

Table 48: Stevens 2011⁴²¹

Study	Stevens 2011 ⁴²¹
Aim	To investigate the views of healthcare professionals regarding ACP.
Population	Healthcare professionals: 34 Healthcare professionals:

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	<p>Focus group 1: HCPs working with people affected by non-malignant disease (GP, motor neurone disease CNS, heart failure CNS, district nurse, Parkinson’s disease CNS, palliative care community CNS x2)</p> <p>Focus group 2: HCPs working with people affected by COPD (GP, palliative care CNS, respiratory CNS x2, physiotherapist, district nurse, practice nurse).</p> <p>Focus group 3: HCPs working with people affected by lung cancer (respiratory physician, GP, lung CNS x2, palliative care CNS, palliative care community CNS, occupational therapist, physiotherapist, specialty doctor – respiratory medicine, care home manager, ward manager – community hospital, district nurse, community staff nurse).</p> <p>Focus group 4: HCP working with people affected by metastatic breast cancer (oncologist, breast care CNS, district nurse, student district nurse, chemotherapy nurse, breast care CNS).</p> <p>HCP: Healthcare professional, CNS: clinical nurse specialist.</p>
Setting	West of Scotland.
Study design	Focus group discussions.
Methods and analysis	<p>Healthcare professionals were identified by key personnel in the west of Scotland and invited to participate in focus group discussions. The focus groups were designed to obtain the views of professionals who may become involved in ACP scenarios. Each focus group lasted between 1 and 1 and a half hours, and had a skilled facilitator and observer/note taker. A semi-structured interview schedule was used to encourage discussion. Comments were tape-recorded, transcribed verbatim and analysed independently by the authors.</p>
Themes with findings	<p>Common themes reported: Malignant vs. non-malignant disease, knowing the patient, communication, education and training, primary/secondary care interface.</p> <p>Malignant vs. non-malignant disease:</p> <p>One doctor worried about when it would be appropriate to introduce ACP to her patients: ‘My only worry is, with malignant patients you have a time frame whereas with non-malignant you really don’t have a time frame, especially chronic obstructive pulmonary disease (COPD)’. Specialty doctor in respiratory medicine.</p> <p>Due to improvements in treatments, professionals no longer felt confident at accurately making a prognosis. ‘It’s very difficult, they keep getting new treatments; it would have been easier ten years ago because you would only have 2 treatments, now we’ve got about six.’ Oncologist.</p> <p>‘Breast cancer is becoming kind of chronic.’ District nurse.</p> <p>However, some participants identified ways round an uncertain prognosis and believed there can be similarities between different patient groups. prognostic indicators [could be used] as a prompt’ as well as ‘looking at the rate of chance/decline’ of a particular individual. ‘Intuition’ was thought to play a part in identifying deteriorating people. Respiratory clinical nurse specialist.</p> <p>There were inconsistencies around perceived ‘capacity’; that is, the ability to care for the potentially large numbers of people who could be added to the palliative care register.</p>

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	<p>'If you went from the relatively small number of patients that the average practice has in the terminal phase with cancer, to the large numbers of patients with severe COPD, there's a huge capacity issue.' GP.</p>
	<p>Knowing the patient: Most participants felt that a relationship with the patient was paramount when initiating sensitive conversations around ACP. 'It's about having a relationship with somebody and that is [developed] over years.' Palliative care CNS. 'I think it's important to that whoever does [the ACP discussion] knows exactly what they are doing ... it's a discussion between a team, not just one person.' Oncologist. Some agreed it was up to the person to decide who to have these discussions with. 'Anyone can lead the discussion; I think it's very much who the patient feels comfortable with.' Respiratory physician. There was consensus that views of the carer should be sought, as they have the expertise regarding the person being cared for. 'The person that's been telling me about the patient's deterioration is the carer.' Palliative care CNS.</p>
	<p>Communication: Almost all focus group participants expressed the need for improved communication for patients and their families, between teams and across care settings. They described people constantly asking: 'When am I going to get better, when is my breathlessness gonna improve?' Respiratory CNS. While participants expressed that communication could be better and there was recognition that information needs to be sensitively assessed, some were hesitant: 'You're frightened to open a can of worms; what if they fall to pieces?' Physiotherapist. 'I certainly wouldn't want to inhibit anyone's lifestyle when they grasp that they've got a life-limiting illness, twenty years before it's going to limit their life.' GP. Where hospital palliative care teams were involved, communication appeared timelier and reference was made in the letters to discussions that had taken place with a person while in hospital. 'The discharge letter includes the discussions we've had with the patient and the plan for the future...' Palliative care CNS.</p>
	<p>Education: Almost all participants expressed the need for improved education regarding ACP, communication skills and in some cases education related to specific diseases, such as COPD. '...difficult conversations which nobody trains you for.' GP. 'I've never done [ACP] ... we've not been taught how to use it in practice.' GP.</p>
	<p>Primary/secondary care interface Many participants recognised that there was tension between primary and secondary care.</p>

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	<p>'Historically there has been a lot of stuff about primary and secondary care not working optimally.' GP.</p> <p>There was real concern from community staffs regarding the time hospital discharge letters take to arrive, meaning that people could have been re-admitted before they had received correspondence pertaining to the first admission.</p> <p>'It can take weeks to get discharge letters.' GP.</p> <p>However, communication across settings was good in some areas.</p> <p>'Our discharge letters go out within 48 hours of the clinic appointment.' Oncologist.</p>
Limitations	Serious limitations. No comment as to whether data saturation achieved.
Applicability of evidence	Direct evidence from UK setting with non-cancer and cancer populations.