



## **Improving Patient Experience with Digital Services in Cancer Care**

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## Executive summary

Patient experience refers to the subjective experience of patients as they proceed through different touchpoints during the continuum of care<sup>1</sup>. The concept has gathered increasing interest in recent years<sup>2</sup>. Patient experience is especially important in cancer care, where treatments can be long, expensive and demanding both physically and psychologically.

This whitepaper discusses how digital services can improve patient experience in cancer care. It is based on existing research on patient experience and cancer care and original research conducted at Kaiku Health. Part of this original research is available in the author's masters' thesis<sup>3</sup>.

Digital services support personalized care in two ways. First, gathering electronic patient-reported outcomes enables efficient provision of personalized care<sup>3</sup>. Second, digital applications can be used to automatically tailor information for the patient's specific case and provide it at the right time.

Continuity of care and communication between patients and clinical staff can be significantly improved with digital services. Complementing existing communication methods with new interactive forums, such as online chat, enables patients to better retain information and foster a close relationship with the staff.<sup>3</sup>

**Digital services are not a silver bullet that can fix a broken patient experience. What is required is empathy toward patients and developing healthcare services holistically and deliberately.**

Digital services contribute to patients' psychosocial well-being in several ways. First, they foster a sense of safety for patients. For example, measuring patient-reported outcomes ensures that the staff has the best possible knowledge on the patient's status and symptoms and can thus provide the best possible treatment. Second, digital services enable cost-efficient screening of the patients' psychosocial well-being, allowing the clinical staff to focus on those needing the most attention.<sup>3</sup> Third, digital therapeutics<sup>4</sup> can be used for providing psychosocial interventions at an affordable price or help patients maintain a healthy lifestyle.

Through digital tools, patients can be more involved in their care process. Asking patients to report their symptoms consistently or supporting them with the self-management of minor symptoms increases the sense of control and commitment.<sup>3</sup>

Digital services are not a silver bullet that can fix a broken patient experience. What is required is empathy toward patients and developing healthcare services holistically and deliberately. The digital environment will be a key part of those services in the future.

## What is patient experience?

Patient experience refers to the subjective experience of patients as they proceed through different touchpoints during the continuum of care. Touchpoints include for example staff, processes, communication and physical and digital environments of the healthcare organization <sup>1</sup>. Patient experience can be seen as a specific case of customer experience, but taking into consideration the specific features of the healthcare context. Patient experience is increasingly considered as one of the three pillars of healthcare quality, along with clinical effectiveness and patient safety <sup>5</sup>. In fact, a good patient experience is associated with better clinical outcomes <sup>5</sup>.

Patient experience starts already before the care <sup>1</sup>, for example when the patient chooses between healthcare providers. The experience continues beyond clinical visits, throughout the whole recovery process <sup>1</sup>. Patient experience is affected by the culture, values and people of the organization <sup>1</sup> but also by the patient's expectations <sup>2</sup>. Patient experience cannot be fully encompassed by survey results or satisfaction ratings – even though these can give indications of the patient's experience, they fail to capture the breadth and depth of the experience <sup>2</sup>. Personalized care and patient-centeredness contribute to a good patient experience <sup>2</sup>.

Creating a positive patient experience requires building empathy with patients, deep knowledge about patients' needs and meticulous design of the healthcare services from the patient's point of view.



## Patient experience in cancer care

Patient experience is especially important in cancer care, because the treatments can be demanding both physically and psychologically. Physical symptoms such as nausea, fatigue or pain affect nearly half of patients<sup>6</sup>. 35% of patients experience elevated levels of psychological distress, such as depression or anxiety<sup>7</sup>. 27% of female and 10% of male cancer patients develop symptoms of post-traumatic stress disorder<sup>8</sup>. Cancer can also affect sexuality<sup>9</sup> and family<sup>10</sup>. Patients have varying expectations about the treatment, adverse effects and the impact cancer has on their lives. These expectations affect their patient experience<sup>2</sup>.

