

# A Literature Review of Possible Barriers and Knowledge Gaps of General Practitioners in Implementing Advance Care Planning in Ireland: Experience from Other Countries

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## Abstract

**Background:** An Advance Care Plan (ACP) is a decision-making process concerning end-of-life care that embodies a patient's values and preferences, for a time when patients are unable to make such choices on their own. ACPs have been employed into medical practices worldwide; however, they remain largely uncompleted by general practitioners (GPs), regardless of their benefits to patients and their families with respect to end of life (EOL) care. Furthermore, ACPs will soon be implemented into clinician practices across Ireland, as part of the Assisted Decision Making (Capacity) Act 2015. This review aims to explore the literature to examine challenges GPs may face in employing ACPs into clinical practice. **Methods:** An electronic search was performed through three databases: PubMed, MEDLINE, and CINAHL Plus, through which a total of eleven studies met the selection criteria. Additionally, three studies were provided by experts in the field. Thus, a total of fourteen studies were condensed and critically appraised through CASP (Critical Appraisal Skills Program), which concluded that the quality of the studies was high. **Conclusion:** Through this review, knowledge gaps and barriers for GPs regarding ACPs were identified. Barriers for implementing ACPs into practice were categorized into three major themes: barriers for the GPs, barriers in the healthcare system, and barriers regarding the patient. These included insufficient time, complexity of the ACP documents themselves, uncertainty of the disease prognosis, and the ultimate fear of inducing anxiety and loss of hope in patients.

**Key Words:** General Practitioners; General Practice; Advance Care Planning; Advance Care; End of Life Care; Terminal Care (Source: MeSH-NLM).

## Introduction

The average life expectancy has increased as technology and medical breakthroughs continue to improve. As the population ages end of life (EOL) care issues become increasingly important. Individuals have preferences when it comes to their final days, which has created a large demand for Advance Care Planning.<sup>1</sup>

An Advance Care Plan (ACP) provides instructions on healthcare procedures that a person may choose when they no longer have the capacity to do so.<sup>1,2</sup> It can be made freely by patients <18 years of age who are capable of making decisions, and only comes into play if they lose this capacity to make decisions in the future.<sup>2</sup> Patients' views, attitudes, and aspirations concerning their healthcare and treatment preferences regarding how they will die are taken into account by ACPs.<sup>3,4</sup> ACPs were originally created in the late 1990s in the United States of America<sup>5</sup>. Although they have been around for many years, their utilization by physicians remains moderately low, especially in regions outside of the USA. It has been described that ACPs are more prevalent in the USA than throughout Europe.<sup>6</sup>

ACPs have several advantages, including allowing patients to take charge of their own health, reducing worry about death, and eventually reducing pain and unnecessary treatments that may prolong life needlessly.<sup>7,8</sup> They've also been found to help patients' family feel less worried and burdened.<sup>4,9,10</sup>

ACPs can lead to advance healthcare directives (AHCDS); however, AHCDS are legally drafted papers, whereas ACPs do not always require paperwork, and can be completed merely through discussions between

the physician and patient.<sup>11,12</sup> In addition, unlike ACPs, AHCDS take into account particular restricted conditions and treatments, as well as the refusal of such therapies.<sup>11,13</sup>

ACPs are recommended to be performed by the patient's general practitioner (GP), as they are the ones who are most involved in EOL care.<sup>14,15</sup> Over time, GPs have built strong, trustworthy patient-provider relationships that should promote such talks, since patients may feel more at ease discussing their concerns such material with a trustworthy doctor.<sup>14,17</sup> ACPs are created with patients, their GP, and, sometimes family members and other healthcare providers.<sup>14,16</sup> To begin the process, GPs are required to assess their patient's mental capacity. Capacity is the ability to grasp the importance and nature of the decision being made in the context of the available options.<sup>17</sup> Furthermore, an individual must be able to comprehend, remember, and consider the information presented before being able to successfully convey their decision.<sup>2,17</sup>

The exact completion of ACPs by GPs in Ireland is currently unknown, however it does remain fairly low.<sup>18</sup> Furthermore, there is currently no legislation in action in Ireland to govern ACPs or AHCDS. The Assisted Decision Making (Capacity) Act 2015 was signed into Irish law on December 30<sup>th</sup>, 2015 to support an individual's decision-making regarding EOL care.<sup>19</sup> However, its commencement remains incomplete, as numerous challenges to the health sector regarding its implementation remain unsettled.

