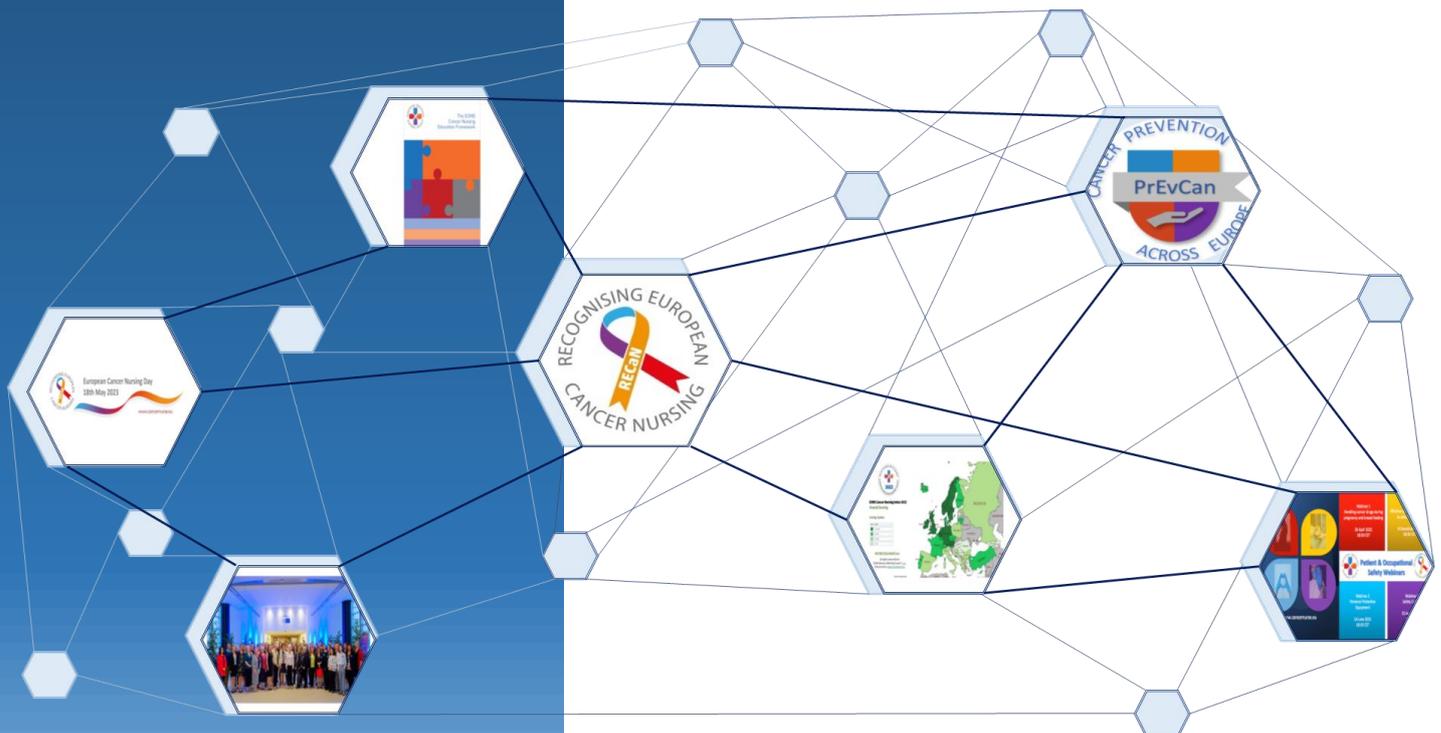




# European Oncology Nursing Society

## Advocacy Toolkit

A guide to influencing policy that improves cancer nursing status and recognition in Europe



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## Introduction

Advocacy is a broad concept and sometimes even trying to translate it is difficult. However, we *can* say that advocacy is a deliberate process to directly and indirectly influence decision-makers, stakeholders and relevant target groups to support and implement measures that contribute to the fulfilment of the rights of specific groups of people. Nurses in their daily practice are in a position to support vulnerable people who often are not able to speak up for themselves because of factors such as illness, mental capacity or social position. However, for various reasons such as age, gender, attitude to power, personality, social situation or conflict regarding professional roles, nurses may be reluctant to raise their voice for their patients. When this is the case, nurses experience moral distress, feeling too weak to advocate in favour of their patients due to external pressure.

In cancer healthcare, cancer nurses have a crucial role in advocating for nurses, patients, and the healthcare system. Furthermore, cancer nurses can be leaders within their profession and show an increasing need to have a role in influencing policy, legislation and in lobbying. There are useful documents and guides available on how to approach advocacy work, but none is attempting to highlight the key advocacy tools that are specifically of relevance to cancer nursing societies and cancer nurses. One of the aims of the European Oncology Nursing Society's (EONS) advocacy working group then, is to create a guide on how to influence decisions that improve cancer nursing status and recognition in Europe. To that effect, we have conducted a semi-structured literature review, using international resources and references. Toolkits of other organisations were also assessed and EONS' advocacy activities were identified.

This work has led to this two-part toolkit. Part 1, an introduction to advocacy, explains advocacy in general and specifically in cancer nursing. It is divided into four targets in advocacy: 1) advocacy in general in order to get a better grasp of definitions 2) advocacy for people affected by cancer 3) advocacy in nursing education to increase quality of care and create awareness among early career cancer nurses, and 4) advocacy for cancer nurses, to help nurses support each other. Part 2 describes advocacy tools that can be used, with some examples.

It is important to remember that this toolkit presents only one set of potentially useful tools and that there is not one sole approach or method that should apply to advocacy work. The aim is to give readers ideas and inspiration for their own advocacy initiatives based on the realities of the environment in which they work and offer a way to focus on what makes a real difference in cancer nursing.

