EU PROJECTS

EU Navigate
Supporting older people with cancer

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Patient Navigation: The Path Towards Reduced Cancer Inequalities in Europe?

EU Navigate - Supporting older people with cancer

STAKEHOLDER FORUM REPORT

Executive summary

The increasing complexity of the healthcare landscape, particularly for diseases such as cancer, requires patient navigation to guide individuals through the system, reduce barriers, ensure timely access to essential services, improve shared decision-making and improve health literacy.

However, despite significant progress in the United States (US) and Canada over three decades, European cancer patient navigation remains fragmented with limited support and no EU-level strategy. Greater collaboration and stakeholder involvement is needed to bridge this gap and advocate for high-level commitment.

Inspired by the Canadian Nav-CARE initiative, the EU Navigate research project aims to implement and evaluate a patient-centred navigation intervention for older cancer patients, their carers and their families in different European healthcare systems.

The project consortium therefore organised a stakeholder forum to discuss the obstacles and facilitate ways of improving dialogue between stakeholders including representatives of European and international entities, as well as initiatives and projects such as My Cancer Navigator, CANCERLESS, CO-CAPTAIN, Nav-CARE, the American Society of Clinical Oncology (ASCO) and the White House Office of the United States (US).

Key findings of the stakeholder forum:

- Patient navigators play an invaluable role in the cancer journey, benefiting patients and healthcare professionals through their comprehensive nature, connecting patients to vital resources by bridging health and social services, and providing emotional support.
- A patient- and family-centred approach with flexible navigation models is essential to meet diverse needs and improve quality of life, particularly for older cancer patients.
- The integration of patient navigators into multidisciplinary teams remains challenging due to perceptions of their voluntary or non-clinical status, highlighting the need for appropriate training.
- Ensuring the sustainability of navigators is a challenge; suggestions include adopting a participatory design during interventions, institutionalising patient navigation as a formal service, and securing ongoing funding from private and public sources, possibly through health insurance schemes.
- Evidence-based recommendations, including cost-effectiveness studies and qualitative data, are essential to drive policy change, with stakeholder involvement key to advocating for these changes.
- Global collaboration between initiatives is essential to share evidence and increase the impact of patient navigation efforts.

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Guiding principles for stronger patient-navigation programmes

In developing stronger patient-navigation systems across Europe, a holistic and ambitious approach is imperative. These guiding principles aim to transform patient care, by integrating navigation practices. By adhering to these principles, Europe can establish a comprehensive patient navigation framework that empowers individuals, enhances healthcare outcomes, and advances societal well-being. These guiding principles should be disseminated to all policymakers and politicians, healthcare professionals, representatives of healthcare professionals, patients and patient representatives, to best inform them of best practices on patient navigation.

MAKE IT EMPOWERING!

1. Support patients in their journey to make informed choices and receive relevant information thanks to innovative healthcare systems and digital solutions, taking their specificities into consideration.
2. Connect patients with essential resources such as social services, logistical support and emotional support to contribute to their well-being and empowerment.
3. Integrate patient navigators into the multidisciplinary team and organisational systems. Challenge the perception that their work is solely voluntary, non-important and non-clinical.
4. Alleviate the workload of healthcare professionals, notably by relieving emergency services, in an effort to streamline the patient pathway.

MAKE IT FUNCTIONAL!

5. Encourage socialisation and engagement within the community, to benefit both the patient's quality of life and to access the services that communities offer.
6. Enable flexibility in the navigation model, to meet the different needs of patients and their families or carers.

MAKE IT SUSTAINABLE!

7. Institutionalise patient navigation as a service, rather than relying on individual volunteers.

8. Develop and implement aappropriate training sessions and training of trainers, to equip navigators with the necessary knowledge and competence to provide effective support and navigation services.

9. Ensure continued funding from private and/or public sectors, notably by integrating patient navigation into health insurance schemes, and by securing funding for marginalised groups excluded from insurance coverage.

10. Finance piloting in additional countries, for EU Navigate and other allied initiatives, promoting a vision extending beyond short-term and cyclical funding.

11. Integrate patient navigation in national cancer plans and health insurance schemes.

MAKE IT EVIDENCE-BASED!

12. Produce evidence-based recommendations that include cost-effectiveness studies.

13. Rely on qualitative data, such as individual patient stories, to advocate for progress.

MAKE IT COLLABORATIVE!

14. Foster collaboration and participation between different initiatives in Europe, through the sharing of best practices and challenges encountered.

