

# The promise of virtual navigation in cancer care: Insights from patients and health care providers

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## ABSTRACT

*Virtual navigation (VN) in health care is a proactive process by which patients obtain information and support via Internet resources to manage their illness demands. The objective of this analysis was to explore converging and diverging perspectives of key stakeholders: patients with cancer and Health Care Providers (HCPs), about a cancer-related VN tool called the Oncology Interactive Navigator (OIN™). A qualitative secondary analysis was performed combining data sets from two prior studies exploring perspectives of VN among patients (study 1, n=20) and HCPs (study 2, n=13). An inductive approach was used to explore converging and diverging views across groups. Findings explore how patients' and HCPs' views converge and diverge and the processes necessary to ensure optimal uptake of VN innovations in cancer care.*

**Key words:** cancer, oncology, virtual navigation, e-health, patient experience, health care providers' views

## INTRODUCTION

Cancer is a leading cause of significant morbidity and death in North America (CCS, 2014) and around the world (World Health Organization, 2008). The needs of people with cancer are multidimensional and include physical, emotional, psychosocial, financial, and occupational concerns (Harrison, Young, Price, Butow, & Solomon, 2009). Those

newly diagnosed often experience anxiety and distress, as they are confronted with massive amounts of cancer information and complex health care systems and services (Rutten, 2005). At diagnosis, and through ensuing treatment, the provision of timely informational support that is tailored to patients' needs is critical (Arora et al., 2008; Li et al., 2012). Health care providers (HCPs) are often challenged to find solutions to support cancer patients' psychosocial and informational needs within constraints of time and costs (Davis, Schoenbaum, & Audet, 2005; Leykin et al., 2011). Virtual navigation (VN), defined as the proactive process of obtaining information and guidance from evidence-informed Internet resources, is an increasingly available modality to manage personal illness demands, find support, and negotiate the intricacies of the health care system (Canadian Partnership Against Cancer, 2010; Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011). To date, knowledge about relevance, acceptability and usability of VN from the perspective of patients with cancer and oncology HCPs is limited (Carroll et al., 2010; Pedersen & Hack, 2010).

## INTERACTIVE HEALTH COMMUNICATION (IHC)

VN belongs to a group of tailored computer or internet technologies designed to help patients and family members adjust, manage, and cope with serious illness known as IHC interventions (Suggs, 2006). IHC interventions include supportive tools to manage patients' visits and follow-up, connect individuals with their health care team, and provide informational interventions to address patients' specific health needs (Loiselle & Dubois, 2003). Patient acceptability of IHC has risen in recent years, as society has become increasingly reliant on the Internet for their health information. For example, in North America, it is estimated that 87 percent of households now have internet access, and approximately 60 percent of individuals surveyed report looking for health information online (IWS, 2014). It has also been suggested that IHC interventions, as a complement to usual care, can maximize HCPs' ability to provide person-centred care (Cote, 2007; Lustria, Cortese, Noar, & Glueckauf, 2009).

IHC interventions have been received favourably by people with chronic diseases, particularly those with diabetes (Sutcliffe et al., 2011) or engaged in health-related behaviour change (Webb, Joseph, Yardley, & Michie, 2010). Cochrane reviewers identified 24 randomized clinical trials of IHC for adults and children with chronic illness with 3,739 participants (Murray, Burns, SeeTai, Lai, & Nazareth, 2005), finding that IHC produced statistically significant ( $p < 0.05$ ) positive effects on knowledge, social support, and clinical outcomes. IHC has particular relevance for individuals with cancer, given

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the unmet information and supportive care needs identified at diagnosis and throughout the cancer trajectory (Annunziata, Muzzatti, & Bidoli, 2011; Harrison et al., 2009) and the potential downfalls of unguided internet searches (James et al., 2007).

## PATIENT NAVIGATION IN CANCER

Patient navigation is an approach to care that endeavours to assist patients with timely access to appropriate health services and information (Carroll et al., 2010). Individuals facing the myriad of challenges associated with cancer, when combined with an overwhelmingly complex health care system, need to feel guided and supported (Pedersen & Hack, 2010; Wells et al., 2008). Three dominant types of patient navigation have emerged so far: professional, peer, and virtual (Canadian Partnership Against Cancer, 2010). Professional navigators, usually nurses, provide a structured approach to care intended to connect and monitor the needs of individuals, as they move through the cancer trajectory (Fillion et al., 2006). Peer navigation is typically led by community members or volunteers familiar with cancer and knowledgeable about the health care system. Virtual navigation adopts the principles of IHC to provide internet, self-paced information that complements and enhances the patient-professional relationship through educational and supportive care initiatives (Loiselle, 2010). This potential synergy among internet technology, professional, and peer guidance holds great promise in addressing the diverse needs of individuals with cancer.