## **Who is this toolkit for?**

The EONS Advocacy Toolkit is designed for both individuals (cancer nurses) and organisations (cancer nursing societies, health settings) in healthcare who are seeking a better grasp of the concept of advocacy and ways to build a structured approach for sustainable advocacy. The toolkit will be particularly relevant for cancer nurses and their workplaces. Different disciplines are advocating for different aspects of healthcare, so this toolkit will not cover all there is to know. EONS intends this toolkit to be a living document as advocacy changes and evolves over time.

# Part 1: Introduction to Advocacy

## Understanding advocacy

Advocacy is a deliberate process, based on proven evidence, to directly and indirectly influence decision-makers, stakeholders and relevant target groups to support and implement measures that contribute to the fulfilment of the rights of specific groups of people. The word 'advocacy' originates from 'advocare, 'call to one's aid' or to speak out on behalf of someone as a legal counsellor. Advocacy covers a range of activities that include organising, lobbying and campaigning.

1. **Organising** is a broad-based activity designed to ensure that the views represented in advocacy come from those who are actually affected by the issue.
2. **Lobbying** derives from the Latin word loggia, a room where one would meet directly with decision makers to engage in (often private) quality discussions and debate. Compared to organising, lobbying takes a more targeted approach and reaches out to fewer people.
3. **Campaigning** derives from the Latin campus, the wider battlefield. An advocacy campaign publicly promotes an agenda, involving platforms where a wide audience can hear the advocate's message.

Advocacy goals and outcomes should be formulated using SMART objectives: specific, measurable and monitorable, achievable, results oriented, realistic and relevant, timebound (Advocacy toolkit, Unicef, 2010).

Initially, in cancer nursing care, patients may be unacquainted with illness, treatment, prognosis, healthcare system characteristics and unfamiliar with their rights as patients. Misunderstanding cancer-related information results in health illiteracy (Vaartio et al., 2009). These tendencies are particularly critical in cancer nursing because patients may wish to change their involvement in care throughout the care process depending on where they are in the disease trajectory (Vogel et al., 2008). Overall, oncology nurses are present and support patients in understanding health information during meetings with clinical team members and remain available and guide patients systematically, passively or actively. In the latter case, cancer nurses give voice to the patients' preferences and overcome health illiteracy barriers, including cultural and financial issues (Swanson & Kock, 2010; Corish 2005).

## Understanding advocacy in cancer nursing

The World Health Organization (WHO, 1995) describes advocacy for health as a “combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or programme”. Two main goals underpin health advocacy (www.who.nl):

- a. that of protecting people who are vulnerable or discriminated against; and
- b. that of empowering people who need a stronger voice by enabling them to express their needs and make their own decisions.

Both these goals are challenging when looking at the growing numbers of cancer patients combined with nursing shortages. A recent Macmillan report shows that this leads to 21% of cancer patients being treated but not cared for. Furthermore, 25% of people diagnosed with cancer in the UK in the past two years have lacked specialist cancer nursing support during their diagnosis or treatment (Macmillan report, 2021).

## Advocacy for patients

One of the most important roles as a cancer nurse is *Patient Advocacy*, described as promoting patient safety and quality of care (Nsiah et al, 2019). Interventions and situations that require patient advocacy may be: end of life decisions, inadequate consent, cultural and ethnic diversity and sensitivity, or even provider-patient conflicts with regard to expectations and desired outcomes (Marquis and Huston, 2021). Figure 1 presents a summary of patient advocacy aspects.

Patient advocacy can be influenced by facilitators and barriers associated with the settings within which nurses work. When nurses advocate for a patient, there is a possibility of failure, and many difficulties may be experienced when addressing the rights, choices or welfare of patients. In the international literature, powerlessness, lack of support and legal issues have been identified as barriers to patient advocacy which can impede nurses from satisfactorily fulfilling this role in accordance with their ideals (Tomaschewski-Barlem et al, 2017).

Other barriers that hinder the nurse’s advocacy role and hinder the questioning of decisions made by others (e.g., physicians, patients’ relatives) include personality, age, gender, fear, lack of confidence and occupational hierarchy (Churchman & Doherty, 2010). The predominant culture still present in some clinical contexts regards physicians as having hierarchical superiority over nurses and the actions performed by nurses as ancillary. This type of hierarchical structure puts nurses in a subordinate position to physicians and represents a barrier that complicates or prevents the application of the advocacy role by nurses, potentially causing damage to the care needed by the patient (Francis, 2013).