15. Create and participate in an International Coalition of Support for patient navigation - notably seeking inspiration from the United States and other leading countries.

16. Collaborate closely with the United States – a pioneer – within the EU-US Public Health Taskforce to develop future partnerships, yet also with other leading countries in the field whose best practises Europe can seek inspiration from.

17. Develop a Code of Conduct for Insurance – urging national health systems to integrate reimbursement of patient navigation.

Introduction: The patient navigation context

In today's dynamic healthcare environment, characterised by the increasing prevalence of complex conditions such as cancer, accompanied by long-term care needs and co-morbidities, the spectrum of health needs has become more diverse. Depending on the context, patients may need access to a full range of services, including clinical, psychosocial and spiritual care. **In response to this evolving landscape, patient navigation has emerged as a promising solution in a community context. Navigation interventions are non-pharmacological approaches designed to support, educate and empower patients and, in some cases, their families. At its heart is a patient navigator, a dedicated person with or without a health background who works with patients on an individual basis. These holistic approaches aim to inform and connect patients with tailored services and resources, facilitating their journey through complexities of health and social care systems and promoting shared decision-making. By reducing barriers and ensuring timely access to essential services, patient navigation has significant potential to improve the quality of care and the quality of life of individuals with cancer[1].**

The US pioneered cancer patient navigation three decades ago and continues to lead the field, alongside Canada with initiatives such as the Nav-CARE programme[2]. Developed by Wendy Duggleby and Barbara Pesut in Canada over a decade ago, Nav-CARE was created to meet the needs of people facing declining health. Nav-CARE, which stands for 'Navigation Connecting-Advocating-Resourcing-Engaging', aims to improve the quality of life for individuals and their families by training volunteer navigators and pairing them with people with declining health. Its holistic approach goes beyond healthcare navigation, to connect patients with social resources and their community, promoting socialisation and empowerment. Central to Nav-CARE is its patient- and family-centred methodology, which focuses on the needs of the patient and their household, including family and carers. Nav-CARE helps patients overcome barriers, improve decision-making skills and become active participants in their communities. By improving the quality of life

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[1] European Observatory on Health Systems and Policies (2022). What are patient navigators and how can they improve integration of care? Policy Brief 44 (https://iris.who.int/bitstream/handle/10665/350972/Policy-brief-44-1997-8073-eng.pdf, accessed 10 April)

[2] https://www.nav-care.ca/

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for both patients and their families, Nav-CARE has a significant impact on the lives of those it serves[3].

In recent years, several initiatives, such as the Cancer Moonshot programme[4], have significantly improved cancer patient navigation. However, European countries have yet to catch up. There is a lack of structural support and coherent strategy for cancer patient navigation at EU level, with only scattered local or regional programmes existing, such as the German Onkolotse[5]. Some EU-funded projects have also been initiated, such as Co-CAPTAIN, CANCERLESS[6] and the EU Navigate projects, alongside privately funded initiatives such as My Cancer Navigator. Bridging this gap requires greater collaboration between existing initiatives and stakeholder involvement to develop evidence-based recommendations and advocate for high-level commitment. Recognising this need, EU Navigate organised an online Stakeholder Forum in 2024 to respond to the urgent need for improved cancer patient navigation in Europe, in light of the Parliamentary elections reshaping healthcare priorities for the next five years.

The EU Navigate Stakeholder Forum, 'Bridging the gap: Patient navigation – the path towards reduced cancer inequalities in Europe?', was held on 26 March 2024, and was attended by more than 100 participants. Stakeholders and representatives from other cancer patient navigation initiatives discussed the project's latest developments, gaining insight on the project and cancer patient navigation in general, and informing the development of evidence-based policy recommendations. This report focuses on the high-level messages, consensus and recommendations that emerged from the forum. In light of the 2024 European Parliament elections and the renewal of the College of European Commissioners, the implementation of cancer patient navigation is a promising approach to address the need for comprehensive care and bridge the gaps between essential care services.