Patients have a number of concerns related to the disease and treatment. However, the clinical staff is often not aware of the patient's concerns because patients don't always openly tell about their concerns and the clinical staff may not ask about them either<sup>11</sup>. Zabora et al.<sup>7</sup> recommend screening cancer patients for their psychosocial wellbeing and argue that if elevated levels of distress are not discovered, it will endanger the outcomes of treatment, weaken the quality of life of patients and increase costs.

Patients utilize different coping strategies to cope with the illness. According to Livneh<sup>12</sup>, engagement-focused strategies such as problem solving, information seeking and positive reinterpretation are more effective and result in better adaptation than disengagement-focused strategies like denial, substance abuse or wishful thinking. Livneh<sup>12</sup> argues that the treatment staff should support effective coping skills in patients.

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## How digital services can improve patient experience in cancer care

### Personalized care

Every cancer patient is unique – physically, psychologically and socially. Thus the treatment should also be tailored to the individual. Patient-reported outcome measures are a prerequisite for personalized treatment, but psychosocial screening and quality of life follow-up are also necessary in order to treat the patient comprehensively. Personalized management of adverse effects supports the quality of life of patients and results in better clinical outcomes <sup>13,14</sup>. Digital services are an invaluable tool for gathering these data: up to 50% of patients' adverse effects go unnoticed by staff when patient-reported outcomes are not gathered systematically <sup>15</sup>.

The patients have different needs for information. Information is helpful to some extent, but too much information might also cause anxiety <sup>3</sup>. Patient data can be used to tailor the information to a particular patient's situation and digital tools make it possible to communicate the information at the right time and at a depth appropriate for the patient. For example, the patient can be provided with information about chemotherapy related adverse effects just before each treatment session.

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## Continuity of care and effective communication

A good relationship between the patient and medical professionals throughout the continuum of care is vital for a positive patient experience<sup>3</sup>. Effective communication helps create a warm relationship with the staff. This requires not only good communication skills but also the right mix of communication mediums<sup>3</sup>. For example, face-to-face communication is crucial for empathy and human contact, but for patients it is difficult to remember details and numbers from conversations. According to Kessels, 40-80% of information given to patients was immediately forgotten<sup>16</sup>. Digital communication services are practical in that the numbers and details are available in one place, when needed.

The healthcare system can be complicated and the treatments too. Digital tools such as treatment diaries, symptom tracking and intelligent support materials can help patients make sense of their treatment progress and to guide the patient through the treatments and recovery.

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## Psychosocial well-being

Digital services can support the patient's sense of safety in various ways. Secure, low-barrier online messaging tools allow patients to message staff when they have questions or doubts, so they can get the issue off their mind immediately – the staff can then respond when they have time. Electronic patient-reported outcome measures also facilitate the sense of safety. Patients know that when the treatment staff has the best possible information on their state and well-being, they can provide the best possible care.<sup>3</sup>

In our experience, asking patients about common adverse effects also helps them to understand that adverse effects are a normal part of cancer treatments. As some of the common adverse effects appear in cycles, visualizing the adverse effects reported by the patient often reduces anxiety. Patients know when to expect which type of symptoms.

In addition to screening for symptoms of the cancer patients, the psychosocial well-being of patients needs to be screened as well<sup>12</sup>. Digital services provide an effortless way of doing this<sup>3</sup>. Additionally, since patients may not talk openly about their concerns to the medical staff<sup>11</sup>, a digital screening survey can elicit concerns or psychological symptoms that would otherwise go unnoticed.

Digital services also offer new, affordable ways to provide psychosocial support. Anonymous, low-barrier peer support can be provided as a digital service. Digital therapeutics has shown promise in treating, for example, depression and pre-diabetes<sup>17,18</sup>. Digital therapeutics refers to the use of software applications to change the behavior of patients with the goal to augment the use of traditional medication or even replace it<sup>4</sup>. Digital therapeutics could be used for low-barrier psychosocial interventions or coping skills training programs for cancer patients as well.