As previously mentioned, it has been advised that ACPs should be completed by a patient and their GP. However, previous studies have illustrated that majority of GPs do not complete ACPs, even though they

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have been shown to improve patient satisfaction and quality of life.<sup>16</sup> ACPs have been shown to increase relationship satisfaction between patients and their families, increase psychological well-being, and ultimately enlist a sense of control in patients.<sup>20,21</sup> Nonetheless, it has been noted that Irish individuals are less likely to plan ahead for their own death, and thus this may create an additional barrier.<sup>18</sup>

This review thus aims to identify potential limitations in implementing ACPs into clinics, along with the current understanding and knowledge of GPs regarding ACPs. This study will also examine the potential barriers GPs perceive regarding its employment into daily practice.

The aims of this study were to condense and appraise the existing literature regarding GPs' perspectives regarding ACPs and their use in everyday clinical practice. The specific objectives were: (i) to establish the level of knowledge of GPs regarding ACPs; (ii) to establish the perspective of GPs regarding ACPs; and (iii) to establish the current barriers in implementing ACPs into daily clinical practice.

## Methods

### Search Strategy

On 12<sup>th</sup> April 2019, electronic searches were conducted using a total of three databases to retrieve the relevant articles that may answer the research objectives of this review. The primary search was conducted through PubMed, and EBSCOhost research databases, which include MEDLINE and CINAHL Plus. The following strategy was assumed: "Advance Care" [Title] AND "General Practice" [All Fields] or "General Pract\*" [All Fields]

The equation initially generated 156 results from PubMed, 122 results from MEDLINE, and 45 results from CINAHL Plus. Any duplicates were removed. Inclusion and exclusion criteria, found in **Table 1**, were applied to the abstracts and then to the full articles remaining. This search yielded a total of eleven articles that were used in the review. **Figure 1** details the search selection process. Critical appraisal was carried out on all 14 studies via CASP (Critical Appraisal Skills Program), which concluded that the quality of the studies was high. Thirteen of the fourteen studies used a qualitative methodology, so the CASP qualitative checklist was applied (Supplementary **Table 2**). Additionally, 2 studies conducted systematic reviews and thus the systematic review CASP checklist was utilized in these cases (Supplementary **Table 3**).