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[3] Pesut, B., Duggleby, W., Warner, G., Fassbender, K., Antifeau, E., Hooper, B., Greig, M., & Sullivan, K. (2018). Volunteer navigation partnerships: Piloting a compassionate community approach to early palliative care. BMC Palliative Care, 17(1). https://doi.org/10.1186/s12904-017-0210-3

[4] https://www.whitehouse.gov/cancermoonshot/

[5] https://www.onkolotse.de/

[6] https://cancerless.eu/

The forum included:

- **Three break-out rooms** where participants had the opportunity to select their discussion group based on their interest and profile:
    - **The case for navigation – how it can support cancer patients and caregivers**
    - **The path towards patient-centred care – how can patient navigation integrate with multidisciplinary cancer care?**
    - **Driving policy change – how to implement patient navigation in health systems**

- **A panel discussion bringing together major initiatives in the field of cancer patient navigation** – aimed at discussing key findings between initiatives and informing early discussions on long-term implementation, sustainability and synergies for the project.

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About the EU Navigate project

The EU Navigate project, funded by the Horizon Europe programme, will run from 2022 to 2027 and aims to implement and evaluate a patient-centred navigation intervention for older people with cancer and their caregivers in different healthcare systems across Europe.

Inspired by the successful Nav-CARE initiative in Canada, the EU Navigate programme aims to replicate and adapt a similar patient navigation model for older persons with cancer (over 70 years old) and their family. The programme's focus on palliative care goes beyond end-of-life issues to encompass supportive care throughout the life course, ensuring that people receive the right care at the right time.

The main aim of the research is to implement and evaluate this Nav-CARE-EU navigation intervention through an international pragmatic randomised controlled trial (RCT) using a multi-site approach with a total of 489 participants in six European countries.

The EU Navigate project involves close collaboration with sites of implementation in Ireland, Belgium, the Netherlands, Poland, Italy and Portugal. Recognising the diversity of healthcare systems, cultures and situations in these countries, the project focuses on creating an adaptable model that can effectively meet the unique needs of each country and be implemented in more European countries in the long-term. Initial efforts have focused on recruitment of navigators and patients, with volunteers being used as Navigators in most countries, while Poland is opting for social workers.

The overall objective of the project is to evaluate the intervention and provide insights into its wider applicability and sustainability by examining several aspects. Effectiveness will be assessed after six months of intervention compared to usual care, focusing on global health status/quality of life and levels of social support. These outcomes will be measured for patients as well as for their family and navigator to provide a comprehensive analysis. This project also has a strong focus on the cost-effectiveness of the programme. These evaluations aim to provide strong evidence-based recommendations and increase the chances of the programme being adopted in European countries.

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The project consortium

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Empowering patients – how navigation can change lives

Participants highlighted **the key role of patient navigation in cancer care and the need to tailor initiatives to individual needs and interests**. The critical importance of comprehensive support systems was stressed, particularly in providing key information about cancer diagnosis, treatment options, and psychosocial support.

A common concern expressed by participants was **the challenge of bridging the gap between patients and the healthcare system**. Patients often feel helpless after diagnosis, during treatment and beyond, unsure of what will happen. They face barriers due to poor communication and systemic hurdles. Patient navigators have a crucial role to play in providing information and meeting patients' needs to understand their cancer, the journey ahead and the options available to them.

Furthermore, it became evident that effective navigation strategies must not only address medical concerns but also **encompass social and emotional support, especially for older patients, who encounter unique complexities and challenges**. In particular, the frequent isolation of older people and their need for socialisation has been emphasised, with patient navigation seen as a way to reconnect with the community and improve their quality of life.

Another significant aspect explored was **the imperative of family-centric navigation programmes**. The need to involve family carers in patient navigation initiatives was highlighted. As the primary supporters of the patient, not only can no intervention be implemented without their involvement, but they should also benefit from the support of the intervention. Furthermore, discussions revolved around the need for flexibility and adaptability in navigation approaches, acknowledging that a one-size-fits-all model is insufficient.

Challenges such as reaching isolated patients and building trust between patients and non-medical navigators were also highlighted, underscoring the ongoing efforts needed to refine and enhance patient navigation initiatives.

Patient-centred care – how patient navigation can integrate with multidisciplinary cancer care

Insights on the integration of navigators into multidisciplinary teams and cancer care were shared by participants from different countries, and despite different systems and cultural contexts, there was agreement on **the key role of navigators in bridging existing gaps between social and health services**.

Navigators are seen as essential not only to help patients navigate the healthcare system, but also to **provide logistical and emotional support to patients**. Navigators can address critical needs, such as finding the appropriate transportation, and provide companionship throughout the healthcare journey.

Challenges were identified in integrating navigators into healthcare teams, particularly in countries where the voluntary role of navigators is not perceived as professional. The place of patient navigation was questioned and it was suggested that navigators should be included as part of the patient team, complementing the clinical and social team. However, it emerged from the discussions that all national systems are different and that the place of the navigator must be chosen as the most appropriate according to the structure of the system.

