



# **Report on Renewal of Membership – 2019**

October 2019

## **Purpose and Context**

Through Voices4Care, All Ireland Institute of Hospice and Palliative Care (AIHPC) is committed to the meaningful involvement of people with palliative care needs, their carers and the wider community, in palliative care education, research, policy and practice. Voices4Care has been an invaluable part of the Institute's work since 2013 with members bringing their views to improve the palliative care experience. It is much appreciated that members voluntarily give their time. Voices4Care is greatly valued by our partners, many of whom have availed of the opportunity to engage with members through AIHPC.

AIHPC managed the refresh and renewal of Voices4Care, supported significantly by resources from the Public Health Agency/Health and Social Care Board in Northern Ireland, support from the Health Service Executive in the Republic of Ireland, and across the Institute's all island partners.

The refresh of Voices4Care membership was a significant part of AIHPC's work towards the end of 2018 and during the early part of 2019.

## **Background Refresh/Renewal**

Voices4Care had 40 members (29 ROI and 11 NI) at December 2018. This membership was in place from September 2016 following the refresh of the first membership cohort in 2013. Activity to begin renewal of Voices4Care began on 21 November 2018 at the second of two annual meetings of Voices4Care members. There was an opportunity for members to provide suggestions/ideas which informed the renewal process. There was also discussion on how the Institute could continue to support members to be involved. The Director paid particular tribute to three members at the meeting who had been involved in Voices4Care from its establishment in 2013, and whose membership was ending. Members have an opportunity to renew Voices4Care membership for a second term.

## **Promotion**

Promotion of the opportunity to join Voices4Care formally began in January 2019 with the inclusion of an item in the monthly newsletter. This was supported by a suite of information on the AIHPC website – video, information leaflet, guidance for applicants and an expression of interest form.

There followed a pro-active campaign from mid-January through February which included:

- contact with AIHPC partners and a range of organisations across the island
- targeted emails to more than 500 contacts
- targeted distribution of a promotional leaflet with more than 5,700 printed leaflets distributed
- promotion of the opportunity at external meetings and specific events
- press release issued 5 February 2019 with comments from two members (specific to north and south)
- radio advertising from Tuesday 12 Feb 2019 to Sunday 17 Feb 2019 across the two jurisdictions on the island
- promotion on social media including Facebook (paid for promotion) and Twitter
- contact with key organisations with an interest in personal and public involvement

The opportunity to submit an Expression of Interest form to join Voces4Care was initially open until 28 February 2019. This was extended to 15 March 2019.

As a major opportunity to engage with the public was planned by the Palliative Care in Partnership (NI) team in mid-May at the Balmoral Show, it was agreed that any further expressions of interest received through this engagement would be considered for membership.

Promotional opportunities were identified with key contacts with a remit for personal (or patient) and public involvement including in the Public Health Agency and the Patient and Client Council in the north and the HSE's Quality Improvement Division in the south. The opportunity was promoted on the HSCNI's Engage website. An opportunity was provided by the Patient and Client Council (NI) for a current Voices4Care member to guest blog, encouraging people to join.

The opportunity to join was shared with organisations working with what are sometimes considered harder to reach groups (mindful of Section 75 duties for Public Authorities in NI, and equality legislation in the Republic of Ireland) including: the Men's Sheds Association, Healthy Living Centres (NI), women's groups, travellers groups, new communities, LGBT groups, rural organisations, older people's organisations, faith communities and volunteering organisations.

In addition, promotional opportunities were identified at several key events, for example,

- Regional Social Prescribing Workshop, Craigavon Civic Centre, 16 January 2019
- Presentation to PIER (Public Involvement Enhancing Research) group, Belfast, 14 February 2019
- Rare Diseases Day - Bridging Health & Social Care, Rare Diseases Ireland (all Ireland conference), Dublin, 28 February 2019
- Reflecting on Bereavement - Breaking the Taboo by Talking, hosted by Cruse Bereavement Care/Public Health Agency, Seamus Heaney Home Place, Bellaghy, 14 March 2019

## **Response**

A total of 78 people contacted AllHPC interested in Voices4Care membership (although these contacts did not all result in Expressions of Interest forms being submitted). The guidance for applicants and an expression of interest form were provided to those who wanted to find out more.