<b>1. Ensure Safety</b>	<ul style="list-style-type: none"> <li>•Ensure that the patient is safe and receives the best quality of care when they are being treated in a healthcare facility or at home. Also, when they are discharged, by communicating with case managers or social workers about the patient’s needs for home health or assistance after discharge, so that it is arranged before they go home (Nitzky, 2018; Nsiah et al., 2019).</li> </ul>
<b>2. Give Patients a Voice</b>	<ul style="list-style-type: none"> <li>•Give patients a voice when they are vulnerable by staying in the room with other professionals (Nsiah et al., 2019; Nitzky, 2018) ; to help the patients and informal caregivers to ask questions, get answers, and translate information from medical jargon (Ellis and Hartley 2005, Choi et al 2014) ; and to provide essential information for promoting self-care (Ellis and Hartley 2005, Choi et al 2014).</li> </ul>
<b>3. Educate</b>	<ul style="list-style-type: none"> <li>•Educate patients on how to manage their current or chronic conditions to improve the quality of their daily life. For example, teaching how to take their anti-nausea medication in a way that will be most effective for them and will allow them to feel better between treatments is an example of undertaking advocacy work (Nitzky, 2018).</li> </ul>
<b>4. Protect Patients’ Rights</b>	<ul style="list-style-type: none"> <li>•Act on behalf of patients, as a mediator, or carry out certain activities for the patient (Nsiah et al., 2019). Nurses have a unique relationship with patients and their informal caregivers since they spend more time with them than any other healthcare professional (Josse-Eklund A et al, 2014). Thus, nurses are the best professionals to help patients to practice assertiveness within healthcare teams, by expressing their wishes and cultural values to other people involved in decision-making (Ellis and Hartley 2005, Choi et al, 2014).</li> </ul>
<b>5. Double Check for Errors</b>	<ul style="list-style-type: none"> <li>•Identify and prevent errors that may occur in healthcare (Ellis and Hartley 2005, Choi et al. 2014), and flag conflicting orders, information, or oversights by other disciplines (Nitzky, 2018). Nurses function as advocates for patients, however sometimes tasks performed become automatic which may lead to shortcomings in advocacy. Also organisational issues may affect advocacy work, e.g. short-staffed or tiredness. The ability to advocate for our patients may be comprised (Nitzky, 2018).</li> </ul>
<b>6. Connect Patients to Resources</b>	<ul style="list-style-type: none"> <li>•Be available and help patients to find resources inside or outside the hospital (Nsiah et al., 2019; Nitzky, 2018). Be aware of resources in the community that you can share with the patient, such as financial assistance, transportation, patient or caregiver support networks, or helping them meet other needs (Nitzky, 2018). Creating good channels of communication is fundamental, for example, to foster interaction and collaboration among patients, families and the healthcare team (Ellis and Hartley 2005, Choi et al. 2014).</li> </ul>

**Fig.1** Summary of patient advocacy aspects.

A variety of strategies and actions have been identified to help nurses overcome barriers to advocacy. A key one is improvement of knowledge, which could be achieved through training, professional qualification and continuing education, thus enhancing nurses’ autonomy to advocate for patients and their loved ones (Simmonds, 2008). Moreover, nurses can share common values and goals with physicians regarding the care provided to patients and promote advocacy together, which can eliminate potential conflicts. However, the way that nurses become effective advocators is, first and foremost, to recognise themselves to be at the same level as other healthcare and administrative members of their workplace and to try to obtain the support of their

employers at the institutions at which they work (Hyland, 2002; Tomaschewski-Barlem et al, 2017).

The efficacy of patient advocacy efforts does not depend only on nurses' traits, skills and knowledge but also on a receptive environment. Therefore, it is important to note that advocacy always occurs in a social environment and that identification of the characteristics of this environment is essential to facilitate patient advocacy (Hanks, 2010). Among the various elements that facilitate the practice of patient advocacy, the following are highlighted (Seal, 2007; Hanks, 2010):

- nurses' knowledge and competencies
- personal traits
- multidisciplinary teams
- communication
- relationship with patients and families
- recognition of patient needs and desires
- nursing staff
- head nurse

In conclusion, patient advocacy is an important component in daily practice. Cancer nurses have a responsibility to advocate for the rights, values, wellbeing and best interests of patients thus helping patients maintain good health, ensuring quality care and quick recovery and minimising the burden on the healthcare system. To support this however, professional education, workplace learning and the collaborative efforts of interested groups are necessary.

## Advocacy in education

Education is necessary to increase nurses and student nurses' awareness of advocacy and help them cope with contradictory situations and obstacles, even though it has been stated in the literature that the experience gained in the nursing practice area is more crucial than education (Hanks, 2008).

The International Council of Nurses (ICN, 2019) and the World Health Organisation (WHO, 2019) have called upon nurses to get more involved in leadership, policy development and advocacy. This call has helped to drive leadership, policy development and advocacy education for nurses (Turale & Kunaviktikul, 2019) and with appropriate academic preparation will increase nurses' abilities and skills.

### **1. Advocacy in nursing education to increase quality of care (ethical obligation)**

Speaking up for patients is a key skill for nurses and one that is best developed through education and practice in a variety of situations (AACN, 2021; Okuyama et al., 2014). Advocacy is a professional responsibility in nursing but is also regarded as an ethical obligation because individuals and families are in a sensitive position within the

healthcare environment and hierarchical system (Akin & Kurşun, 2020, O'Connor & Kelly, 2015; Davis, Konishi, Tashiro, 2003). For example, patients who are generally vulnerable while dealing with a disease like cancer at the end-of-life stage can benefit from the care of highly-trusted professional nurses who can advocate for them when they are unable to do so themselves.

Nursing advocacy education plays a crucial role in increasing nurses' and students' awareness of advocacy (Boswell et al., 2005; Turale & Kunaviktikul, 2019) and ethical sensitivity. However, although the advocating role of nurses is considered essential, little in the nursing literature indicates *how* nurses learn this role (Foley, 2002, Hanks, 2008, 2010; Kalaitzidis & Jewell, 2015).

According to the literature, nursing education helps:

- raise positive attitudes toward advocacy (Agom et al., 2015)
- create learning experiences for students that reflect the complexities of the current healthcare system and broaden students' knowledge and application of advocacy (Peltzer et al., 2016)
- put an emphasis on political advocacy (Fyffe, 2009).

Regarding political astuteness among nurses, multiple advocacy strategies are available, such as (Primomo, 2007):

- having the ability to identify and communicate with policymakers
- organising and mobilising community groups as resources, and
- belonging to a professional organisation.

