

INTRODUCTION: Why we need standards for carer engagement

No one would argue that unpaid family carers should not be equal partners in care, as their care constitutes over 50% of all care provided in every local authority and NHS region of Scotland. Consistent and meaningful carer engagement must therefore be at the heart of all good health and social care policy.

But a great gulf remains between good intentions and good practice.

The Coalition of Carers in Scotland is pleased to offer the carer engagement standards in this document as a bridge to help planning officers and commissioners of services move from good intentions to better practice. The standards were developed jointly with carers and carer organisations, with support from the Scottish Government's carer policy unit and the Scottish Health Council.

Investment in carers and carer engagement will bring many valuable returns - stronger planning and policy, improved services, more creative use of resources and improved outcomes for carers. In short, better care for people with support need. We commend these standards to all planning partners.

STANDARD ONE: Carer engagement is fully resourced

To fulfil a representative role on any strategic group takes time and effort in the preparation for, attendance at and follow up to meetings. To ensure carers are able to give of their best they need training, induction, mentoring and support with clear structures to exchange views and information with a strong network of carers. In addition to the reimbursement of normal expenses such as travel that are provided for volunteers on strategic groups, there needs to be a commitment on the part of statutory authorities to meet the costs of any substitutionary care that carers require to put in place to fulfil their roles. They also need to invest in local structures for carer engagement, such as carer forums and social media platforms.

OUTCOMES

1. Carer representatives will feel confident in undertaking the responsibilities of their role and be able to express clearly and fully the views of other carers.
2. The strategic groups will benefit from the views of carers being regularly and directly represented and will produce work which address the needs and meets the aspirations of carers more fully.

EVIDENCE OF IMPLEMENTATION

Carers in representative roles will:

1. Receive training and a full induction.
2. Be supplied with the information they require timeously.
3. Be mentored.
4. Be able to obtain the views of other carers via a strong network of carers.
5. Have the full costs of their work in and for the strategic groups met – this includes the costs of any substitutionary care that is required.

BEST PRACTICE EXAMPLE: TRAINING FOR CARERS ON PLANNING GROUPS

The Coalition of Carers in Scotland provides training for carers who are representatives on strategic planning groups, or who are interested in getting involved in local community planning. Courses have been held both nationally and locally, providing carers with the opportunity to develop their knowledge and skills and learn how best to promote the carers' voice.

The course includes information on policy and legislation relating to community involvement, preparing for meetings, speaking with intent and how to challenge effectively. The training provides carers with the confidence and authority to fully participate in meetings. It also increases the number of carers who are involved in community planning, so that the responsibility doesn't fall on one or two people.

As one carer commented after attending the course: "I now know the amount of work and preparation which is needed and I feel confident in taking on such a role. I'm looking forward to being able to make a difference to benefit other carers."

STANDARD TWO: Carers on strategic planning groups represent the views of local carers

Carers fulfilling a representative role need to engage with a strong, healthy network of carers from different caring backgrounds. This network needs to be sustained and developed by a carer organisation, properly resourced for this task. Without this, carers cannot speak with authority and may be viewed as an unrepresentative lone voice.

OUTCOMES

1. Carers on strategic groups will be:
 - (a) representative of the various communities of carers
 - (b) able to express in informed ways the views of a range of carers
2. The other partners on the strategic groups will know with confidence that they are learning of the views of a range of carers.
3. The work produced by the strategic groups will fully take into account the views of carers

EVIDENCE OF IMPLEMENTATION

1. Carer organisations will be properly resourced to establish and support a strong carer network, which offers a variety of ways for carers to get involved
2. The number and carers involved in exchanging views through the network will grow
3. The diversity of carers involved in the network will be broad
4. There will be a continual emergence of new carers willing to undertake representative roles
5. The information provided through and by the supported network will be of a high quality

