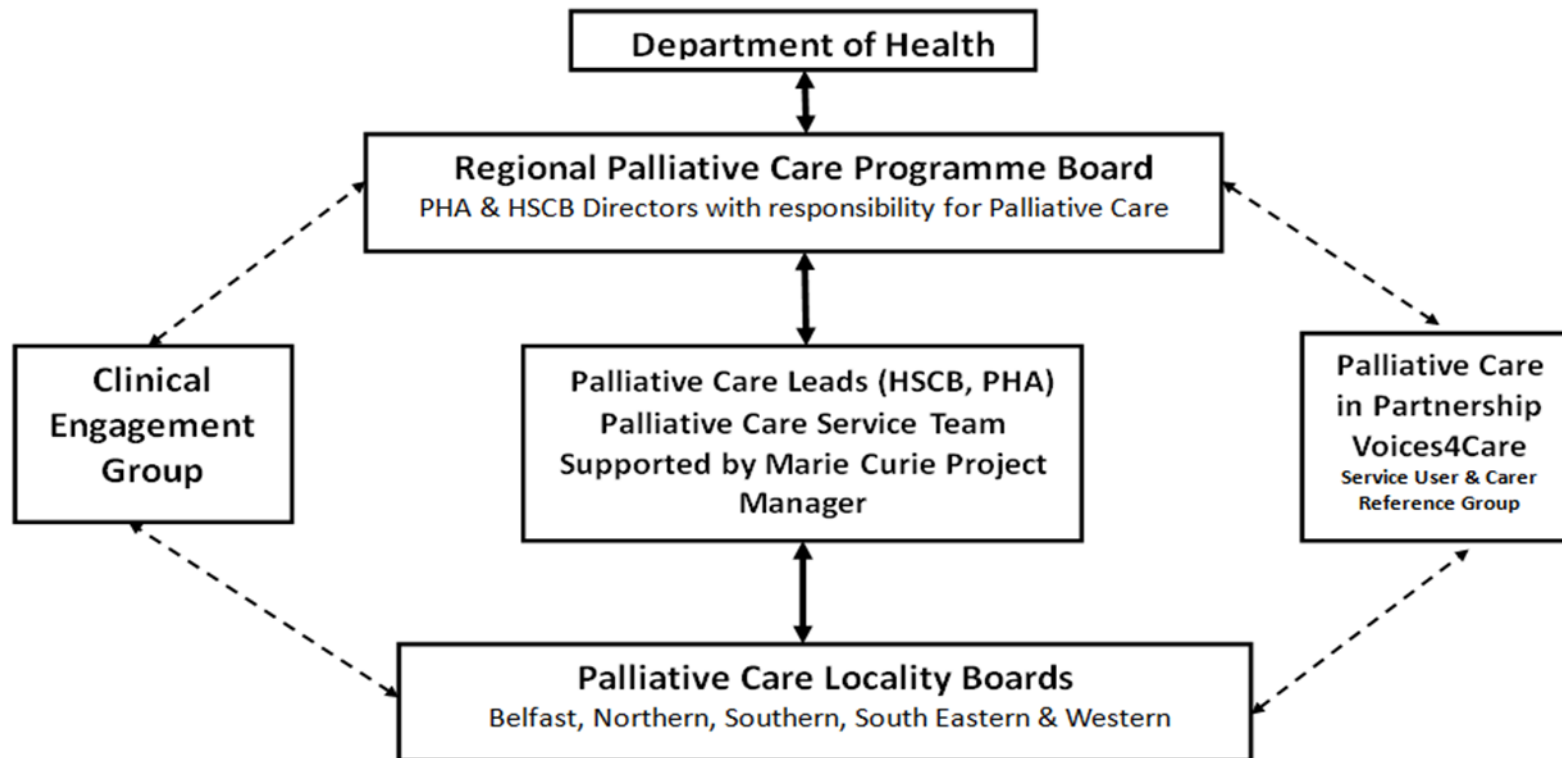
Date: _____

Name: _____ **(AllHPC Director)**

Date: _____

Appendix A:

Regional Palliative Care Structure – Northern Ireland



Please note: This structure may be subject to change given the Ministerial review of Health and Social Care.

