



A New Framework for Co-Creating Telehealth for Cancer Care with the Patient Community

Bonnie Addario¹ · Violeta Astratiner² · Louise Binder³ · Jan Geissler⁴ · Marcia K. Horn⁵ · Linda U. Krebs⁶ · Bryan Lewis⁷ · Kathy Oliver⁸ · Andrew Spiegel⁹

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Abstract

The increased use of telehealth in cancer care during the coronavirus disease 2019 pandemic has added to our knowledge and experience of the modality with benefits in terms of efficacy, cost, and patient and healthcare professional experience reported. However, telehealth has also been found not to be universally available to all patients with cancer, nor to be appropriate for every healthcare interaction; additionally, not all patients prefer it. Now that coronavirus disease restrictions have essentially ended and an opportunity to re-assess telehealth provision in cancer care presents, we offer a framework that aims to ensure that the needs and preferences of the patient community are included in the development of telehealth provision. Stakeholders in this process include patients, patient advocates, healthcare providers, healthcare services commissioners, managers, and policy makers. The framework outlines how patient advocates can work with other stakeholders as equal partners at all stages of telehealth service development. The patient advocate community has a unique understanding of the patient perspective as well as expertise in healthcare design and delivery. This enables advocates to contribute to shaping telehealth provision, from policy and guideline formulation to patient navigation. Appropriate resources, education and training may be needed for all stakeholders to support the development of an effective telehealth system. Together with other stakeholders, patient advocates can make an important contribution to optimizing appropriate patient-centred telehealth provision in cancer care.

1 Introduction

The use of telehealth in cancer care grew rapidly with the onset of the coronavirus disease 2019 (COVID-19) pandemic and it has become axiomatic that this form of healthcare delivery is here to stay. For people with cancer, telehealth can provide access to care and monitoring without the risks associated with face-to-face meetings and with the convenience of at-home appointments [1, 2]. However, for some patients, telehealth has not proved to be the modality of choice and for others it has hindered, rather than facilitated access to care [1, 3, 4].

The establishment of new patterns of care post-pandemic creates an opportunity to re-assess how telehealth is provided to people with cancer. The authors of this piece, experienced members of the international oncology patient advocacy community and one from a professional nursing background, believe that integrating the patient perspective in telehealth service design and provision are central in

realizing the medium's potential. Accordingly, we propose a framework to guide how the patient advocate community can work in partnership with stakeholders to include the patient perspective in the design, monitoring, and implementation of telehealth systems in order to optimize the experience of cancer care delivered by telehealth for all patients and to have a positive impact on patient outcomes.

2 The Telehealth Context

Although much of the literature on telehealth in cancer care pre-pandemic comprises small-scale studies without standardization of outcome measures, it does provide an indication of the benefits and challenges that the modality can bring for patients [5, 6]. The increased use of telehealth in cancer care during the pandemic led to further studies with a focus on the patient experience [1, 7–11]. The evidence produced combined with a policy focus on the delivery of cancer care during the pandemic [12, 13] and the lived experience of local communities provide a context for the authors' framework recommendations.

Extended author information available on the last page of the article

Key Points for Decision Makers

The positive impacts and unintended negative impacts of telehealth in cancer care need further assessment as new services are commissioned and designed. The meaningful involvement of the patient community is vital to ensure that patient needs and preferences are being met with these services.

The patient experience of telehealth is shaped by many factors including socioeconomic background, age, race, where the patient lives, and personal preference. Taking these factors into account when planning or shaping telehealth provision may help to optimize the modality for all patients.

A framework for the inclusion of the patient in the development, implementation, monitoring, and evaluation of telehealth in cancer care is detailed. Patient advocates have knowledge of the patient community and expertise in healthcare systems and policy formulation and as such are well placed to work with other stakeholders as equal partners in shaping telehealth solutions in cancer care.