## **2. Advocacy in nursing education creates students' awareness of advocacy**

Several studies mention that the majority of faculty surveyed lacked professional preparation and practical experience (Radius et al., 2009):

- Student nurses lacked formal advocacy education and learned advocacy from other nurses after graduation (Radius et al., 2009; Davis et al., 2003).
- Student nurses see practicing nurses as role models and mentors (emphasised the importance of role modelling by expert nurses) (Choi et al 2014).

Modelling positive professional behaviours and helping those new to the profession to acquire these behaviours is a form of advocacy. Providing guidance during a difficult learning situation, such as the first time a novice performs a procedure, can advocate for both the patient and the novice (Tomajan, 2012). Hence, the effective implementation of continuing education in health institutions will be an important strategy to encourage the exercise of patient advocacy on the part of nurses (Barlem, 2017).

More recent studies have shown that a higher level of education is associated with a greater perceived autonomy, yielding a greater likelihood for the nurse to advocate for his or her patient (O'Connor and Kelly, 2005; Hanks, 2010 and Duffy et al. all, 2012). It is also recommended to include nursing ethics and patient advocacy in the curriculum for nursing student education (Nesime & Belgin, 2022). In particular, Duffy et al. (2012) advocate for early intervention with nursing students to utilise clinical experiences as opportunities for reflection about patient care concerns, while providing feedback and support to the student. O'Connor and Kelly (2005) acknowledged that teaching an abstract concept such as nursing advocacy requires active engagement with clinical experience through workshops or role play scenarios and simulation, that is, by providing learning opportunities in a controlled setting – for example, using standardised patients (SP), actors trained to portray patients, family members or healthcare providers, is an effective approach to teach communication skills (Webster, 2019).

Practicing advocacy skills in a safe and controlled environment may improve students' comfort with speaking up in clinical practice.

## Advocacy for nurses

Safeguarding the health of the cancer population occurs through the growth of the government of cancer nursing care processes. At the current time, the quality and safety of cancer nursing care processes are under threat in Europe from financial and workload forces (Kelly et al., 2020). The data demonstrates a worrying shortage of nurses leading to excessive workloads that put the health of people affected by cancer and the wellbeing of cancer nurses at risk. From this latter perspective, nurses play a key role in advocating for the wellbeing of nurses through individual and collective initiatives, including nursing societies, who have a key role in advocating for nursing profession.

A central component of the nurse's role is the promotion of a safe environment and the shaping of health policy, education, and research (ICN, 2012). The advocacy actions of nurses also seek to improve the work environment thus leading to a change in clinical cancer care practice with positive impacts on the needs of people affected by cancer and cancer nurses' wellbeing – especially through the values and standards of nursing practice and shaping and improving the knowledge, attitudes, beliefs and behaviours of nurses (Devereux, 2022).

Nurse-oriented advocacy requires a genuine interest in continuing education not only in issues related to clinical practice but also in the norms and policies ruling the profession, in developing skills in mentoring, peer reviewing, teaching, and in expanding knowledge through research to protect and raise the quality and safety of patient care (Institute of Medicine, 2011).

Only through formal advocacy initiatives by nurses for nurses will it be possible to guarantee future benefits for the profession and, more generally, for health systems. The numerous critical issues that nurses are facing today will have to be progressively addressed by the benefits deriving from advocacy and achieved through specific skills such as negotiation, collaboration, so that influence is brought to bear to protect nurses.

In summary, effective advocating for nurses is a complex process requiring skills and actions that give voice to nurses in decisions regarding themselves and healthcare systems; thus delivering cancer treatment innovations through cancer nurses who are trained and motivated to bring about excellent, safe and high quality nursing care processes and protection of nurses' wellbeing.

## Part 2: Advocacy Tools

The fundamental aim of advocacy is to gain access to decision-makers to sensitise and influence them on an issue or concern of a group or society. (Coulby 2010: 6) Change will not happen if the ideas and concerns are not communicated effectively. Often, advocacy work by organisations is necessary to facilitate this communication.

To be a good advocate as a cancer nurse, there must be a certain foundation. This foundation will lead to effective and far-reaching advocacy and will cover different areas. It is crucial, when advocating as an EONS delegate, to have credibility. EONS and individual cancer nurses must be trusted and what they say believed to have value. EONS is effective in advocating for cancer nurses because of its many years of credibility and expertise in cancer nursing across Europe.

The second area is skills. Advocacy is a skill that combines knowledge, good judgement and creative problem solving. As a cancer nurse, you are not only advocating for your patients, but also for yourself. Building skills for advocacy takes time and training. This must be facilitated by management but has to start at the very beginning of nursing school. Education is key in developing skills to advocate for patients first and foremost, but also for the nurse's role and for policymaking in healthcare (UNICEF toolkit).

The final level is the way in which the organisational conditions influence patient advocacy (Josse-Eklund A et al, 2014). Managers must understand nurses' role as advocates for patients, so they can provide adequate staffing levels and an environment that allows us to fully care for our patients (Nitzky, 2018). It's part of our advocacy duty to be familiar with the bureaucracy and aim to challenge ineffective rules and policies in an organisation – as well as to create health policy task forces and committees to support legislation that benefits healthcare consumers (Ellis and Hartley 2005, Choi et al. 2014). As a matter of fact, the third level of influencers could be connected to the two previous levels since these influencers create the surroundings where the nurses work and bond with the patient (Josse-Eklund A et al, 2014).