## BENEFITS OF VIRTUAL NAVIGATION IN CANCER CARE

Due to widespread access of the internet and the proliferation of IHC (Murray et al., 2005), VN has been lauded for its benefits over the more traditional face-to-face means of providing information. VN tools allow for wide accessibility to reach geographically distant individuals, self-paced exposure to health information, and ease in tailoring or updating content (Aalbers, Baars, & Rikkert, 2011; Griffiths, 2006). VN is also valued for its ability to provide timely support in terms of meeting patients' informational, psychosocial, and instrumental needs, as patients are often unaware of how or where to readily access information and services when they need them (Pedersen & Hack, 2010).

VN tools may include informational websites, patient support and networking websites, and evidence-based online interventions (Leykin et al., 2011; Ventura, Ohlen, & Koinberg, 2012). VN tools can be 'simple', with the same content being delivered to all users, or 'complex', with interactive features tailored to individuals' needs (Aalbers et al., 2011).

As with IHC in general, seeking information and support through VN has gained favour worldwide. Several factors are driving the dynamic introduction of VN particularly in the current cancer care context (Walkinshaw, 2011). First, individuals with cancer are increasingly using the internet for cancer information, despite concerns raised about the quality of some of the information provided (James et al., 2007; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). Second, as in the broader health care context, HCPs in cancer care face finite resources, time constraints, growing cancer rates, and complexities of treatment and follow up (Berry et al., 2010; Yancik, 2005). These factors challenge HCPs as they attempt to direct patients to the most suitable cancer information and supportive resources.

## EVIDENCE FOR THE ONCOLOGY INTERACTIVE NAVIGATOR (OIN™)

The OIN™ is an example of a VN tool designed to support individuals newly diagnosed with cancer (Figure 1) (Jack Digital Productions, 2008). The OIN™ is available for 23 different types of cancer, and provides evidence-informed information, high-quality graphics and animations, key information about the patients' own treatment centre, videos of patient experiences, and links to community resources. To date, studies have documented how the OIN™ may contribute positively to the cancer experience. A large quasi-experimental study with an earlier CD-ROM version of the tool (the Oncology Interactive Educational Series [OIES]; N=250) showed enhanced dimensions of health-related quality of life for patients who used the tool in comparison to controls (usual care) (Loiselle, Edgar, Batist, Lu, & Lauzier, 2010). In addition, a mixed methods pre-post study with individuals newly diagnosed with cancer (N=151) demonstrated increased levels of cancer knowledge ( $p=0.003$ ) and cancer competence ( $p=0.035$ ) after an eight-week exposure to the tool (Loiselle, 2010).



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Figure 1.

Prior qualitative findings also point to differing perceptions of the role of VN within the patient experience and with HCPs, which warranted a secondary analysis with the specific purpose to explore patients' and HCPs' converging and diverging perceptions.

## METHOD

This qualitative secondary analysis compares and contrasts data collected from two independent qualitative studies; one with patients (Loiselle et al., 2013) and one with HCP (Haase & Loiselle, 2012). Each study used a qualitative descriptive approach and semi-structured interviews to explore and describe participants' perceptions of the OIN™ (Sandelowski, 2000). In study 1, patients (N=151) were recruited from five large cancer centers in Canada for a pilot study where they had access to the OIN™ for eight weeks. Participants were invited to participate in a subsequent follow-up interview exploring their perceptions of the OIN™. In the second study, HCPs and volunteers were recruited via convenience sampling in a large university-affiliated hospital in Montreal, Canada (one site of the pilot study), and were able to access the tool for 7-10 days prior to being interviewed. Methodological and sample characteristics for both studies are described in Tables 1 and 2. The OIN™ was developed by an independent company in which the researchers hold no financial interests, thus eliminating any conflict of interests. Both studies were approved by the relevant institutional ethics review boards.