3 Telehealth and the Patient Experience

Many patients with cancer perceive telehealth as safe and effective and are happy with the quality of care they receive using a video or telephone [1, 14, 15]. Improvement in pain management, depression and quality of life, engagement in an exercise program, and associated health gains have all been reported by patients [16–20]. However, other patients are concerned about the security of their personal information, delays to imaging or clinical appointments, the accuracy of measurement done at home, or poor communication during a consultation [1, 3, 11, 15, 17]. For some, telehealth offers continuity of contact with their healthcare professional and provides reassurance between consultations through telephone or video access to their oncology nurse [21]. For others, it has a detrimental effect on their bond with their healthcare provider [1, 3, 11, 15, 17, 21].

Access to care can be facilitated by telehealth with patients saving both time and the costs associated with travel [7–9]. Patients with cancer receiving palliative care also reported an enhanced sense of safety and security [4]. Yet, telehealth can, unintentionally, present barriers to some patients. Older people are reported to be more reluctant to use technology to access healthcare [22, 23]. Indeed, internet use is lower in older people, people with lower levels of education, and those from lower income groups [24–26]. Among Medicare patients in the USA in 2018, 26.3% lacked

digital access at home with higher proportions found in those with a low socioeconomic status, aged 85 years or older, and in communities of color [27]. Of 10,620 patients with cancer in one US center, American Indian, Alaska Native, Native Hawaiian, Pacific Islander, and Black/African American patients with cancer, those aged older than 69 years, and those living in rural locations used a video for telehealth visits less than patients of other racial and ethnic groups, those living in an urban setting, and those aged 18–69 years [10].

A lack of technical knowledge can also hinder access for patients and providers alike [28]. The availability of a language translator where required, homelessness, or the lack of space in the home for a confidential conversation are further barriers to participation in a virtual appointment [28]. Reported increased financial vulnerability as a result of the pandemic may make the necessary equipment or services for telehealth more difficult to afford [29]. Reduced-cost internet access was provided to some individuals with a low income in one US state during the pandemic, but this did not include the purchase of devices or technical support [27].

Telehealth access is also governed by policy and regulation. Across the European Union, there is a long-standing commitment to allow citizens to access healthcare, including telehealth, in any European Union country and to be reimbursed by their home country [30]. However, in practice, there are barriers to this, including payment and reimbursement issues and access to information [31]. Across Europe, differences in telehealth provision are evident between countries, with swift development, particularly following the pandemic, in some western European countries but generally slower development in Central Eastern Europe [32–34]. In North America, licensure restrictions have inhibited the provision of care delivered by telehealth across national, state, provincial, or territorial boundaries [35–37]. Emergency policies were introduced in the USA during the COVID-19 pandemic that allowed for patients in one state to be treated by healthcare providers in another state and addressed financial barriers to the provision of telehealth by improving reimbursement and reducing or waiving cost sharing for patients [36]. However, there is uncertainty about the continuation of legislative and regulatory support for telehealth in the longer term [12].

4 A Framework for Patient Community Inclusion in Telehealth Solutions

While it commonly occurs that patient advocates are consulted once a service is in place, their unique expertise in understanding patient perspectives makes them ideal partners and co-creators in the design and development of telehealth-based care [38]. The framework shown in Fig. 1 was developed by the authors in order to detail the integral

role that patient advocates can play in the development, implementation, monitoring, and evaluation of telehealth in cancer care. Patient engagement guidance, as well as the authors' professional experience, were used in the design of the framework [39–41]. The concept of 'active partnership' as set out by Carman et al. in a 2013 framework devised in conjunction with patients provided a starting point. Two further guidance documents from 2019 and 2022 provided detail for healthcare professionals on embedding an active partnership in the development and delivery of healthcare services [40, 41]. The new framework described here follows these models in terms of the commitment to early and ongoing involvement of the patient community as well as engagement at multiple levels of healthcare provision and with a range of stakeholders [39–41]. The stakeholders involved in working together to optimize the telehealth development process include patients, patient advocates, healthcare providers, healthcare commissioners of services, managers, and policy makers. Table 1 details elements that were included or omitted from the guidance referenced.

