

Designing for Healthcare Experiences from a Multi-stakeholder Perspective

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Recent publications:

Karisalmi, N., Mäenpää, K., Kaipio, J. & Lahdenne, P. (2020) **Measuring patient experiences in a Children's hospital with a medical clowning intervention: a case-control study**, BMC Health Services Research, 20:360. DOI: <https://doi.org/10.1186/s12913-020-05128-2>

Martikainen, S., Kaipio, J. & Lääveri, T. (2020) **End-user participation in health information systems (HIS) development: Physicians' and nurses' experiences**. International Journal of Medical Informatics. 137, 104117. DOI: <https://doi.org/10.1016/j.ijmedinf.2020.104117>

Kaipio, J., Kuusisto, A., Hyppönen, H., Heponiemi, T. & Lääveri, T. (2020) **Physicians' and nurses' experiences on EHR usability: Comparison between the professional groups by employment sector and system brand**. International Journal of Medical Informatics, 134, p.104018. DOI: <https://doi.org/10.1016/j.ijmedinf.2019.104018>

Themes:

- **Patient experience – more than user experience (UX)**
- **Involving patients in studies – things to consider**
- **Clinicians' perspective on health information technology and eHealth services**

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User experience (UX)

User's perceptions and responses that results from the use and/or anticipated use of a system, product or service

Note 1 to entry: Users' perceptions and responses include the users' emotions, beliefs, preferences, perceptions, comfort, behaviour, and accomplishments that occur before, during and after use.

Note 2 to entry: User experience is a consequence of brand image, presentation, functionality, system performance, interactive behaviour, and assistive capabilities of a system, product or service. It also results from the user's internal and physical state resulting from prior experiences, attitudes, skills, abilities and personality, and from the context of use.

ISO 9241-210:2019(E)

Designing for user experience

There is a common misconception that usability refers solely to making products easy to use. However, the concept of usability used in ISO 9241 is broader and, when interpreted from the perspectives of the users' personal goals, can include the kind of perceptual and emotional aspects typically associated with user experience....

Designing for the user's experience involves considering, where appropriate, organizational impacts, user documentation, on-line help, support and maintenance, training, long-term use, and product packaging.

Torpie, K. (2014).
**Customer service vs.
patient care.**

*Patient Experience
Journal, 1(2), 6-8.*

Patients as ‘Customers’

There is no getting past the fact that healthcare is a business and that the economic cost of providing healthcare will always have to be considered in seeking solutions to the healthcare crisis. From a purely business perspective, focusing on the bottom line (and, in private care, on profit) makes perfect sense. That is the goal of any capital venture. But, healthcare is not like other businesses and patients are unlike other kinds of customers.

‘Customers’ are generally well people who enjoy elevated status by virtue of their potential to purchase goods or services. Patients, on the other hand, are (by current definition), not well. Their status is greatly reduced by illness or injury that renders them vulnerable, frightened, often in pain, medicated, exhausted and confused. In spite of these limiting factors, patients sometimes have to make important, often complex, decisions in a short time frame.

The ‘goods’ they are purchasing are a return to health and the ‘services’ they seek often require an unspeakable level of trust in their ‘service provider’. It makes little sense to relate to patients as traditional ‘customers’ in a business model that simply doesn’t fit.

Patient experience???

- Reflects occurrences and events that happen independently and collectively across the **continuum of care**
- Is **more than satisfaction** alone
- Embedded is a focus on **individualized care** and **tailoring of services** to meet patient needs and engage them as partners in their care
- Is strongly tied to **patients' expectations**
- Is integrally tied to the principles and practices of **patient- and family- centered care**

2014

Defining Patient Experience

Jason A. Wolf PhD, CPXP

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Victoria Niederhauser DrPH, RN

Dean & Professor, The University of Tennessee Knoxville, College of Nursing, vniederh@utk.edu