Two authors (KRH, CGL) conducted the secondary analysis. Initial analysis of the rich descriptive accounts of each

group's views of the OIN™ for each respective study suggested important differences and similarities by group, so the researchers intentionally compared these data sets more closely. Given the similar designs used in both studies and the rich qualitative data, these data sets were amenable to further interrogation via secondary qualitative analysis (Heaton, 2008). Methodologically, this secondary analysis fits the definition of 'analytic expansion' (one of five types of secondary analysis described by Thorne), where a researcher interrogates an existing data set, to answer new questions (Thorne, 1998).

Data from both studies were analyzed by thematic content analysis (Braun & Clarke, 2008). With the purpose of inductively generating themes, immersion with the pooled data was achieved by reading and re-reading each participant's transcript (Thorne, 1994). The over-arching question driving this inductive approach was: how are patients and HCPs' perceptions and expectations of the OIN™ similar and different? Data were organized by generating codes, categories and subsequently assigning a suitable thematic label, presenting a concise picture of the perceptions of each group (Thorne, 2008). We then engaged in a process of comparing and contrasting views of patients and HCPs to identify themes of convergence and divergence until consensus was reached. The draft themes were shared with the other authors who assisted with refining the themes and articulating the areas of convergence and divergence. The analytic process was complete when all authors agreed with the content of the resulting themes.

**Table 1: Study Details**

	<b>Study 1- Patients (Loiselle et al, 2013)</b>	<b>Study 2- Health Care Providers (Haase &amp; Loiselle, 2012)</b>
Design	Qualitative descriptive	Qualitative descriptive
Original research question	How do newly diagnosed adults with CRC or MEL perceive the OIN™ and its potential role pertaining to their adjustment to cancer when provided with unlimited access for 8 weeks	(a) What are HCPs' perceptions of the OIN™ as a new Internet tool for patients? (b) What are HCPs' perceived benefits and challenges regarding potential implementation or integration of the OIN™ into clinical practice?
Inclusion criteria	Patients newly diagnosed with colorectal cancer and melanoma	Healthcare professionals and volunteers working with those with colorectal cancer *
Sampling	Convenience Participants in quasi-experimental study asked to participate in follow-up interviews	Convenience
Setting	Five Canadian cancer centres	University affiliated hospital in Montreal, Canada
Recruitment	As part of a pilot multi-method multi-site study, participants were approached to take part in follow-up in-depth interviews	Approached via interdisciplinary rounds
Exposure to OIN™	8-week unlimited access	1-week-10 days unlimited access
Interview Topics	<ul style="list-style-type: none"> <li>• General questions about cancer diagnosis and information provided by HCP.</li> <li>• Questions about experience using the OIN™ (e.g., what type of information did you use, how often did you use it, how much and how often did you use the OIN™).</li> </ul>	<ul style="list-style-type: none"> <li>• Elicit overall views on the tool.</li> <li>• Probe benefits and potential challenges in terms of clinical implementation.</li> <li>• Explore role of the OIN™ in ongoing patient education initiatives.</li> </ul>

## RESULTS

### Convergence of patients' and HCPs' perspectives

Patients' and HCPs' views converged on several central themes, including identification of the OIN™ as: (1) easy to access, reliable, and comprehensive (2) knowledge to enable navigation of illness and care, (3) useful for cross-checking specific cancer information, and (4) potentially overwhelming.

### Easy to access, reliable, and comprehensive

Both patients and HCPs stressed the importance of having access to a reliable, comprehensive and readily accessible source of cancer information. As one patient stated: "I didn't need to go anywhere else to look for information once I got on the website [the OIN]". HCPs discussed the benefits of patients having access to reliable information, compared to the pitfalls associated with inaccurate information: "A lot of patients have gone to the Internet sites and come back with information either not accurate, not appropriate, and it's just causing them more anxiety" (Nurse).

