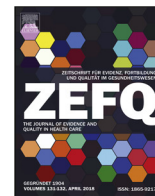




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## Implementation of Advance Care Planning in Norway

## Implementierung von Advance Care Planning in Norwegen

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## ABSTRACT

Advance Care Planning has a relatively short history in the Norwegian health care services. This article gives an overview of advance care planning research and its implementation in the health care services in Norway. Advance care planning has received increased attention from policymakers and the health care services. Research projects have been performed, and several are on-going. Implementation has largely treated advance care planning as a complex intervention, with a whole-system approach that puts emphasis on the conversation and patient activation. Advance directives have a peripheral role in this context.

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## ZUSAMMENFASSUNG

Advance Care Planning (ACP) besteht im norwegischen Gesundheitswesen erst relativ kurze Zeit. In diesem Beitrag geben wir einen Überblick über die Forschung zum Thema und die Implementierung von ACP in der norwegischen Gesundheitsversorgung. Von Seiten der politischen Entscheidungsträger und der Gesundheitsdienstleister erfährt ACP zunehmend Aufmerksamkeit. Es wurden Forschungsprojekte durchgeführt, und mehrere Projekte zum Thema laufen noch. Die Implementierung von ACP wird größtenteils als komplexe Intervention behandelt, die ein gesamtsystemisches Vorgehen beinhaltet, bei dem der Schwerpunkt auf dem Gespräch und einer aktiven Rolle der Patientinnen und Patienten liegt. Patientenverfügungen spielen in diesem Zusammenhang nur eine untergeordnete Rolle.

## Background of the health care system

The Norwegian health care system is organized into primary health care services and specialist health care services. The municipalities are responsible for the primary health care services, for ex-

ample general practitioners, nursing homes and home-care services. The specialist health care services are the responsibility of the government and organized into four regional health care trusts. Although the health care services are predominantly publicly funded, the purchaser-provider split model has been

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prevalent since the introduction of New Public Management in the 1990s [1].

The patients' disease trajectories are divided between the municipal primary care and the specialized hospital care. Even though a considerable improvement work has been performed during the recent years intending to create better pathways for patient trajectories, the goal of seamless trajectories is still not reached. With a system of person-centered communication based on shared decision-making, and a system for documentation and sharing of important information as patients' preferences, Advance Care Planning (ACP) has been considered as part of the solution for better patient trajectories in the Norwegian palliative care. However, we would like to emphasize that ACP is not considered to be exclusively a palliative care initiative in Norway.

Two current challenges of relevance for the implementation of ACP in Norway are related to the heavy workload for general practitioners, and deficiencies in communication and cooperation between health care service levels. Challenges for general practitioners have been labelled as a 'general practitioner crisis', and stems from an increased workload caused by increased demands and new assignments [2]. Challenges regarding communication and cooperation are due to several electronic health record systems where communication between them is not possible, resulting in adverse consequences for cooperation within the different levels of care in the municipalities and between primary and specialist health care services [3,4].

In this article, we give an overview of research on ACP in Norway and provide context to its implementation in the Norwegian health care services.

### Policy or legislative efforts

Patient rights for informed consent and participation in decision making processes are safeguarded through the Patient and User rights Act of 1999 [5]. In Norway, next of kin have rights concerning involvement, but they do not have medical decision-making rights if the patient lacks competency to consent [5]. This means that health care personnel are responsible for making decisions about for instance life-prolonging treatment in these situations. However, such decisions presupposes a presumed consent, meaning that the health care is viewed as in the patient's best interest and that it is likely that the patient would have consented [6]. Furthermore, health care personnel shall, if possible, ask the closest next of kin what the patient presumably would have wanted before any decision is made [6]. Not giving decision-making rights to next of kin about for instance life-prolonging treatment may be because proxy decision making can be stressful [7] and considered a burden [8,9]. Importantly, ACP may alleviate these burdens [10,11], and emphasizes the need to recognize ACP as a complex intervention [12] and implement it as such [13–15]. Next of kin views should be given at least some, but not decisive weight in decision making, according to a majority of a nationally representative panel of Norwegian adults [16]. Norway has ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Advance directives (ADs) are not addressed in Norwegian legislation, making them not legally binding. This may have contributed to the use of ADs not being common in Norway. Nevertheless, if the patient is not competent to give informed consent, any wish to limit life-prolonging treatment on the part of the patient, as known to the next of kin and health personnel, should be respected [17]. However, health care personnel shall conduct their work in accordance with the requirements to professional responsibility and diligent care [18], and that includes that patients cannot demand treatment that is considered futile [19]. ACP is not explicitly ad-

ressed in the Norwegian legislation, however, many white and green papers and national recommendations from the Norwegian Health Directorate recommend implementation of ACP [17,20–23]. ACP is recommended by authorities because it can strengthen the patient's voice in decisions. Next of kin are highlighted as important in the ACP process and for decisions to be made [24].