### Influencing policy

In the field of cancer care, cancer nurses represent the largest group of healthcare workers. They are the first and sometimes the only contact in the health setting, and for more than two decades the public has voted nurses as the most honest and trusted profession (University of North Carolina Wilmington, 2021; Stone, 2021). Moreover, nurses experience in their daily practice the influence of policy and politics in healthcare (University of North Carolina Wilmington, 2021). These are some of the reasons why cancer nurse leaders can and should uniquely and effectively promote

policy and social change. However, both at an institutional and political level, nurses' viewpoints are often missing or are silenced from policymaking (Benyon, 2021).

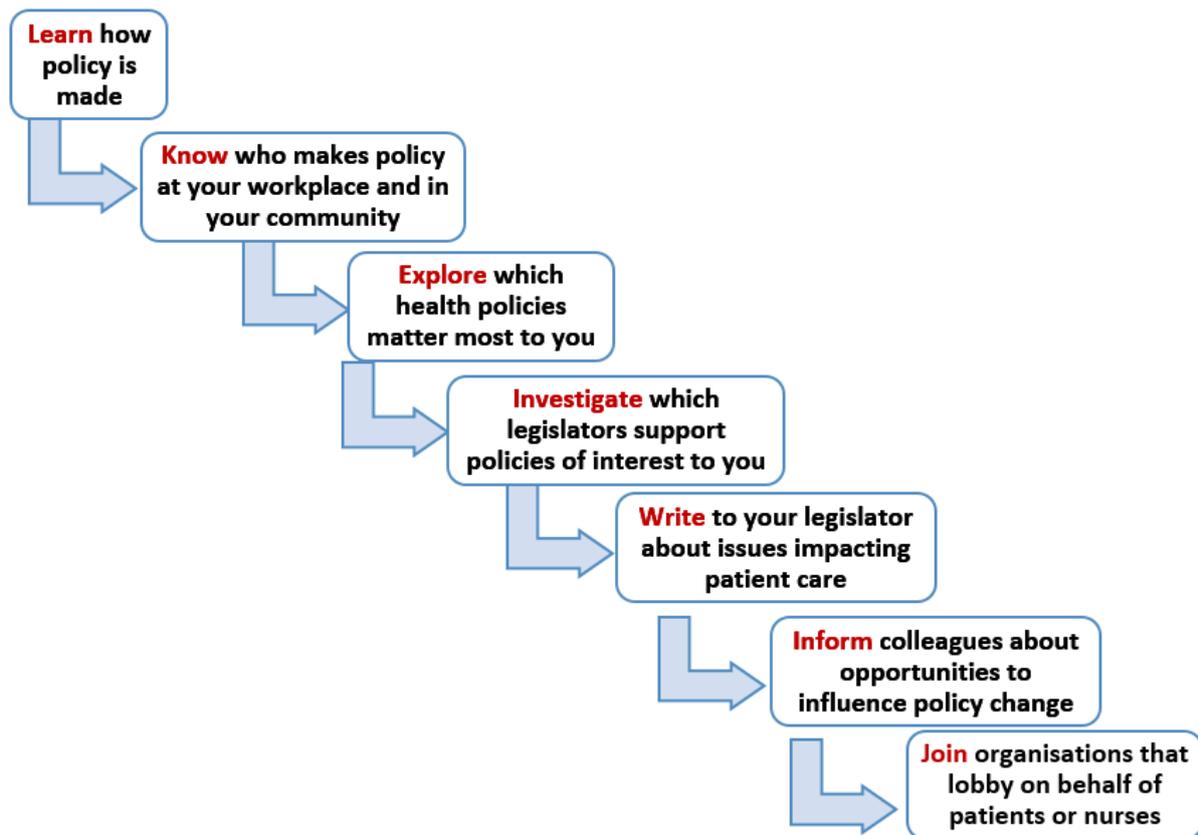
Every nurse by personality as well as profession can advocate for change and use their influence to develop and implement health policy within their organisation, within government agencies or directly with policymakers and elected officials (University of North Carolina Wilmington, 2021).

Health policy is defined by the WHO (WHO, 2011) as “the decision, plans, and actions that are undertaken to achieve specific health care goals within a society and it encompasses any law, regulation or research that impacts patient health and care providers”; cancer nurses as frontline team members can interact with these as follows (University of North Carolina Wilmington, 2021):



**Fig. 2** Effective approaches to health policy advocacy.

Cancer nurses are highly educated professionals and have the experience to influence policy. Some ways that nurses can help shape health policy are presented in Fig. 3. (University of North Carolina Wilmington, 2021):



**Fig. 3** Steps to a successful healthcare strategy.

Cancer nursing societies, at national and European level, have the responsibility to promote a variety of public policy changes that can transform cancer care. Advocacy and policy influence are among the core values and strategic goals of EONS, and the organisation's leadership believes cancer nurses must literally and figurately have a seat at the political table. As nurses are essential advocates for health policy, when they speak, policymakers must listen (University of North Carolina Wilmington, 2021; Stone, 2021).

EONS, through its strong leadership and partnerships, adds a vital voice representing cancer nurses' views in order to support the goals of quality care, evidence-based practice, and nurse education and leadership in healthcare. More information about EONS initiatives can be found below:

- Recognising European Cancer Nursing ([RECaN Project](#)).
- Cancer Nursing Education in Europe ([Cancer Nursing Education Framework](#)).
- Work on Patient and Occupational Health ([EONS Work on Safety](#)).
- The Development and Progress of Cancer Nursing across Europe ([European Cancer Nursing Index](#)).
- European College of Cancer Nursing ([ECCN](#)).
- Position statements and joint letters from the EONS Advocacy Working Group ([Position Statements and Joint Letters](#)).