### Knowledge to enable navigation of illness and care

Another salient benefit identified by both patients and HCPs was the prospect that the tool could assist patients to feel in control of their cancer, thereby better able to navigate the health care system: "I think it [the OIN™] gives the patient more chance of knowledge... knowledge is power and that can make people feel a sense of control" (Dietician). This sentiment was echoed by patients who felt that the OIN™ was, at times, more effective than exchanges with their health care provider: "The [OIN™] website was more elaborate than what [physicians] can tell me in a fraction of ten ... fifteen minutes." Both groups identified that the customization of the OIN™ to the specific hospital of the patient was appreciated and beneficial. As one patient stated: "It seemed to be like, okay, these are my people, my health care team ... It all of a sudden became more important to me". Thus, both patients and HCP agreed that providing evidence-based information via VN could be beneficial for increasing patients' knowledge about how to best manage their illness according to the specific hospital in which they were receiving care, and that this could be an excellent and accessible platform to do so.

**Table 2: Sample Description**

Patients (Study 1; N=20)			Health Care Providers (Study 2; N=13)		
Age	Gender	Diagnosis	Gender	Occupation	Oncology Certification
42	F	MEL	M	Pharmacist	NO
45	M	MEL	F	Psychologist	NO
51	M	CRC	M	Psychologist	YES
51	F	CRC	F	Nurse	NO
52	M	MEL	F	Nurse	NO
54	F	MEL	F	Nurse	NO
58	F	CRC	F	Nurse	YES
60	F	MEL	M	Dietitian	NO
62	M	CRC	F	Dietitian	NO
63	M	MEL	M	Social worker	YES
64	M	CRC	M	Physician	YES
64	M	CRC	M	Physician	YES
64	M	CRC	M	Physician	YES
66	M	MEL	F	Physician	YES
66	F	CRC			
66	F	CRC			
71	M	CRC			
72	F	MEL			
76	M	MEL			

Age mean (range): 59 (42-76) years  
 Gender: Male N = 12, Female N = 8  
 Cancer Diagnosis: Melanoma N = 9, Colorectal N = 11

Gender: Male N = 6, Female N=7  
 Professions:- Medicine N = 3, Social work N = 1, Pharmacy N = 1,  
 Nursing N = 4, Psychology N = 2, Nutrition N = 2  
 Oncology certification (across professions): N = 6

### Utility to cross-check information

Using VN to verify accuracy of cancer information was described by both groups. Patients described verifying information they viewed on the tool with their HCP and conversely, validating information from their HCP with the OIN™. As one patient stated, “I went to the [OIN™] website to see if there was information about chemotherapy, which of course there is, and just to ... fact check what the doctor told me”. In addition, one HCP noted that the tool might contain information about things she has not mentioned, but are of importance to the patient, thereby allowing the patient to bring the information back to the clinician. She stated, “The positive aspect is it opens up dialogue for them. To ask questions about things that, you know, I haven’t thought about” (Psychologist).

### Potentially overwhelming

Both patients and HCPs agreed that the tool could be perceived as overwhelming due to the large amount of information available (i.e., between 1,500 and 3,600 pages of content depending on the type of cancer). As one patient said, “It’s hard to retain all that [cancer information] at once”. However, there was also an acknowledgement on the part of HCPs that this was at least occurring via an accurate and reliable information source. One psychologist stated this succinctly: “Well, OIN™ or other sites ... they think it’s going to relieve distress, but actually it increases it. So, I don’t think it is particular to the OIN™.”

The vast amount of information was also described in relation to the perceived complexity of navigating the tool itself—identified as a potential limitation. For example, a few HCPs were concerned with the display of information, which they felt might be confusing for patients. Some patients agreed, feeling that they sometimes had to make repeat visits, stating, “You’re trying to search through [the OIN™] for something that’s relevant to me and there’s just so much other stuff ... you do get lost”.

### Divergence of patients and HCP findings

Although both groups found the tool to be clear, useful and supportive, its purpose and acceptability as a primary psychosocial and informational resource was seen through different lenses. Two key themes emerged in terms of diverging perceptions between patients and providers: (1) Perceptions of the tool as a primary or complementary source of information, and (2) Perceptions of the OIN™ as lessening or adding burden. Each category of divergent findings is reviewed in turn.

#### Perception of the tool as primary or complementary source of information.

Patients viewed the tool as a valuable primary resource to meet their personal health information needs, which then could be supported by information from HCPs. Patients wished to have access to the tool early in the cancer trajectory to arm themselves with the information prior to their medical consultations: “It’s easier if we have [the OIN™] information first; we [can] understand a little bit and if we need specific information, [we can] ask the doctor ... what I can suggest [is to] use the [OIN™] website first and after you will be able to go farther with the doctor.”