**Table 1.** Selection Criteria.

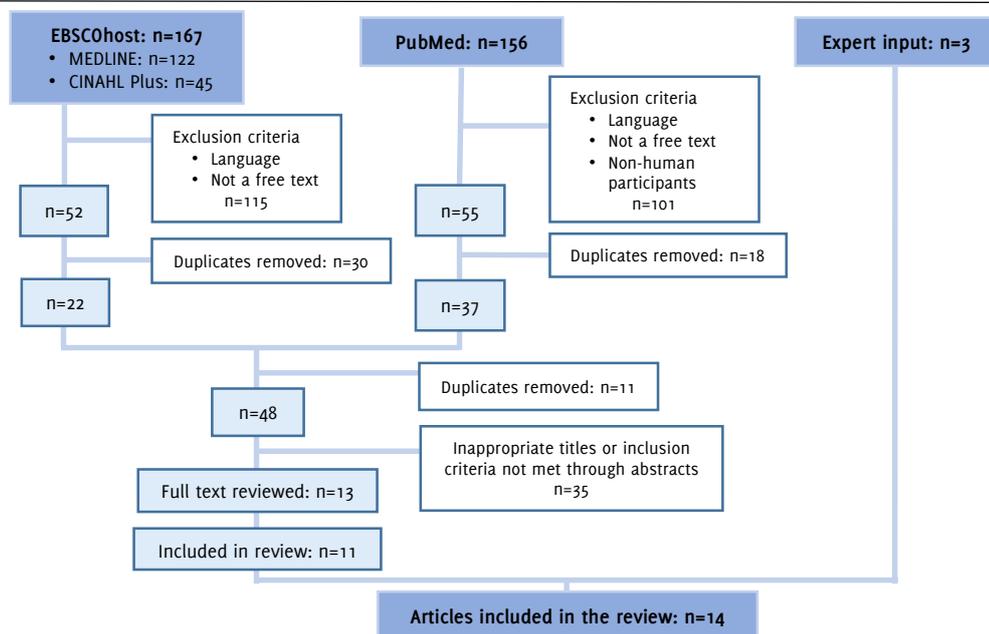
Inclusion Criteria	Exclusion Criteria
Assessed GPs perspectives towards ACPs	Articles not available as free full texts
Evaluated GPs' knowledge of ACPs	Studies not written in English
Evaluated barriers for GPs regarding ACPs	Studies conducted on animal populations
Assessed ACPs implementation into clinical practice	Studies were part of book chapters
Studies conducted on the human population	
Articles available as free full texts	

### Selection Criteria

**Table 1** depicts the article inclusion and exclusion criteria. Articles that were translated to the English language were excluded from this literature review to avoid errors attributed to translation. Due to the limited amount of research regarding the implementation of ACPs into clinical practice, there was no specific timeframe set for the articles. Also, articles that were not available as free full texts were excluded. The 323 articles produced from the initial search using PubMed and the EBSCOhost Research Databases were filtered using the aforementioned criteria, and duplicates were removed. This resulted in 48 articles, that were then manually filtered by titles and abstracts. Articles without a methodology section, and articles considering EOL processes other than ACPs were removed, yielding 13 articles. These 13 articles were then reviewed as full-texts. Many articles considered the patient's perspective regarding ACPs instead of that of the physician, and thus were removed. Furthermore, some articles only considered ACPs for dementia patients specifically and not the wider population, removing such articles yielded 11 articles. In addition, 3 articles were obtained through expert input in the field. These last 3 articles were utilized to create the questionnaire that will be implemented in the future study. Overall, there were a total of 14 articles used in the review to answer the objectives.

A summary flowchart depicting the study selection process is illustrated in **Figure 1**.

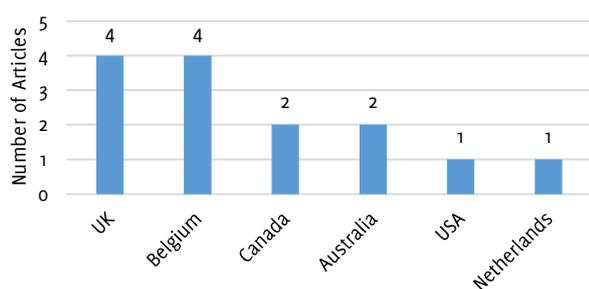
**Figure 1.** Selection Process Flow Chart.



## Results

The 14 studies included in the review were conducted in the UK, Belgium, Australia, Canada, USA, and the Netherlands (Figure 2). Of these 14 qualitative studies, 5 used semi-structured interviews, 5 used questionnaires, 2 used focus groups, 1 used a systematic literature review, and 1 used both a literature review and focus group approach. All results relevant to the current review are summarized in Supplementary Table 4.

Figure 2. Demographics of Included Studies.