## Good practice in advocacy

Advocacy and policy issues affect both cancer nurses and people with cancer. Excellence in clinical and nursing care is crucial as a platform from which to advocate for policy change. The European Oncology Nursing Society (EONS), the leading professional organisation representing cancer nurses in Europe, advocates on a wide range of policy-related issues to ensure the improvement of health and cancer care for all; that all patients with cancer have access to high-quality, high-value cancer care; and to create an environment that is safe, empowering, and satisfying for them.

Showing how cancer nursing can impact in positive cancer outcomes can also be an important catalyst for policy change. Topics reviewed in this section represent some of the issues that EONS is currently addressing. The following activities have been chosen as examples of good practice in political, education, research, fundraising, support, and community advocacy across Europe.

### Building a Young Cancer Nurses Network in Europe

EONS recognises the unique challenges that new generations of cancer nurses experience on a personal and professional level, as a result of rapid political and economic changes globally. In response to the needs and motivations of Young Cancer Nurses (YCN), EONS supports the development of a network for cancer nurses and general nurses who work in cancer settings and / or with people affected by cancer in the WHO Europe region, who are under the age of 35. The EONS Board and each of the EONS working groups (Communication, Advocacy, Research, Education) work in close partnership with the EONS YCN Network.

The network is a source of support, guidance and education for cancer nurses. Several interventions build capacity and provide opportunities for YCNs throughout Europe to enable them to engage in professional development, learning and networking. A study sponsored by EONS in 2019 indicated issues and challenges experienced by YCNs in Europe and barriers they faced in their profession. Its findings highlighted the need for protected time, financial support for educational opportunities, mentorship, engagement with career development, and being empowered to take on leadership roles. To meet these needs, the Network, with the support of EONS, develops strategies to enhance personal and professional development in cancer nursing, such as educational webinars (Nightingale Challenge Webinar Series), reduced fees and sessions about YCN issues at EONS Congresses, grants for YCNs to attend meetings and educational events, participation in EONS' educational, research and other projects, development of a website and blog for YCNs, and workshops with topics relevant to YCNs issues.

However, it is evident that there are inequalities between European countries with regards to the level of recognition, the adequacy of the working environments, education and opportunities in cancer nursing. The Network's vision is to provide

support and guidance and to be a platform for networking. Along with new initiatives, the aim remains to demonstrate how exciting and rewarding a career in cancer nursing can be and to help develop the next generation of young nurses as leaders in cancer care.

## Recognising European Cancer Nursing (RECaN)

RECaN is a major project led by EONS and is supported by the European Cancer Organisation. The overall goal is to increase recognition of the value and contribution of cancer nursing across Europe – focusing on expert cancer nursing skills, research, education, clinical leadership, strategy and management roles, advocacy, and policy development. With the RECaN project, EONS would like to see cancer nursing better recognised to ensure that:

- Cancer nurses are core members of the multi-professional team,
- Cancer nursing should be a recognised speciality across Europe based on a mutually agreed educational curriculum,
- Education for specialist cancer nurses should be made available,
- Enhanced free movement of cancer nurses across Europe should be promoted and facilitated to help address rising demand,

## Survey on patient and occupational safety

To gain knowledge on both patient- and occupational safety from European cancer nurses, a survey was developed and conducted by EONS' Advocacy Working Group. A database was developed by the Regional Cancer Centre in Stockholm-Gotland, Sweden. Based on these results, advocacy is ongoing to clarify the need for clear guidelines and to implement both guidelines and training. Several areas that need attention were identified. These areas became the focus of a series of webinars. The webinars focussed on:

1. handling cancer drugs during pregnancy and breastfeeding
2. personal protective equipment (PPE)
3. safety culture, and
4. effective communication, key to safe cancer care.

These findings have also led to the Cancer Nursing Index.

## European Cancer Nursing Index

The EONS Cancer Nursing Index is important for the work EONS does in seeking recognition for cancer nursing as a profession by the community and by national- and European level policy makers. This index was developed to illustrate the development and status of the cancer nursing profession within different countries in Europe. The

purpose is to illustrate cancer nursing profiles and identify disparities and areas in need of development. The index was originally developed from the survey on patient and occupational safety, starting in 2020. This was supplemented by data on work force statistics and has led to a series of maps showing the status of cancer nursing within 5 domains. These domains are:

1. education and career development
2. patient and occupational safety
3. recognition
4. working conditions and impact, and
5. workforce statistics.

Each country's national Cancer Nursing Index can be downloaded and used for advocacy in that country.

## The European College of Cancer Nursing

The European College of Cancer Nursing (ECCN) offers an exciting and innovative structured nursing educational pathway which spans from early nursing careers through to taking on strong leadership and research responsibilities. The ECCN offers a collegiate environment promoting and providing cancer education, professional development and networking opportunities for all nurses working with people affected by cancer and their families/carers across Europe to enhance care for people of all ages affected by cancer.

## Raising awareness

### Raising awareness through digital advocacy

Digital advocacy refers to the use of digital technology, such as social media, to contact, inform, and mobilise a group of people and/or organisations around an issue or cause, and to incite them to take action (Community Tool Box)

Social media is a powerful tool that has transformed how modern advocacy campaigns are run and allows them to extend their reach to tap into new audiences, strengthen their connections with supporters, and spread awareness to a greater degree than they could through traditional methods alone (Vaughn, 2022). However, any campaign's social media advocacy strategy requires additional knowledge of what platforms to use and how to leverage them for the campaign's goals (Vaughn, 2022).

The following scheme summarises the three main benefits of the social media advocacy campaigns (Madrazo, 2021):

## Raise Awareness

- The first and most immediate benefit of using social media for advocacy. The first goal is to let as many people know that your cause exists.

## Educate

- An excellent tool for educating the public, colleagues and connected supporters.