Patients expressed enthusiasm about having access to a high-quality repository of information, which they could choose to use as they needed, for as little or as long as they liked. As one patient states, “As soon as I had enough [information] ... for my [treatment] decision, I didn’t need more information [and discontinued use of the OIN™].” Another patient described choosing to view only positive information: “Most of the time it’s the negative side [of CRC] you’re thinking [about] ... what I want to read is only the good part.”

In contrast, HCPs reported viewing this tool as a useful source to complement the information and teaching they initially provided to patients. The OIN™ was further seen as a catalyst for building communication and support between HCPs and patients. It was emphasized that the tool was not a replacement for the invaluable teaching of clinicians: “[The OIN is] a useful complement to what we do as a team. I don’t think it can replace the teaching that’s done by the multidisciplinary team, be it the doctor, the resident, nurse, or dietitian” (Pharmacist). Other HCPs felt that the tool could open up dialogue with clinicians, who may provide clearer information: “I think it would be important for the patient to know that there is someone he or she can go to for explanation ... [for] a better understanding of what it is that they’re actually reading” (Nurse). HCPs also viewed the tool as enhancing and strengthening communication with patients: “Eventually, if we have such a thing [as the OIN™] all the time, physicians would comfortably say, ‘Go back to the website and you’ll see the information for the details’” (Physician).

HCPs saw the tool not only as a means to facilitate communication with patients, but with family members, as well. As a social worker stated: “I think the children would welcome the opportunity to go through this type of tool ... when one person is sick, the whole family is sick”. One physician noted that the tool would not be relevant to older adults if not technically savvy, prompting her to suggest it be given directly to family members instead.

#### Perception of OIN™ as lessening or adding burden

Both patients and HCPs recognized the time constraints that face HCPs. However, patients saw the tool as a potential means to ease burden on HCPs, whereas HCPs viewed it as adding burden to patient education. Although the OIN™ is not intended by its developers to be introduced by HCPs during in-depth teaching sessions, it was clear that HCPs perceived a need to spend time with patients introducing the tool. As a result, many HCPs expressed concerns about familiarizing patients with the OIN™: the time it would take, and the possibility of lengthening consultation sessions. One nurse stated, “If I start providing explanations [about the OIN™], it would generate more questions ... I just wish that time was an elastic commodity, so I could really go in-depth, as my patients need it.” Another HCP stated, “I don’t have the time that it would take to sit down ... with the patient [to go through the OIN™]... You know, I would lose an hour” (Pharmacist).

HCPs also noted that when patients do not receive information directly from their health care team, or there isn’t time for patient teaching, the OIN™ could have a negative

effect. One nurse detailed how patients might feel if they are directed to look for information on the tool instead of receiving it directly from HCPs: “I think they find it frustrating. Their anxieties go up, they get frustrated. I think it also has to do with trust”.

Conversely, patients viewed the tool quite differently: as a way to take stress off of their HCP team and meet their personal health information needs without having to go directly to a busy HCP. For example, patients felt it was a positive way to corroborate information and follow up on exchanges initiated with their HCP, who may not have adequate time to answer follow-up questions: “These folks are so extremely busy [clinicians]. I just don’t think they have the time to physically sit down and hold your hand for a long period of time and slowly walk you through the process.”

Patients saw the tool as a way of doing their part to lessen the burden on clinicians and become more informed about their diagnosis, enabling them to take initiative on their own, at their own pace. They also described how the tool assisted them to identify, on an individual level, where they were at, and where they were going: “It gave me context in terms of ... here’s the big picture and here you are in the big picture ... here’s what’s available to you and ... this is what you could go through”.

## DISCUSSION

The findings from this secondary analysis provide insight about the subjective interpretations, expectations, and preferences of VN tools from two key user groups in the context of cancer care. This analysis brings to light new knowledge that had not been previously extracted from the independently conducted studies. Our findings confirm that VN tools are well received for their accessibility, usability, reliability, and high-quality information. Patients and HCPs agreed it was beneficial to provide access to reliable, comprehensive information, that the OIN™ can increase knowledge to enable navigation of illness and care, has utility for cross-checking information, and could be potentially overwhelming.