Additionally, participants emphasised **the need for comprehensive training to ensure their emotional resilience and effectiveness in guiding patients through the healthcare system**. Navigators need to have a deep understanding of the healthcare landscape to provide valuable support in the hospital decision-making process by offering clear explanations to patients based on an empathetic relationship. However, it was recognised that **without proper training, navigators risk being limited to providing companionship rather than actively helping patients navigate the healthcare system**.

One of the main challenges discussed was the sustainability of the Navigator model, particularly in relation to the involvement of volunteers. Participants highlighted **the complexity of relying on volunteers who may have other commitments such as other health aspects, family responsibilities or employment**. While training programmes are essential, placing sole responsibility on individual navigators is challenging. A group approach was suggested as a potential solution to improve sustainability and ensure ongoing support for patients. In addition, identifying the target group and assessing their level of commitment emerged as relevant factors in the selection of navigators for sustainability. These varied significantly depending on cultural norms and health system structures.

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Driving policy change – how to implement patient navigation in health systems

Participants discussed the implementation and policy perspectives of both patient navigation and the EU Navigate project, recognising the limited attention this topic has received in Europe so far. They notably acknowledged the momentum to address it in the upcoming European legislative cycle for 2024-2029.

Participants agreed on the long-term health and societal benefits of patient navigation, drawing on the successful implementation examples of the US and Canada. **Patient navigation empowers patients to make informed decisions – with the support of navigators – and reduces the burden of healthcare professionals**, who may experience difficulties in providing appropriate information to patients. Patient navigation provides an opportunity to address gaps and inequalities in health literacy, cultural understanding and language differences, and proves to be particularly instrumental for vulnerable groups.

Patient navigation goes beyond traditional health-centred approaches, as it indeed includes psychological well-being and community engagement components, which is particularly important for vulnerable populations, such as older people, as is the case in the EU Navigate project. These types of programmes could also be useful for other patient groups, particularly adolescents and young adults (AYAs), for whom navigating between the paediatric and adult systems can be challenging.

Despite the perceived benefits, participants also recognised some obstacles and challenges. **Budgetary constraints and the financial burden associated with training and maintaining navigators emerged as significant barriers.** In addition, the diverse range of individuals requiring navigation across different age groups **requires navigation strategies to be adapted to each unique context, adding another layer of complexity to implementation processes**.

Stakeholders experienced in patient navigation programmes or health policy-making debated how **advocacy on this issue could lead to policy changes**. They stressed **the importance of producing evidence-based recommendations**, particularly from a health economic perspective. Cost-effectiveness analyses – which the EU Navigate project will produce – are of particular importance, as they help emphasise the long-term economic benefits of navigation. It is nevertheless equally important to complement **quantitative data with qualitative insights**, showcasing individual patient stories and pathways of change. Strong advocacy strategies, involving all stakeholders from health professionals to policymakers, were also considered essential to promote evidence-based recommendations and secure support for patient navigation initiatives.

Building synergies for enhanced and collaborative navigation programmes

The panel discussion brought together **different patient navigation initiatives with the aim of presenting each one and discussing their key findings and concerns**. The overarching aim was to build synergies and learn from each other's experiences in order to improve programmes.

- Representatives from the **American Society of Clinical Oncology (ASCO)** and the **White House Office of Science and Technology Policy** discussed patient navigation in the US, particularly as facilitated by the Cancer Moonshot Programme. A widespread practice in the US, patient navigation focuses on removing barriers to care and ensuring access to community social services, addressing issues such as housing or transportation.
    - The diversity of navigation services – ranging from limited to extensive, with each service unique in its approach – was highlighted. Despite this variability, there is a minimum standard for quality and organisations as Academy of Oncology Nurse & Patient Navigators (AONN+) has established standards and training for oncology patient navigators. **Additionally, patient navigation was presented as a service rather than an individual effort in the US approach.** Non-profit organisations were also acknowledged for their important role in connecting patients to essential resources, both nationally and locally.
    - **Reimbursement for these services emerged as a critical issue**, as they were not initially covered by programmes such as Medicare or Medicaid. **The Cancer Moonshot, developed under the Biden presidency, played a pivotal role in securing reimbursement for navigation services**, moving away from a reliance on grant funding that posed sustainability challenges for the healthcare system. In particular, a major step forward was the provision of fixed payment codes (Current Procedural Terminology, or CPT codes) for reporting navigation services, with updated guidelines from the American Medical Association. There are now 40 comprehensive cancer centres that have committed to using specific codes for navigation services, as well as seven health insurance companies that cover navigation.