4.1 Supporting the Individual Patient

The patient advocate can work with other stakeholders to facilitate access and to create a flexible telehealth system that supports the needs and preferences of each patient. The patient advocate community has links with a range of patient populations and can aggregate feedback and experience. It can provide insights into vulnerable populations or migrant communities, which, as the evidence suggests, may face specific issues around access to technology and digital literacy.

Patients may require day-to-day support in navigating a healthcare system that is changing to accommodate virtual care delivery. Advocates can work to assist patients in understanding how telehealth fits with in-person appointments and can offer guidance on whether an in-person or telehealth interaction may be appropriate at each step of the patient pathway. They may support patients in navigating the changing patterns of fees and reimbursements associated with telehealth.

Advocates may also work with patient navigators or advocate for professional or lay navigators to be put in place as a part of the transition to telehealth, particularly for sections of the community for whom access to telehealth is challenging. Patient advocates can collaborate with nurses to support their involvement in the design, implementation, and evaluation of telehealth systems as a key part of establishing systems that are responsive to patient needs. Nurses have been referred to as the 'hub of cancer care,' coordinating care as well as giving medical, health educational, emotional, and social support to patients [42, 43] and, as such, are invaluable in shaping telehealth solutions that work for patients.

Advocacy organizations can facilitate patients in supporting one another, through a phone buddy system, for example [44]. They might also provide resources to support patient participation in telehealth consultations: a checklist so patients can ensure all the necessary health and logistical information is conveyed during a consultation and information on accessing technical support or telehealth instructions written in a clear accessible format.

Patient advocates may also press for the documentation of the telehealth preferences of each patient. A patient in a rural location may prefer an in-person visit to telehealth. A familiar or home environment can feel more reassuring for pediatric patients [45]. Some patients like to see the face of their healthcare providers in person or on-screen and not simply hear a voice [15]. A patient may prefer speaking with either the physician or the nurse.

The patient advocate can emphasize the importance of documenting preferences around privacy during telehealth interactions. This includes preferences around recording telehealth interactions. Advocates may work to support the transparency of information for the patient around any recording of healthcare interactions by either the healthcare professional or the patient as well as advising on access to personal data. Participating in a telephone or video call without being overheard can be difficult to achieve for some patients [3]. Times of day that avoid workplace interactions or busy family times may have implications for scheduling telehealth interactions. Patient advocates can offer guidance on the protocols around the presence of other family members during a call. The presence of a caregiver facilitates a telehealth consultation in some cases [46]. The presence of a spouse may be welcomed because they are able to voice difficult questions, but in an abusive relationship, their presence on or off camera may inhibit open discussion.

4.2 Shaping the Broader Telehealth Environment

A broad range of stakeholders was consulted by the European *EU4Health* programme as part of its aim to strengthen healthcare systems, following the COVID-19 pandemic, including through digital means [13]. The Australian government asked the population for their views on the content of the country's digital health strategy [47]. Guidelines on telehealth in cancer care produced by the American Society of Oncology and the Clinical Oncological Society of Australia have included expert and public consultation in their development [48, 49]. Patient advocates are familiar with healthcare systems and have expertise in contributing to complex healthcare and scientific processes. They can use patient feedback and experience to shape telehealth provision. They may assist in ensuring that a diverse range of patients is represented so that systems or recommendations are appropriate for all patients. Advocates can also call for



Fig. 1 A framework for patient advocate involvement in the development, implementation, monitoring, and evaluation of telehealth in cancer care

Table 1 Elements from patient engagement frameworks included in or omitted from the framework for patient advocate involvement in the development, implementation, monitoring, and evaluation of telehealth in cancer care*Included*