Differences in opinion appeared to stem from how the tool was perceived as a primary or secondary information resource that invariably influenced the patient-HCP interaction. Patients may have readily accepted the tool as a reliable source of information already vetted by their HCP and, therefore, perceived the website as a valuable self-standing reliable resource of information. Patients perceived the OIN™ as a way to lessen some of the burden of additional teaching and appreciated the immediacy of having some of their informational needs met. Essentially, patients saw the tool as a way to reduce their reliance on HCPs for information.

On the other hand, HCPs perceived the tool as a way to strengthen the patient-HCP relationship, but worried that introducing the OIN™ in clinical practice would create more work in an already hectic practice. HCPs continued to value their role, as the primary source of information and teaching. HCPs did not perceive the OIN™ as a self-standing tool, but as a means of connecting with patients and family members.

At the same time, they forecasted and worried about the challenges that would come with the integration of a virtual navigator into their busy clinical worlds.

The areas of divergence between patient and HCPs resulted in important differences in the interpretation of relevance. For patients, the tool was appraised in terms of how the content could be used to decrease the burden associated with the personal lived experience with cancer. Conversely, HCPs emphasized the impact of the tool on system-based issues such as communication, technological familiarity, potential cost, and challenges in implementation. These findings seem to get to the ethos of the differing orientation and needs of patients and providers. It has been previously documented that patients prefer information from HCPs, but when it is unavailable they seek information elsewhere, most predominantly on the internet (James et al., 2007; Mulcahy, Parry, & Glover, 2010; Shea–Budgell et al., 2014). Thus, it could be advantageous for HCPs and cancer centres to preemptively provide access to reliable VN tools in an effort to mitigate pitfalls associated with patients’ online information seeking efforts (Lee, Hoti, Hughes, & Emmerton, 2014). Also, the findings suggest that HCPs need to understand the views of patients to inform how they introduce a tool such as the OIN™, reinforcing their desire to have it enhance rather than replace the patient-HCP relationship.

HCPs in this study seemed to have mixed opinions about the effects of patients’ own cancer information seeking behaviour, which is corroborated in the broader literature (Helft, Hlubocky, & Daugherty, 2003; Newnham et al., 2005). Despite HCPs’ resistance, patients in this study emphasized the desire to use the tool as a trustworthy guide to health information and supportive care resources.

Whereas many HCPs seem to support the inherent good of information and patient education, HCPs worry about the potential fallout beyond patient satisfaction, such as stress on organizational and workload functions. However, these concerns must come with a reminder about the need for person-centred care, and that patients will seek information on their own accord, including from unreliable sources, if they are not initially provided with trustworthy resources (Ziebland et al., 2004). HCPs’ views stipulate a need to reflect upon constraints in clinical practice and how these might impact patient education attempts. HCPs might be reassured by hearing patients’ beliefs that such a tool might decrease the burden placed on HCPs.

## LIMITATIONS

HCPs in this study were all recruited from the same institution. This does not represent the same diversity in perceptions that are reflected in the patient group, who were recruited from multiple institutions. Also, the HCPs’ perspectives were based on using and reviewing the tool independently and reflecting on its value for patients newly diagnosed with cancer. The OIN™ had not been implemented in their clinic setting. Therefore, their perspectives are based on their assumptions and expectations of how they anticipate the tool to impact on their practice rather than actual experiences with patients.

## CONCLUSION

This study documents similarities and differences in how patients and HCPs appraise a comprehensive VN tool to support those newly diagnosed with cancer. These findings suggest that a transdisciplinary team approach paired with patient-focused technology can offer promise in optimizing the patient and family experience in cancer.

Further research must be undertaken regarding the unique person-level factors (pertaining to patients and HCPs) surrounding uptake and implementation of VN tools. Specifically, these findings underscore the importance of exploring new tools in practice, as a way to preemptively mitigate the barriers of implementation and uptake. Despite the enthusiastic face validity and acceptability of VN, the differences in perspectives between patients and HCPs identified in this study highlight the need to explore and clarify stakeholders' expectations when

introducing innovative resources into clinical practice. Explicit communication of converging and especially diverging perspectives and expectations must be intentionally addressed for optimal VN implementation. Maximizing the potential of innovation can only be achieved through buy-in, cooperation, and consideration of multiple perspectives.

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