

Abstract: International Congress on Palliative Care, Montreal 2018

Title

Using Participatory Action Research in the development of an innovative Cottage Hospice model of care in the United Kingdom

Objectives

- a) To contribute to the development of the Cottage Hospice programme and its constituent components.
- b) To ascertain barriers to and facilitators of Cottage Hospice using action cycles to address identified challenges.

Methods

Our three-phase Participatory Action Research (PAR) study comprised:

- 1) A situational analysis using documents (n=150) and stakeholder qualitative interviews (n=28).
- 2) A Core Action Group oversaw action cycles designed to address challenges identified from the situational data. Local stakeholders participated in a deliberative workshop where study results were presented and refined.
- 3) An end of study conference is planned in order to disseminate learning to a wider stakeholder audience

Results

Results presented here align with the objectives in terms of identifying challenges and contributing to the development of the Cottage Hospice programme. Our situational analysis revealed growing support and enthusiasm for the model among hospice staff and volunteers, over time. However, anxieties regarding the viability, reach and conceptual clarity of Cottage Hospice were identified, as were concerns about communication systems and staff feedback to the planning team. Early results demonstrated a need to gather the views of a wider range of health and social care providers regarding the local impact of the initiative. Action cycles included a focus on determining who might use Cottage Hospice; what support family caregivers may need; and conceptual explorations of 'family'. The deliberative workshop enabled findings to be refined in discussion with those most invested in Cottage Hospice, feeding into the final report and dissemination plans.

Conclusions

Using PAR democratises the research process and provided an opportunity for all interested parties to contribute to the development of Cottage Hospice. It enabled 'ground up' development and ownership of the model and led to contextualised solutions to identified challenges. Despite the locally situated setting, we believe the lessons learned are widely applicable.