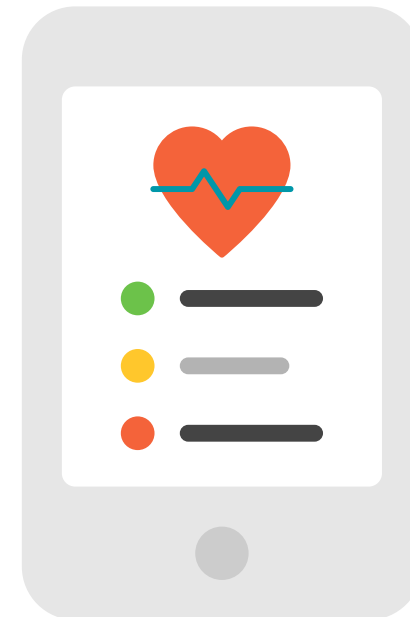
**Digital therapeutics could be used for low-barrier psychosocial interventions or coping skills training programs for cancer patients.**

## Patient participation

Patient participation is an important facet of patient experience<sup>19</sup>. When patients feel they can affect the outcomes of treatment, they cope better<sup>12</sup>. Digital services aid patient participation in various ways. Patients can report patient-reported outcome measures, helping the staff adjust the treatment or provide interventions<sup>3</sup>. Digital services can help with self-management of symptoms and support self-care. Digital patient communications channels empower patients to ask questions when they arise<sup>3</sup>.

Patient participation must be meaningful for the patient and useful for the treatment<sup>3</sup>. For example, if patients report outcome measures through a digital service but the clinical staff does not use – or appear to use – that information in any way, the patients will not experience that as real participation. Patient participation should be voluntary and based on motivating the patient rather than mandatory: not all patients want to actively participate, for example in decision-making about their treatment<sup>20</sup>.

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## Digital services and patient experience in practice

Digital services form only a part of the touchpoints patients encounter during the continuum of care. To create a positive patient experience the processes, touchpoints and culture of the whole healthcare organization need to be patient-centered. The services should be designed deliberately with the patient at the center. A digital service augments, but does not replace, in-person encounters or other means of communication such as telephone <sup>3</sup>. If the staff communicates poorly and the doctors and nurses the patient encounters frequently change, the benefits of digital services are limited.

In our experience, the digital services should be fully integrated in the clinical practices, processes and the whole continuum of care to deliver real value. This guarantees that the same familiar personnel from the clinic are available for the patient through the digital service, and that the patient's actions in the digital environment have real-world effects on their treatment. The service also needs to be marketed to the patients effectively; our experiences have shown that a personal introduction by a familiar nurse works best.

Digital services are first and foremost a tool to change the behavior of people and the organization. Organizations utilize digital services not because they are cool, but because they want to transform the way they work in order to increase efficiency, to achieve better clinical outcomes or to improve the patient experience. Whatever the goal for the organization is, the digital services patients use must be designed in a patient-centered way. The digital application must be accessible for patients of different ages, abilities and preferences on different devices. In the spirit of personalized care it must also be possible for patients to decline using a digital service, if they so wish.

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## Digital services and patient experience in the future

In the future, patient experience and patient-centric thinking will only increase in importance. Instead of patients navigating a complex jungle of a healthcare service, the services will be built around the patient. Instead of treating an illness, services will move toward treating the patient. Comprehensive care will include actively managing adverse effects, improving quality of life and also monitoring the psychosocial well-being of the patient.

Digital services will be a natural part of comprehensive cancer care. These services will be based on real needs, benefiting clinical outcomes, efficiency or patient experience. Patient portals, digital therapeutics and automated follow-up have already shown their value <sup>13,17,18</sup>, but other services will emerge, utilizing different devices, sensors and other technologies. When designed well, these services can create significant improvements in patients' lives.

## About the author

Emil Virkki, M.Sc. (Tech) is a user experience designer at Kaiku Health. In 2017, his master's thesis <sup>3</sup> on patient experience and digital services was accepted at Aalto University, one of the top universities in Finland.