## Inspire in Action

- Get people to do something about the cause, either by supporting the organisation through donations or participating in your events, or doing something in their community.

**Fig. 4** Benefits of digital advocacy campaigns.

For a social media campaign to be successful, a clear goal should be set. Advocators must remember that the goal is the basis for everything they do in the campaign. Identifying the target audience is also of central importance (Madrazo, 2021). If the goal of the campaign is to get people to act, calls to action must not only ask them to help, but also tell them *how* to help. To inspire action, they also need to know *why* they should do what you are asking them to do (Madrazo, 2021).

Cancer nurses can also use social media for digital advocacy by joining and participating in social media networks. Digital advocacy can support cancer nursing advocacy campaigns by extending the reach and influence of the mission-critical agenda (Vaughn, 2022). Social media advantages include (University of Kansas, 2005):

- little or no cost to set-up
- a potentially wide reach
- allowing messages to be shared instantly
- offering new opportunities to listen, engage, and monitor campaign's progress.

Cancer nurses might use digital advocacy when (University of Kansas, 2005):

- developing a content plan or editorial calendar of topics to post, which will include the timing of advocacy requests and key dates for desired outcomes
- integrating any online efforts with offline efforts (printed materials, public relations, media outreach) to maximise success. Social media reference should be on printed materials, and promote content from printed materials online.
- posting messages and other communications with consideration to who the audience is and when they are most likely to be on social networking sites, to maximise the number of interactions.

A practical guide for a successful strategy for social media advocacy in 8 steps (Vaughn, 2022):



**Fig. 5** Eight components for a successful digital advocacy campaign.

Further information on how to use social media platforms professionally can be found in the EONS Social Media Guidelines which are available on the EONS website [here](#).

### Involving the public and developing strategy

Effective advocacy of any kind requires a solid strategy or plan and the necessary skills so that the advocator feels confident in achieving his / her goals.

A strategy defines the area of focus, gives guidance on how the assets and resources can be located, and helps set out what is achievable. A step-by-step approach includes:



**Fig. 5** A step-by-step strategy for advocacy (UNICEF's Advocacy Toolkit, 2010).

**Table 1.** Taking inventory of advocacy assets and gaps (adapted from PATH Advocacy Workbook, 2014).

Skills, expertise, and resources	Specific individuals or materials (Names of people, departments, Advocacy Partners etc.)	Available for advocacy?
Staff who are available to work on advocacy		
Staff who can be influential spokespeople		
Staff relationships with decision-makers		
Expertise in the area of the problem/target		
Expertise in (web) communications and media relations		
Expertise in coalition-building		
Expertise in community and social mobilisation		
Evidence to support		

## Monitoring and evaluating advocacy

Although the patient advocacy nurses' role has been well described, there is a lack of developed measures to assess nurses' knowledge and attitudes towards cancer patient advocacy. Also, there is a scarcity of tools to assess patients' perception of nurses' advocacy actions in protecting and defending the choices of people affected by cancer. The following Table (2) briefly describes measurements developed to assess advocacy from the nurse and/or patient perspective available in the literature; only one measure was developed in the cancer population: The Female Self-Advocacy in Cancer Survivorship (Hagan et al., 2016).

**Table 2.** Patient advocacy measurements from nurses' and patients' perspectives.

Nurses' Perspective		Patients' Perspective	
Scale	Key Characteristics	Scale	Key Characteristics
Patient Advocacy Engagement Scale (Jansson et al., 2014)	<ul style="list-style-type: none"> <li>▪ multidimensional scale</li> <li>▪ measures advocacy engagement in addressing:                             <ol style="list-style-type: none"> <li>1. ethical problems</li> <li>2. problems related to quality of care</li> <li>3. lack of culturally responsive care</li> <li>4. lack of preventive care</li> <li>5. lack of affordable or accessible care</li> <li>6. lack of care for mental health issues and distress</li> <li>7. lack of care that addresses household and community barriers to care</li> </ol> </li> </ul>	Patient Self-Advocacy Scale (Brashers et al., 1999)	Assesses: <ul style="list-style-type: none"> <li>▪ patient self-advocacy behaviors</li> <li>▪ patients' communication skills with healthcare professionals</li> </ul>
Policy Advocacy Engagement Scale (Jansson et al., 2015)	<ul style="list-style-type: none"> <li>▪ unidimensional scale</li> <li>▪ assesses the commitment in policy advocacy to:                             <ol style="list-style-type: none"> <li>1. patients' ethical rights</li> <li>2. quality of care</li> <li>3. culturally competent care</li> <li>4. preventive care</li> <li>5. affordability/accessibility of care</li> <li>6. mental healthcare</li> <li>7. community-based care</li> </ol> </li> </ul>	Female Self-Advocacy in Cancer Survivorship (Hagan et al., 2016)	<ul style="list-style-type: none"> <li>▪ self-administered tool</li> <li>▪ 57 Likert-type self-reported items</li> <li>▪ three subscales:                             <ol style="list-style-type: none"> <li>1. application of information</li> <li>2. leading my health care</li> <li>3. connected, strength</li> </ol> </li> </ul>
Protective Nursing Advocacy Scale (Hanks et al., 2010)	<ul style="list-style-type: none"> <li>▪ measures nurses' actions in terms of attitudes and beliefs toward patient advocacy</li> <li>▪ assesses quality of nursing advocacy within patient safety initiatives</li> <li>▪ evaluates educational advancement for nurses</li> </ul>	Seniors Empowerment and Advocacy in Patient Safety (Elder et al., 2007)	<ul style="list-style-type: none"> <li>▪ 21 items</li> <li>▪ assesses senior patients' behaviours on embracement of outpatient safety self-advocacy actions</li> <li>▪ four subscales:                             <ol style="list-style-type: none"> <li>1. outcome efficacy</li> <li>2. attitudes,</li> <li>3. self-efficacy</li> <li>4. behaviours</li> </ol> </li> </ul>
Ethical Assertiveness Scale (Dodd et al., 2004)	<ul style="list-style-type: none"> <li>▪ assesses engagement of acute care nurses in helping patients in resolving ethical issues</li> </ul>	Perceived Involvement in Care Scale (Lerman et al., 1990)	<ul style="list-style-type: none"> <li>▪ measures in what extent patients perceived to be involved during health care consultation visits</li> </ul>
Nursing Professional Values Scale Revised (Weis et al. 2000)	<ul style="list-style-type: none"> <li>▪ 26 items measuring code of ethics' professional nursing values</li> </ul>	Modified Perceived Involvement in Care Scale (Jonsdottir et al., 2012)	<ul style="list-style-type: none"> <li>▪ 20 items</li> <li>▪ four subscales:                             <ol style="list-style-type: none"> <li>1. health care provider information</li> <li>2. patient information</li> <li>3. patient participation in decision-making</li> <li>4. health care provider facilitation</li> </ol> </li> </ul>
Attitude Toward Patient Advocacy Scale (Bu & Wu, 2008)	<ul style="list-style-type: none"> <li>▪ measures nurse's patient advocacy role at macrosocial (inequity and disparity) and microsocial level (safeguarding patients' autonomy, and acting on behalf of patients)</li> </ul>	Modified Perceived Involvement in Care Scale (Smith et al., 2006)	<ul style="list-style-type: none"> <li>▪ one more modified version of the PICS that included three more items specific on pain management and some</li> </ul>