### Definition and model of ACP

The national R & D network for ACP [25] failed in attempting to define ACP for the Norwegian context. Some wanted the definition to be close to the EAPC definition of ACP [15], while others wanted the definition to a stronger degree to accommodate persons who lack competence to consent. Despite the failed attempt, there is a quite strong agreement on how to conduct ACP, and that the main aim of ACP is to let the patient express what is important to him/her, thus preparing for future health care. ACP is commonly performed by health care personnel who have a professional knowledge and relation with the patient and without the making of ADs.

### Groups addressed

ACP research in Norway has focused on patients, their next of kin and health care personnel in nursing homes [26–37], in a thoracic medicine inpatient ward with patients having life-threatening pulmonary diseases [38,39], and in primary health care [40]. One study was on patients in a geriatric ward in hospital [41], while another was a survey among relatives of recently deceased cancer patients [42].

Patients addressed in Norway are from what is written above, primarily seriously and chronically ill, or in geriatric or nursing home institutions. However, a general public survey indicated that the vast majority of persons are positive to participating in ACP [43]. Noteworthy in this survey, a vast majority of respondents wanted to be accompanied by their next of kin in an ACP conversation [43].

### Education and training in ACP

There is currently no national initiative in educating and training health care personnel in ACP. Still, some education programs introduce the concept of ACP, however we believe that most educational institutions do not include ACP in their curriculum. Consequently, there is a need for strengthening the education and training in ACP in Norway. The Norwegian Directorate of Health will later in 2023 publish national professional advice on ACP. This will likely address competence requirements in conducting ACP. Hopefully, this will initiate several educational initiatives in the educational institutions on both bachelor and master levels, and in the health care services. Additionally, a common understanding among healthcare providers of what ACP is will potentially support facilitating the implementation of ACP in different levels of the health care services in Norway.

Nevertheless, there are opportunities to obtain education and training in ACP. Several competency building projects, especially in elderly care, do focus on ACP and some are inspired by simulation as a tool for learning the skill [44–46]. Different e-learning courses are available [47–49]. In addition, video lectures are freely available [50].

### Information materials used, documentation and digitalization of ACP processes

Several tools, information, documentation and guidelines related to ACP have been developed in different research projects in

Norway to facilitate the implementation of ACP [29,51–53]. The national R & D network have made resources available [25]. As far as we are concerned, the Directorate for e-health in Norway are contemporarily working on how ACP conversations may be documented and shared in an effective, but secure way.

### Examples of institutional and community implementation

Implementation of ACP in Norway has largely had a whole-system approach. This includes trying to involve as many health care personnel as possible in carrying out ACP and having support from leaders and management of the institution when implementing ACP. When implementing ACP voluntariness has been a guiding principle: Thus, all participation in ACP should be voluntary. More, ACP conversations should be adapted to the individual patient with flexibility when having conversations. Informal conversations where the patient expresses some existential concern or anxiety, also described as windows of opportunity, has been viewed as opening possibilities for broaching ACP. Finally, next of kin involvement has been highlighted as important when it is likely to benefit the patient.

Our impression is that there is an increasing attention in the health care services for ACP, especially in primary health care. Many professional and service development projects have been initiated, several by Centre for Development of Institutional and Home Care Services [54], and some by the four Regional Centres of Excellence for Palliative Care.

Some ACP projects have emphasized the need for ethics reflection [45]. One example is a large, on-going research project on seriously ill home-dwelling elderly [55]. In this project ACP is implemented in hospital wards with geriatric care. Formative evaluation is emphasized in the project, as it has been in other Norwegian ACP projects.

### Research agenda on ACP?

There have been no research grant calls specifically on ACP in Norway. However, there have been 3 PhD dissertations that have been publicly defended, and several PhD-projects are ongoing.