- The two EU-funded projects **CANCERLESS** and **CO-CAPTAIN** were presented during the panel discussion. **CANCERLESS focuses on improving access to primary and secondary cancer prevention services for people experiencing homelessness**, while **CO-CAPTAIN aims to improve access to primary cancer prevention services for people with mental health problems**. Both projects share the common goal of reducing the cancer burden in Europe, by providing access to cancer prevention – especially screening services – to underserved communities. These projects implement patient navigation interventions as an innovative approach, in a context where up to 40% of the cancer burden can be reduced through targeted preventive efforts. Nevertheless, there is **a general lack of knowledge and application of navigation models in preventive services**. Participants discussed the implementation and policy perspectives of both patient navigation and the EU Navigate project, recognising the limited attention this topic has received in Europe so far. They notably acknowledged the momentum to address it in the upcoming European legislative cycle for 2024-2029.
  - A key aspect of the success of both projects is the use of a participatory co-design approach, combining patient empowerment and navigation models to promote access, engagement and health literacy. **This approach involves working closely with the community to co-create and co-design navigation interventions**, ensuring that they are tailored to the specific needs and preferences of the target population.

- The final presentation touched upon the **My Cancer Navigator** initiative, which has been developed by the Anticancer Fund. This patient navigation service **focuses on empowering patients through information navigation** for optimal access to cancer treatment and information. It operates globally for English, French or Dutch speakers and addresses the challenges patients face in understanding and retaining health information after diagnosis. Independent of hospitals, the service works with a team of physicians, scientists and consultant-specialists to provide evidence-based, personalised information and ensure patients understand their rights and the information provided. **They provide free support to patients and healthcare professionals alike**, offering guidance on accessing treatments and informing patients of their options. Through an enquiry website, they conduct literature searches, summarise results and facilitate video calls with patients to address their questions and concerns. The project has been running since 2019 and its sustainability relies on philanthropy, grants and other funding.

Overall, this panel discussion **highlighted the diversity of cancer patient navigation initiatives from around the world**. These initiatives focus on different target groups, but also on different aspects of cancer care (post-diagnosis information, care pathways and even prevention), always with the aim of empowering the individual in the face of the complexity of the health system.

It also emerged that these projects have a lot to contribute and learn from each other. My Cancer Navigator notably appears to be a valuable resource for all the initiatives being set up worldwide, particularly for EU Navigate's volunteers.

The issue of sustainability was also discussed, and in particular the question of continuity of funding for projects such as CANCERLESS, CO-CAPTAIN and even EU Navigate. **Political support for the Cancer Moonshot has been a very important catalyst** in the United States and should be considered a source of inspiration for Europe, especially in light of the upcoming European legislative cycle of 2024-2029. Overall, there is a real desire for collaboration between initiatives. In particular, a call for collaboration between the US and Europe to expand the Cancer Moonshot initiative and promote patient navigation demonstrated the success of this discussion.

Conclusion

The next step for EU Navigate will be to complete the recruitment of volunteers and clients. Once recruitment is complete and the volunteer navigators have been trained, the project will start the pilot phase of the programme. In parallel, it will evaluate the effectiveness and cost-effectiveness of the programme based on the results of the pilot.

Stakeholder engagement is also a core part of the project, alongside programme implementation and evaluation. The evidence gathered during the Stakeholder Forum and presented in this report will be considered during the development of policy recommendations. The project will continue to engage with stakeholders throughout to gather insights and develop comprehensive evidence-based policy recommendations.

EU Navigate will strive to further promote and disseminate the key messages raised during the 26 March 2024 Stakeholder Forum. National and European policymakers will be contacted in an effort to speak a common language. Similar high-level events will be held through to the project's conclusion in 2027.

Acknowledgements

This report summarises the key presentations, contributions and recommendations shared at the first EU Navigate Stakeholder Forum 'Bridging the gap: Patient navigation — the path towards reduced cancer inequalities in Europe?' organised on 26 March 2024 by the European Cancer Organisation together with the project consortium.

We thank all speakers who contributed their perspectives and expertise. We also thank those who provided contributions online during the forum and provided supplementary commentary after the event. Finally, we also convey gratitude to all those who took time to review and comment on this report during its wider review, as part of the EU Navigate project.

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