

South West End of Life Expert Reference Group

This summary paper outlines terms of reference and the composition of an End of Life Expert Reference Group, as agreed at the Regional End of Life Planning Day held on 3rd April 2014, at Somerset County Cricket Ground, Taunton.

Draft Terms of Reference

1. The group is hosted by the South West Strategic Clinical Network (SCN). The SCN will work with commissioners, providers and other stakeholders to improve patient outcomes and experience through:

- Providing strategic advice
- Identifying and reducing unwarranted clinical variation
- Supporting clinical quality improvement
- Promoting best practice and benchmarking
- Involving patients and the public.

2. The purpose of the group is to:

- Support and advise CCGs on commissioning to improve the care people receive in the South West, in particular whole systems change via:
 - Setting the development work plan for end of life care in the region
 - Monitoring progress against that work plan
 - Defining task and finish groups for delivering specific pieces of work within the work plan
- Ensure that the national priorities identified by the National Palliative Care and End of Life Network are delivered in the South West. Also that the region actively participates in the national network and thereby influences the direction of the national agenda
- Share good, and emergent promising practice within the region by promoting effective networking across all organisations involved in the commissioning and delivery of end of life care

3. The group will be co-chaired by the Specialist and Generalist End of Life Care Clinical Leads, elected by the South West End of Life Champions.

4. Programme management and administrative support for the group will be provided via the SCN's Quality Improvement team.

5. The SCN will maintain a regional end of life care Champions list to ensure that the work of the group is disseminated throughout the region. Each organisation concerned with end of life care within the region will be invited to register a champion to represent them. There can be more than one champion per organisation, however to be a champion people must have a leadership role within their organisation regarding end of life care and must be willing to commit to participating in the work of the group and to feedback within their organisation.

6. The group will ensure input by patients and the public in the work it undertakes, including through working with Healthwatch, use of the Voices survey, patient and carer feedback, links to relevant community and voluntary sector organisations and the creative use of social media.

7. The group will produce an annual report of its activity which will be published via the SCN's website. Minutes of meetings, work undertaken by any task and finish sub groups and good and promising practice developed within the region will all be shared via the SCN's website End of Life page. This site has full public access.

8. The group will hold an annual conference for the regional end of life champions group, which the SCN will fund (this does not include backfill costs)

9. Composition of the group:

The group is comprised of a broad range of representation from all relevant provider settings and professional disciplines across health and social care, including commissioners (Specialist Palliative Care Consultants, GPs with an interest in end of life care, CCG Commissioners, Palliative Care Nurses, Community Nurses, End of Life Care Facilitators, Social Care, Hospice and hospice at home staff, Patient/Carer representatives, Occupational Therapists with an interest in end of life care, Chaplains, Ambulance service, Out of Hours and 111 services, SCN Clinical leads with an interest in end of life care).

Each CCG area should send at least one representative to the Reference Group, at least six CCG areas should be represented for a meeting to be quorate.

The group will have approximately 25 members to ensure this level of representation, with decisions taken by those able to contribute to the meetings – whether that be in person, by video/telephone conference, or by making written submissions in advance.

The group meets quarterly to identify priorities in the regional work plan, monitor progress and initiate task and finish groups to complete specific pieces of work.

Membership on the group will be on a voluntary basis. Members will come from the wider regional group of end of life care champions.