A range of sources were indicated about where these people found out about Voices4Care:

- sixteen people had seen an ad through the Volunteer Ireland (ROI) network
- nine people learned about Voices4Care through Facebook
- seven through Council of Partner links
- five via an Activelink ad and three through Volunteer Now (NI)
- other sources included Healthy Living Centres (NI), NI MND Association, Civil Service Intranet, Carers Association, HSE Engaging Patients and Families, and personal contact with Voices4Care members and health and social care professionals at events.

## **Induction Meeting**

Following review of the Expressions of Interest received, invitations were issued on 28 March 2019 to potential new members to a meeting held on Friday 3 May 2019 in the Ashling Hotel, Dublin. Invitations were sent to 43 people - 33 women and 10 men (30 ROI & 13 NI). AllHPC decided that this meeting would be for potential new members only, and this contributed to a productive engagement.

This meeting on 3 May was an opportunity to ensure that potential new members had the right information and support to play an effective role. Information was provided on the work of the Institute and input of Voices4Care members to AllHPC partners and across the health and social care systems, as well as practical arrangements to support members' involvement.

Following the induction meeting on 3 May, a meeting of Palliative Care in Partnership Voices4Care was held on Thursday 16 May in Belfast Central Mission, Belfast city centre. This is the northern Voices4Care members who comprise the Service User and Carer Reference Group in the Northern Ireland regional Palliative Care in Partnership Programme. Those leading the regional programme provided an overview of Palliative Care in Partnership and the role of Voices4Care in that structure.

Between the meetings in Dublin (3 May) and Belfast (16 May), of the 43 potential new members who had been invited to the meetings, a total of 29 people signed up to the Voices4Care Terms of Reference & Agreement (NI: 11; ROI: 18) becoming members.

There was also direct follow up with those members who had submitted an Expression of Interest form but who were unable to attend either of these meetings. AllHPC wanted to meet (in person, by video conference or phonecall) all those interested in joining Voices4Care before membership would be confirmed. Membership of a further four people was confirmed as a result of this follow up. A number of people initially interested failed to respond to several follow up communications.

### Existing Members

In addition to the new members, Voices4Care members who joined as new members in 2016 were invited to renew membership for a further two years. Of the 31 existing members at December 2018 eligible to renew for a further term, a total of 17 renewed their membership. One of them subsequently resigned due to other commitments as a hospice volunteer.

The Institute Director wrote a letter of thanks to all those members whose membership ended in 2019, which included those who had already completed two terms as a Voices4Care member and those who did not opt to renew membership.

### Membership at October 2019

At October 2019, a total of 49 members (33 new and 16 renewing) of Voices4Care are being supported by AllHPC. These members are from across the island and from 20 counties including: Antrim, Armagh, Clare, Cork, Derry/Londonderry, Donegal, Down, Dublin, Galway, Kerry, Laois, Limerick, Mayo, Meath, Roscommon, Tipperary, Tyrone, Westmeath, Wexford, Wicklow.

**Table 1: Breakdown of Voices4Care membership**

<b>Voices4Care Membership at October 2019</b>						
	Person with life-limiting illness /palliative care needs	Carer/Former Carer	Interested citizen	Female	Male	<b>Total (new &amp; renewing)</b>
NI Members	1	11	4	11	5	<b>16 (11 &amp; 5)</b>
ROI Members	4	20	9	24	9	<b>33 (22 &amp; 11)</b>
						<b>49 (33 &amp; 16)</b>



**Attending the Voices4Care induction meeting on 3 May 2019 in Dublin**



**Attending the Voices4Care Palliative Care in Partnership meeting on 16 May 2019 in Belfast**

A further full meeting of Voices4Care took place on 9 August attended by 21 members. All members (new and renewing members) were invited to this meeting. A meeting of Palliative Care in Partnership Voices4Care (northern members) was arranged for the Palliative Care in Partnership programme team and took place on the 27 August.

As members join for a period of two years, membership of Voices4Care will be due for renewal again in mid to late 2021.