Nurses' Perspective		Patients' Perspective	
Scale	Key Characteristics	Scale	Key Characteristics
			changes were made on the response scale
(Reed et al., 2018)	<ul style="list-style-type: none"> <li>▪ 62 Likert-type self-reported items and 8 open-ended questions</li> <li>▪ three subscales:               <ol style="list-style-type: none"> <li>1. factors enabling successful district nurse advocacy</li> <li>2. advocacy action in end-of-life advocacy</li> <li>3. emotional intelligence</li> </ol> </li> </ul>		
Nurse and Patient's Perspectives			
Advocacy in Procedural Pain Care (Vaartio et al., 2009)	<ul style="list-style-type: none"> <li>▪ measures nursing advocacy from nurses and patients' perspectives</li> <li>▪ 58 items focused on antecedents, activities, and consequences of advocacy by procedural pain care nurses</li> <li>▪ includes activities aimed at:               <ol style="list-style-type: none"> <li>1. fostering and protecting patients' wellbeing</li> <li>2. awareness of patients about their rights and access to information necessary to give their informed consent</li> </ol> </li> </ul>		

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## Appendices

### Appendix 1. Checklist for advocating

Checklist		
<b>What do we want?</b>	Describe the issue, who or what it affects, and its impacts	
	Describe your advocacy goal	
<b>Who can make it happen?</b>	Mapping stakeholders' interests, influence and importance ( <u>Stakeholder Analysis</u> ) <ul style="list-style-type: none"> <li>• Decision-makers</li> <li>• Influencers</li> </ul>	
<b>What and when do they need to hear?</b>	Developing evidence-based messages	
	Develop key messages	
	Develop calls for action	
	Link important messages to meaningful days e.g. ECND, World Cancer Day, Colorectal Awareness Month, European Week Against Cancer etc.	
<b>Who do they need to hear it from?</b>	To Identify the right messenger for your audience <ul style="list-style-type: none"> <li>• Choosing <u>messengers</u> strategically</li> </ul>	
<b>How can we make sure they hear it?</b>	To identify processes, opportunities and entry points Choosing appropriate medium and the best channels to deliver your message	
	Identifying and planning opportunities	
	Lobbying	
	Negotiating	
<b>What do we have? What do we need?</b>	To recognise capacities and gaps Advantages, challenges, threats, opportunities,	
	Generate support – advocacy partners, influencers	
<b>How do we begin to take action?</b>	To set goals and interim outcomes and develop an action plan Being <u>SMART</u>	
	Advocacy action planning	
<b>How can we tell if it's working</b>	To monitor and evaluate advocacy: Using e.g. ' <u>logical frameworks</u> ' to plan advocacy action	

*Adapted from UNICEF's Advocacy Toolkit, 2010*

## Appendix 2. Smart goals template

<b>S</b>	Specific	<ul style="list-style-type: none"> <li>• Who is involved?</li> <li>• What do I want to achieve?</li> <li>• When do I need to achieve this?</li> <li>• Why is the goal important?</li> </ul>	
<b>M</b>	Measurable	<ul style="list-style-type: none"> <li>• How will I measure my progress?</li> <li>• How will I know if my goal is achieved?</li> </ul>	
<b>A</b>	Achievable	<ul style="list-style-type: none"> <li>• Will it be clear when the goal is complete?</li> <li>• Is it reasonable to complete the goal in the time allotted?</li> </ul>	
<b>R</b>	Relevant	<ul style="list-style-type: none"> <li>• Is this goal related to my overall success (or the success of my work/organisation)</li> </ul>	
<b>T</b>	Time-Bound	<ul style="list-style-type: none"> <li>• How long should it take to accomplish this goal?</li> <li>• When will I check in on whether the goal has been completed?</li> <li>• Am I ready to start work on the goal?</li> </ul>	

*Adapted from UNICEF's Advocacy Toolkit, 2010*