

CONFERENCE ABSTRACT

Planning for the Future: Addressing the Information Gaps for People Living with COPD:

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Introduction: COPD is recognised as a life limiting illness (1). There is growing acknowledgement that people want to have conversations, are willing to record their end of life preferences and feel relieved when issues have been discussed (2–4). This is coupled with more recent trends indicating that people with illnesses can and should contribute to research and quality improvement initiatives that affect them, as promoted by the Health Research Board Ireland.

Description: People with COPD and those that care for someone with COPD identified gaps and developed a resource about planning for the future with COPD.

Aim: The aim of this work was to determine existing information gaps in relation to planning for the future for people living with COPD and to develop practical measures to fill this gap.

Population and Stakeholders: People with COPD are the main stakeholders. However the resource is useful for people with other respiratory illnesses and can be used by healthcare professionals to assist them with having conversations about the future.

Timeline: The project took place over a 7 month period and is near completion.

Highlights: Getting a group of people living with COPD for 5 participatory workshop to discuss planning for the future with COPD

Successfully creating a space where the group could safely explore, reflect and express their thoughts and feelings with regard to COPD, palliative care and advance planning.

Participants reporting engagement with others and representing the views of the wider COPD community as well as other people in their lives.

Development of a booklet that will be of use to people living with COPD.

Sustainability: The booklet developed is a new resource that is likely to be used by people, healthcare professionals and voluntary organisations supporting people with COPD/

Transferability: Though aimed at people with COPD the information in the booklet about planning for the future is appropriate for all people.

Result: Information gaps and barriers to this topic being discussed were identified. This led to the development of an information booklet entitled 'Planning for the future with COPD'

Conclusion: An information booklet entitled 'Planning for the future with COPD' was developed.

Discussion: The process of engagement with patients and carers about this difficult topic has the potential to inform future patient - health carer collaboration. Dissemination of the booklet has the potential to inform many people affected by COPD.

Lessons Learned: People living with COPD can meaningfully participate in the development of resources that will be used by them.

People living with chronic illnesses such as COPD want to have conversations about planning for the future.

References:

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