Of the 323 relevant articles found, 11 records met the selection criteria. Additionally, 3 studies were included through recommendation by experts in the field; thus, 14 studies in total were reviewed. The use of qualitative methodology was appropriate, as the studies set out to determine the subjective experience and perspective of GPs regarding ACPs. In studies involving interviews, the presence of interview bias was at times unknown. However, one study did mention that interview biases may have played a role, as the interviewer was a member of the faculty that was being interviewed, which may have altered the findings. Furthermore, one of the studies conducting surveys did not base their questionnaire on a previously validated survey and did not discuss how they developed their own survey. It was therefore assumed that the questionnaire utilized was not validated. Additionally, in one of the studies conducting systemic reviews, the methodology of the included articles was inconsistent, hence combining their results may not be accurate.

## Themes

### Current Knowledge of GPs regarding ACPs

This review found that the current understanding of GPs concerning ACPs is inadequate. GPs are unsure of when and how to initiate EOL care discussions.<sup>2,3,17</sup> They have not received adequate training regarding ACP documents, including how to initiate such a sensitive topic and whom to include in the process.<sup>14,19,22</sup> It was also shown that ACPs are conducted in a distinct manner, depending on if they are completed in an out-patient versus in-patient setting, and in rural or urban areas.<sup>16,23</sup> No single technique has been implemented in conducting ACPs across different settings, hence, the understanding of ACPs by GPs is fairly poor.

### Barriers in Implementing ACPs into Clinical Practice

All fourteen studies revealed overlapping barriers for implementing ACPs into practice that fell into three categories: barriers for the GP, barriers in the healthcare system itself, and barriers involving the patients (Figure 3). Each of these will be described independently below.

#### Barriers for the GP

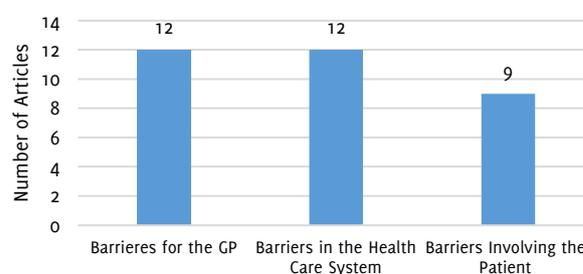
Twelve studies determined barriers for healthcare workers in conducting ACPs. Nine studies looked solely at GPs.<sup>1,3,13,14,16,17,19,22,24</sup> From these studies, one of the main barriers for GPs included the fear of eliciting anxiety and loss of hope in their patients,<sup>2,9,14,16,17,19</sup> as well as imposing personal distress on themselves<sup>1,22</sup>. GPs were also unsure on

when to introduce such discussions and whom to involve, such as family members or other healthcare professionals.<sup>2,3,14</sup> Even when ACPs were initiated, many GPs felt a lack of confidence in their abilities, due to their poor understanding of ACPs and scarce EOL care experience.<sup>2,3,11,13,16,17,19,22,23</sup>

#### Barriers in the Health Care System

The current healthcare system has not appropriately prepared GPs to initiate ACPs. Essentially, there is insufficient time available in consultations to complete such a process and provide empathy for family members and the patient themselves.<sup>3,11,17,22,24</sup> Likewise, there is no means of compensation provided for conducting ACPs, which leaves little incentive for GPs to complete them.<sup>23</sup> Additionally, there is no means of communication between GPs and specialist physicians that take over patient care towards the EOL or in debilitating conditions, thus hindering GPs from proceeding with ACPs.<sup>1,3,16</sup>

Figure 3. Major Themes of Articles



Furthermore, the process itself is tedious and paper-based. As many GP practices have shifted towards electronic databases, paper-based documentation is unsuitable.<sup>19,24</sup> The healthcare system has not created a single system to incorporate ACPs into practice with ease, which impedes physicians' confidence levels regarding their execution.<sup>16,17</sup>

#### Barriers Involving the Patient

ACP discussions can involve family members; however, many members may be in denial of their loved one's diagnosis or have disagreements concerning their preference of care. This can result in added difficulty for physicians to commence the necessary modifications required to ensure that patients' EOL care needs are met.<sup>1,13</sup> Multiple studies concluded that lack of understanding of the diagnosis, disease trajectory, and available treatment options for both the GP and the patient were probable barriers.<sup>2,3,11,17,23,24</sup> Additionally, patients lack an understanding of ACPs, as no information about ACPs is provided to patients, which in itself, hinders such a process.<sup>24</sup> It was also illustrated that many patients' requests are vague and may change overtime, making it difficult to meet their needs based on the resources currently available in the health system.<sup>2,3</sup>

## Discussion

This review attempted to explore the current knowledge of GPs regarding ACPs, and the barriers that exist concerning their implementation into everyday clinical practice.