Co-design of services and partnership working [39–41]

Focus on equality of access to healthcare for all patients [40, 41]

Engagement across different areas of care, e.g., organizational design and governance, policy formation [39–41]

Ongoing engagement of patients from early planning through to the evaluation of services [39–41]

Working with a broad range of stakeholders, e.g., community groups, local and national policy makers [39, 41]

Ongoing support and training to enable patient participation [40, 41]

Not included

NHS guidance on working with Healthwatch organizations, country-specific steps have been omitted from this international approach [41]

This framework does not include steps for individual direct care, as defined by Carman et al. [39]

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flexibility in terms of how interactions are delivered so that individual patient needs and preferences are respected at a broad policy level. This should include an option for all healthcare interactions to be in-person if the patient prefers this.

It is likely that further guidelines will be needed to accommodate local geographies and patient populations as well as to detail the approaches of a specific hospital, clinic, or primary care provider [48]. Patient advocates may press for local guideline development and contribute by sharing their knowledge of the patient population. Advocates may have detailed knowledge of the levels of local health literacy and of barriers that a local underserved population may face in accessing telehealth. If more information is required, they are well placed to survey the local patient population. The information that advocates provide can be used to generate guidelines that are responsive to the needs of the local patient population and have the flexibility to be tailored to the needs of the individual patient. Advocates may also commit to reviewing any recommendations as the role of telehealth in oncology develops.

National telehealth strategies and supporting legal frameworks are not in place in all countries despite, or perhaps because of, the rapid implementation of telehealth since 2020 [50]. A lack of widely accepted standards and procedures may undermine trust at all levels and it is important that multiple stakeholders, including patient organizations, are involved in the development, implementation, and monitoring of telehealth strategies and frameworks [50]. Further, patient advocates may work to support appropriate reimbursement mechanisms and equality of access through licensure agreements that allow telehealth to be used across different states, provinces, or countries. In the USA, work is ongoing to make permanent some of the temporary changes

introduced during the pandemic including the removal of geographical restrictions [12, 51, 52].

The potential for expertise to be brought virtually to areas or countries where it is not available in person may be of particular value in complex cases or rare cancers [53, 54]. Patient advocacy is central to the work of the European Reference Networks for rare or low-prevalence cancers (EURACAN for rare adult solid cancers, EuroBloodNET for hematological malignancies, PaedCan for paediatric cancers, and GENTURIS for genetic tumour risk syndromes) that bring together experts from across Europe to discuss patients in a virtual setting, as well as working collaboratively on cancer guidelines and other aspects of rare cancer care [55–57]. Patient advocates can also support telehealth provision in situations where war, civil unrest, or other disasters prevent usual care delivery, such as the current conflict in Ukraine [58].

4.3 Evolution Through Evaluation and Monitoring

The advocate community can make a valuable contribution to the monitoring and evaluation of all aspects of telehealth development and delivery on an ongoing basis by gaining feedback from a diverse range of patients on all aspects of their experience. A mechanism is required by which patient responses may be relayed between an advocate and health-care provider or the body producing the policy or legislation. Based on this feedback, advocates may propose adaptations or amendments so that telehealth provision is patient centered. Indeed, an evaluation may be particularly important given that many services were set up extemporaneously during the pandemic [42]. In this way, advocates can partner with other stakeholders in the evolution of telehealth in cancer care, working to ensure that the needs of all patients

are met, that any changes are made in a timely manner, and that patient outcomes are not compromised.

5 Patient Advocate Involvement in Telehealth: Enabling the Next Steps

Several elements are required to enable the patient advocate community to realize its contribution to telehealth provision. First, patient advocates need to be involved with other stakeholders as equal collaborators at all stages of the process. The advocate community is well placed to establish telehealth systems that are built around the needs, preferences, and lived experience of patients. Consequently, the methodology of designing, implementing, and evaluating a telehealth service needs to facilitate the participation of patient advocates. This entails the provision of adequate resources and timelines that accommodate the contribution of all stakeholders. A 2019 telehealth project in Scotland allowed 6 months for collaboration with patients, clinicians, and other stakeholders at the outset in order to design the service [38].