### CORRESPONDENCE

**Emil Virkki**

[emil.virkki@kaikuhealth.com](mailto:emil.virkki@kaikuhealth.com)

+358 50 3398627

[www.kaikuhealth.com](http://www.kaikuhealth.com)



## References

1. Defining Patient Experience - The Beryl Institute - Improving the Patient Experience n.d.
2. Wolf J, Niederhauser V, Marshburn D, LaVela S. Defining Patient Experience. *Patient Experience Journal* 2014;1:7-19.
3. Virkki E. Characteristics of Digital Services Contributing to a Positive Patient Experience in Cancer Care 2017.
4. Farr C. Can “Digital Therapeutics” Be as Good as Drugs? *MIT Technology Review* n.d.
5. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:e001570. doi:10.1136/bmjopen-2012-001570.
6. Reilly CM, Bruner DW, Mitchell SA, Minasian LM, Basch E, Dueck AC, et al. A literature synthesis of symptom prevalence and severity in persons receiving active cancer treatment. *Supportive Care in Cancer* 2013;21:1525-50. doi:10.1007/s00520-012-1688-0.
7. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001;10:19-28. doi:10.1002/1099-1611(200101/02)10:1<19::AID-PON501>3.0.CO;2-6.
8. Mary Rucklos Hampton IF. Women’s Experience of Traumatic Stress in Cancer Treatment. *Health Care for Women International* 2000;21:67-76. doi:10.1080/073993300245410.
9. Schover LR. Sexuality and Fertility after Cancer. *ASH Education Program Book* 2005;2005:523-7. doi:10.1182/asheducation-2005.1.523.
10. Northouse L. The Impact of Cancer on the Family: An Overview. *The International Journal of Psychiatry in Medicine* 1985;14:215-42. doi:10.2190/C8Y5-4Y2W-WV93-QDAT.
11. Maguire P. Improving communication with cancer patients. *European Journal of Cancer* 1999;35:1415-22. doi:10.1016/S0959-8049(99)00178-1.
12. Livneh H. Psychosocial adaptation to cancer: The role of coping strategies. *Journal of Rehabilitation* 2000;66:40-9.
13. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *Journal of Clinical Oncology* 2016;34:557-65. doi:10.1200/JCO.2015.63.0830.
14. Denis F, Lethrosne C, Poureil N, Molinier O, Pointreau Y, Domont J, et al. Overall survival in patients with lung cancer using a web-application-guided follow-up compared to standard modalities: Results of phase III randomized trial. *Journal of Clinical Oncology* 2016;34:LBA9006-6. doi:10.1200/JCO.2016.34.18\_suppl.LBA9006.
15. Pakhomov S, Jacobsen SJ, Chute CG, Roger VL. Agreement between Patient-reported Symptoms and their Documentation in the Medical Record. *The American Journal of Managed Care* 2008;14:530-9.

16. Kessels RPC. Patients' memory for medical information. *Journal of the Royal Society of Medicine* 2003;96:219–22.
17. Pinto MD, Greenblatt AM, Hickman RL, Rice HM, Thomas TL, Clochesy JM. Assessing the Critical Parameters of eSMART-MH: A Promising Avatar-Based Digital Therapeutic Intervention to Reduce Depressive Symptoms. *Perspectives in Psychiatric Care* 2016;52:157–68. doi:10.1111/ppc.12112.
18. Sepah SC, Jiang L, Peters AL. Long-Term Outcomes of a Web-Based Diabetes Prevention Program: 2-Year Results of a Single-Arm Longitudinal Study. *Journal of Medical Internet Research* 2015;17:e92. doi:10.2196/jmir.4052.
19. Staniszewska S, Boardman F, Gunn L, Roberts J, Clay D, Seers K, et al. The Warwick Patient Experiences Framework: Patient-based evidence in clinical guidelines. *International Journal for Quality in Health Care* 2014;26:151–7. doi:10.1093/intqhc/mzu003.
20. Nanton V, Docherty A, Meystre C, Dale J. Finding a pathway: Information and uncertainty along the prostate cancer patient journey. *British Journal of Health Psychology* 2009;14:437–58. doi:10.1348/135910708X342890.