

Pioneering research to deliver person-centred care

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Researchers at the University of East Anglia and University of Cambridge have developed a way to help people with progressive conditions receive better person-centred care.

From overcoming boredom or loneliness to knowing what to expect in the future, the team started by identifying a range of areas that patients with advanced Chronic Obstructive Pulmonary Disease (COPD) need extra support with.

In a new study published today, which was funded by the National Institute for Health Research (NIHR) and Marie Curie, they identified 15 broad areas that patients need additional help with, and created a tool to help them express these needs to [health care](#) professionals.

The resultant Support Needs Approach for Patients (SNAP) is a health care intervention, which asks patients to consider areas where they need more support.

It is hoped that the concise evidence-based SNAP tool will improve person-centred care and help patients identify their support needs—which can then be discussed with a health care professional.

While the tool was developed with COPD patients and their carers, SNAP is now being offered to patients with other progressive conditions.

And it has been included in a new set of criteria called 'The Daffodil

Standards' for improving palliative and end of life care in primary practice. GP surgeries can now display a daffodil mark as a sign of commitment to improving end of life care, as part of a partnership between the Royal College of GPs and the terminal illness charity Marie Curie.

Lead researcher Dr. Morag Farquhar, from UEA's School of Health Sciences, said: "We know that patients with advanced long term conditions such as COPD experience disabling physical symptoms, which are often combined with psychological and social distress.

"It is internationally recognised that delivering holistic, needs-led, person-centred care is a top priority.

"But patients often have difficulty reporting their support needs to health care professionals, which means they don't always get the person-centred care they need.

"We wanted to develop an evidence-based tool to enable patients to identify and express their individual needs relating to different aspects of their life."

The research team studied 31 published papers about COPD support needs, as well as interviews with 20 patients with advanced COPD to draw up a draft list of support needs.

They then carried out focus groups with both patients and their carers to road-test the list.

Dr. Carole Gardener, from the University of Cambridge, said: "We asked patients and carers which support areas were particularly important to them and why, and we talked about what support they would like but had not had access to.

"They said they wanted things like support to manage breathlessness and tiredness, information about exercising safely, dealing with anxiety and depression, coping with sources of stress such as financial problems and help with sorting out bills and benefits.

"They also wanted practical support for things like cooking, personal care, and support for carers such as respite care."

Using all of this evidence, the team developed a list of 15 questions to enable patients to express their support needs. The tool is short and simple to use for both patients and health care professionals.

"This is more than just a set of 15 questions," added Dr. Farquhar. "It underpins a five-stage intervention for use in clinical practice, and it can also be used as a standalone tool in research studies seeking to identify areas of unmet support need in patients with progressive conditions."

'Enabling [patients](#) with advanced Chronic Obstructive Pulmonary Disease to identify and express their [support](#) needs to [health care professionals](#): a qualitative study to develop a tool' is published in the journal *Palliative Medicine*.

More information: A Carole Gardener et al, Enabling patients with advanced chronic obstructive pulmonary disease to identify and express their support needs to health care professionals: A qualitative study to develop a tool, *Palliative Medicine* (2019). [DOI: 10.1177/0269216319833559](#)

Provided by University of East Anglia

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