Second, advocates need to be informed, trained, and resourced to enable them to play their role. Training opportunities on the requisite skills or knowledge base may be administered by healthcare providers, advocacy training organizations, colleges, or other educational or professional organizations. Advocates may also support patient experiences and outcomes by calling for and helping to shape appropriate training for physicians, nurses, social workers, counselors, allied healthcare professionals, administrative staff, and advocates themselves, in skills that are required for an effective telehealth system that is responsive to patient needs. This may include the medical, technical, and financial training required to implement an effective telehealth solution as well as communication and interpersonal skills to aid effective and personal communication during virtual interactions [59, 60].

Funding is needed to support the meaningful involvement of patient advocates as well as for any related training and education. Some guidance is available on financial compensation for patients' and patient advocates' time and expertise in patient-engagement roles [61]. Patient engagement plans setting out how the advocacy community can be involved and the resource and funding implications at every step would be of great value. Finally, in order to make telehealth services inclusive, patient advocate organizations may need to broaden the patient populations with whom they interact in order to fully understand patient preferences and the reasons for a lack of access.

6 Progression in Partnership

Telehealth has the potential to facilitate access to cancer care, including to specialized multidisciplinary care by breaking down the physical boundaries between a patient and healthcare provider and between healthcare providers themselves. The patient advocacy community can work in partnership with other stakeholders to eliminate current barriers to care and inequalities in access at a local, national, and international level. This is of enormous value in healthcare systems that are fragmented because of reasons such as highly regionalized healthcare or a lack of coordination between sectors, providers, funding, and institutions [62]. Advocates are well placed to co-design telehealth systems that have the flexibility to respond to the preferences of individual patients as to how, and indeed if, telephone and video interactions are conducted. By working in partnership with other stakeholders, patient advocates can aim to create sustainable change that makes the delivery of cancer care better for patients. Indeed, the advocacy community may find further options for telehealth use in cancer care, as the modality expands, based on patient feedback or identified need. The framework set out here aims to demonstrate to all stakeholders how enabling patient advocates to contribute their expertise and experience at this crucial point in the development of telehealth could ensure the patient remains at the heart of how telehealth in cancer care is shaped and delivered now and in the future.

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Authors and Affiliations

Bonnie Addario¹  · Violeta Astratinei² · Louise Binder³ · Jan Geissler⁴  · Marcia K. Horn⁵  · Linda U. Krebs⁶  · Bryan Lewis⁷  · Kathy Oliver⁸  · Andrew Spiegel⁹

✉ Marcia K. Horn
marcia@askican.org

Bonnie Addario
baddario@go2foundation.org

Violeta Astratinei
violeta.astratinei@mpneurope.org

Louise Binder
louise.binder49@gmail.com

Jan Geissler
jan@patvocates.net

Linda U. Krebs
linda.krebs@cuanschutzu.edu

Bryan Lewis
bryan.lewis@kidneycan.org

Kathy Oliver
kathy@theibta.org

Andrew Spiegel
andrew@globalcca.org

¹ GO2 Foundation for Lung Cancer, San Carlos, CA, USA

² Melanoma Patient Network Europe, Uppsala, Sweden

³ Save Your Skin Foundation, Penticton, BC, Canada

⁴ Patvocates, Munich, Germany

⁵ ICAN, International Cancer Advocacy Network, Phoenix, AZ, USA

⁶ International Society of Nurses in Cancer Care, Vancouver, BC, Canada

⁷ KidneyCAN, Philadelphia, PA, USA

⁸ International Brain Tumour Alliance, Tadworth, Surrey, UK

⁹ Global Colon Cancer Association, Washington, DC, USA