#### Knowledge of GPs regarding ACPs

GPs were unsure of when to initiate such discussion with regards to diagnoses, as patients and their families require time to understand and come to terms with their illnesses<sup>2</sup>. Differences amongst GPs also occurred when defining ACPs, as GPs in rural and urban regions had divergent opinions and understanding of the process itself<sup>16</sup>.

#### Barriers for ACP Implementation

Studies found that previous experiences with ACPs and EOL care improved the skills of GPs and thus facilitated discussions<sup>3</sup>. However,

De Vleminck et al (2013) found that younger GPs were more likely to initiate discussions compared to older and more experienced physicians. Therefore, future studies are needed to determine the influence of years of experience on ACP employment.

There were contradictory findings regarding the length of patient/physician relationship and the ease of ACP discussions. Having a stronger relationship with the physician allows patients to feel comfortable when discussing such topics;<sup>2,14,17,24</sup> however, it was suggested that having such a relationship with patients may actually hinder GPs' tendencies to participate in such discussions, due to the emotional impact it causes them.<sup>1</sup> Nonetheless, GPs had no concern that having such discussions with their patients would ruin their relationship.<sup>24</sup> Thus, obtaining further information regarding patient-physician relationship dynamics and the ease of implementing ACPs is needed.

Results regarding interprofessional teams and ACPs also varied. Some studies found that involving other health professionals facilitated EOL discussions, as they specified treatments available that GPs may be unaware of.<sup>2,24</sup> While others discovered that other health professionals lacked role understanding, which resulted in inadequate communication between team members, and ultimately hindered the overall process.<sup>3,16</sup>

Direct comparison of these studies is difficult, as each study used different methodologies. The studies that utilized questionnaires had developed their questionnaires in a distinct manner and had included diverse questions. The sample sizes of 8 of the 14 studies was small, and, thus, the findings may not be applicable on a larger scale. As participation in all studies was voluntary, it is uncertain if the findings

are truly representative of the greater population. Similarly, the process of data collection could introduce biases, as many of the surveys and interview questions were not validated or provided in the articles themselves. Also, the studies included in the analysis were not conducted in a similar manner, thus results obtained could differ amongst the studies themselves. Additionally, only full free texts were included in this review, which does not represent all of the data available. Furthermore, as only one individual evaluated each of the papers in this review, the chance of error in interpretation is not fully removed.

The studies involved did not restrict their use of ACPs to a certain group of illnesses and can be applicable to ACP implementation for a wider array of diseases and health conditions. Likewise, GPs from diverse regions were incorporated into the studies, suggesting that the findings can be applied on a larger scale. Additionally, many of the studies had one lead researcher transcribing and encoding the data, which eliminates biases regarding data analysis.

### Conclusion

It has been suggested that ACPs should be completed by patients' GPs, as they play a central role in the care of patients, yet numerous barriers regarding its completion in clinical practice have been revealed. Lack of knowledge and time, and the fear of provoking anxiety in patients were all found to be potential barriers. There is a lack of data assessing the understanding and knowledge of Irish GPs regarding ACPs, as the Irish healthcare system greatly differs from the studies explored in this review. There is however, an increased need to effectively understand the potential barriers and knowledge of Irish GPs, as ACPs will be incorporated into clinical practices in Ireland through the Assisted Decision Making (Capacity) Act 2015 in the near future.

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