Aasmul's (2020) PhD dissertation [56], describes the development, implementation, and evaluation of a complex intervention, targeting improvement of ACP in nursing homes. The study aimed to optimize communication among patients, families, and staff by providing staff training, guidelines, and communication tools. Results showed successful implementation of ACP, leading to increased frequency and satisfaction within communication between staff and families. However, challenges were identified during the implementation process, emphasizing the need for nursing home management involvement and clearly defined roles and responsibilities for ACP implementation. Sustainability of the intervention beyond the research period was found to be difficult, thus ongoing education, supervision and building staff competence were suggested as crucial for overcoming this challenge.

Hjorth's (2022) PhD dissertation [57] explored hospitalized patients' views on ACP, and how patients, relatives and clinicians experienced ACP conversations. Based on a focus group study with patients, an ACP conversation guide was developed and piloted. Clinicians were interviewed in focus groups, and relatives in a survey. She concluded that ACP should be patient-centered and offered at turning points in the disease trajectory. ACP may support patients and relatives by responding to their needs, and by providing tailored information. Important for implementation of ACP is management support, education, training, feasible routines, and allocated time to perform the conversations, as well

as safe and easily retrievable documentation and sharing of this between healthcare levels.

Sævareid's (2019) PhD dissertation [58] was on implementation of ACP in nursing homes. He concluded that implementation of ACP using a whole-system approach can improve nursing home patients' participation in important decisions about their health, life, and death. Cognitive impairment represented a challenge and indicated that ACP may profit from commencing before nursing home admission. However, patients with cognitive impairment participated actively and relayed relevant information for future decision-making, sometimes with support from their next of kin, which enabled them to participate in the discussions. ACP may lay an important foundation for respecting patient autonomy and person-centered care, which extends to the nursing home context.

### Addressing diversity and vulnerabilities

ACP conversations are situated in a landscape between the practical (making plans) and the personal and private, and conducting these conversations requires the art of balance between hope and reality. We believe that the national professional advice that is expected to be published by the Norwegian Directorate of Health in 2023, will address these issues related to diversity and vulnerability.

### Main challenges and barriers

While Norway has made progress in implementing ACP, there are still barriers that need to be addressed. Here are some central challenges we find are pertinent to the Norwegian context, and that could be pertinent also elsewhere in the world:

1. Lack of awareness and understanding: Many patients, next of kin, and healthcare personnel may not fully understand the purpose and benefits of ACP, which can lead to a lack of engagement in the process.
2. Cultural and language barriers: Norway has a diverse population, and language and cultural barriers can create challenges in delivering effective ACP. Patients from different cultures may have unique beliefs and preferences about end-of-life care that need to be considered.
3. Lack of time: Even though Norway has a resourceful health care system, healthcare personnel may have limited time to engage in ACP with patients, and this can impact the quality and effectiveness of the process.
4. Lack of competency to consent: An example are persons with dementia who may not be invited to ACP because they are considered not capable of participating.
5. Attitudes and culture: Established attitudes and perception among healthcare personnel that there is sufficient communication with patient and next of kin.
6. Legal and ethical Issues: End-of-life care can create uncertainty and disagreement/conflict. This may discourage health care personnel from engaging in ACP discussions.
7. Lack of standardization: There is a lack of standardization in ACP practices across Norway [59], which can lead to inconsistencies in care delivery and documentation.
8. Lack of competence: Health care personnel lack competency in doing ACP [59], creating uncertainty and a barrier to initiating and doing ACP conversations.
9. The need to address ACP as a complex intervention and implement it as such.

To overcome these challenges and barriers, it is important to increase awareness and understanding of ACP among patients, fam-

ilies, and healthcare providers. Healthcare organizations can invest in resources and training to support ACP implementation, and work to develop standardized practices and protocols for ACP delivery. Additionally, addressing language and cultural barriers and providing clear legal and ethical guidance can help to facilitate effective ACP discussions and documentation. Hopefully, the new national professional advice on ACP will contribute positively to the implementation of ACP in Norway.

## Conclusion

This article has given an overview of ACP research and a context to its implementation in Norway. While ACP is still a young clinical intervention in this context, the last few years have seen increased attention from policymakers and the health care services. Research projects largely treats ACP as a complex intervention. These developments indicate optimism concerning ACP implementation in Norway.

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## Conflict of Interest

All authors declare that there is no conflict of interest.

## CRedit author statement

TJLS: Conceptualization; Roles/Writing – original draft; Writing – review & editing. IA: Conceptualization; Writing – review & editing. NEH: Conceptualization; Writing – review & editing.

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