BEST PRACTICE EXAMPLE: DUNDEE CARERS VOICE

In Dundee carer involvement was highlighted as a priority for development in the local Carers Strategy. Carer involvement also featured strongly in NHS Tayside's priorities for implementing the Scottish Government's Carer Information Strategy (CIS). A paper was drawn up outlining a proposal to take this forward, which involved building the capacity of the Dundee Carers Centre to increase the level and quality of carer involvement through the recruitment of a new Deputy Manager post. It was felt that a post at this level would place strategic importance on the development of carer involvement, while also allowing a number of other local CIS priorities to be met: e.g. developing counselling, carers support, and carers training. CIS funding initially met the whole cost of the Deputy Manager post, with the expectation that as capacity was increased so the Carers Centre would commit progressively more core funding towards the position and the involvement agenda.

The funding has enabled the creation of the Carers Voice group which engages carers in a variety of ways, both locally and further afield, and acts as a reference group bringing carers together from all backgrounds to exchange information and discuss issues that are important to them. This ensures that carer representatives on planning groups are able to represent not just their own views, but also the views of the wider carer community. Carers from the group also sit as representatives on the local Carers Strategy action group and have taken part in a number of initiatives including consultation around the development of the new Dundee Carers Strategy.

STANDARD THREE: The involvement of carers on strategic planning groups is meaningful and effective

It is critical to avoid tokenistic involvement of carers on strategic groups. For carers to be assured that their voices will be heard and acted upon, all those involved in the operation of strategic groups need to be ready to accept carers as equal and expert partners. This means having a commitment to listen and respond appropriately to the views of carers. As with other members of the strategic groups, carers need to know that their involvement is meaningful and effective. This will be evidenced when the work produced by these groups is demonstrably leading to an improvement in services and support for carers and the people they care for.

OUTCOMES

1. Carers will be treated as equal and expert partners in strategic groups
2. The views of carer representatives will be evident in the strategic decisions taken and the plans that are developed.
3. Carers will be treated as equal and expert partners in the provision of care.

EVIDENCE OF IMPLEMENTATION

1. Carers will be placed on the right strategic planning groups including at the top level of governance structures.
2. Other partners in strategic groups will have had Carer Awareness training so that the perspectives brought by carers is understood and accepted as the statements of people who are "equal and expert" partners.
3. Meetings will be open and inclusive, allowing time for discussion and contributions from all members of the group. Language will be accessible and jargon will be avoided.
4. Sufficient time will be given for preparation. Papers will be sent out in advance in a timely fashion and carer representatives will have the opportunity to clarify any information in advance.
5. The agenda will be jointly owned with all group members having the opportunity to place items on it or raise issues of concern.
6. All plans and policies produced by strategic groups will be 'carer proofed' so that the impact on carers is explicitly stated to ensure that carers needs and aspirations have been fully considered.
7. Through their network carers will be supplied with information about the opportunities for participation in strategic planning groups.
8. The outcomes of carer engagement will be evaluated.

BEST PRACTICE EXAMPLE: PAUL'S STORY

Paul Weddell, Carer, West Lothian says:

"My involvement in the West Lothian Community Health and Care Partnership was a really positive experience. I was genuinely welcomed into the process and my expertise, views and ideas were valued by everyone involved. Before joining I received an induction which included information on the design of services and local structures. I had on-going support from the Patient Involvement Officer and attended a pre-meeting, prior to each Board meeting, with the Chairperson and the Director of the CHCP Board. This allowed me to bring up any information that I needed clarification on in relation to the papers which were sent out 7 days in advance.

If you want ordinary people to get involved in strategic planning groups, you have to make sure that they are made to feel welcome in what is often a new and intimidating environment. Carer representatives need to feel valued and convinced that their views are treated equally to other members of the group. The use of specialised language and acronyms should be kept to a minimum and where they have to be used explanations should be given on first use.

It is absolutely clear to me that those leading the process in West Lothian were genuinely committed to carer and patient involvement at the strategic decision making level and that it was their attitude that was fundamental to making the system work."