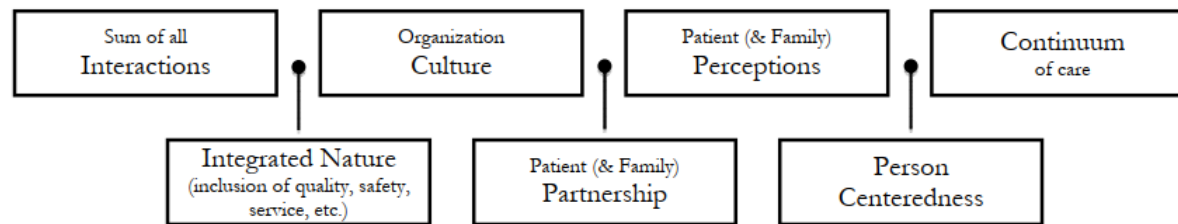
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Sherri L. LaVela PhD, MPH, MBA

Department of Veterans Affairs (VA), Center for Evaluation of Practices and Experiences of Patient-Centered Care; Spinal Cord Injury Quality Enhancement Research Initiative (SCI QUERI), Edward Hines Jr. VA Hospital; Center for Healthcare Studies, Institute for Public Health and Medicine, General Internal Medicine and Geriatrics, Feinberg School of Medicine, Northwestern University, sherri.lavela@va.gov

Figure 2. Definitional themes and recurring constructs for inclusion and consideration in patient experience improvement efforts




Elements	The sum of all interactions	shaped by an organization's culture	that influence patient perceptions	across the continuum of care
Expanded Description	The orchestrated touch-points of people, processes, policies, communications, actions, and environment	The vision, values, people (at all levels and in all parts of the organization) and community engaged and involved with the organization	What is recognized, understood and remembered by patients and support people. Perceptions vary based on individual experiences such as beliefs, values, cultural background, etc.	In all facets of the healthcare system, in all encounters, in all settings from non-clinical proactive experiences to long term or hospice; and across the spectrum of services.
Supporting Themes (for patient experience improvement) and alignment with elements	Integrated Nature reinforces that experience from the patient perspective is singular and aligned, not simply a collection of distinct or disparate efforts. It is encompassing of all encounters whether they include quality, safety or service and these efforts should be coordinated and aligned to support a "one-experience" mindset. [Includes: Beyond survey results, more than satisfaction]		Person-centeredness recognizes that the recipient and deliverer of healthcare experience are at their core human beings. As a component of experience, this reinforces that process or protocol should not trump the broader needs of people engaged (in almost all cases) at any point on the healthcare spectrum. [Includes: Aligned with patient-centered care principles]	
			Patient & Family Partnership (& Engagement) acknowledges that patients, families and members of their support network are active participants in the care experience and must be engaged as participant owners in their encounters. The voices of these individuals are not only significant in situations of care, but also in planning, ongoing operations and change/improvement efforts. [Includes: Focus on expectations, focus on individualized care]	

Note: As mentioned above, the most consistent supporting themes are presented in this graphic, but we suggest other practices or concepts may also be proven to support patient experience improvement and performance.

Patient Experience Journal (PXJ)

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PATIENT EXPERIENCE JOURNAL

Patient Experience Journal (PXJ) is a peer-reviewed, open-access journal published in association with [The Beryl Institute](#). Read in over 200 countries and territories, *PXJ* is committed to disseminating rigorous knowledge and expanding the global conversation on evidence and innovation on patient experience. Grounded in our [core principles](#), *PXJ* engages all perspectives, with a strong commitment to [Patients Included](#). Submissions are accepted on an ongoing basis.

As we all work to address the current crisis and support one another with information that will help in tackling the challenges we face, we have refocused our 2020 special issue to address sustaining a focus on human experience in the face of COVID-19. Submissions for this [special issue](#) must be received by June 1, 2020. All submissions should adhere to the requested [submission types and author guidelines](#). We invite you to join to the conversation and hope this finds you all safe and well at this time.

Current Issue: Volume 7, Issue 1 (2020)

-  PDF The essential nature of experience in a time of crisis and beyond
Jason A. Wolf
-  PDF Paying it forward: A cancer survivor and his wife share their reflections and recommendations as a patient and caregiver
Justin Sandler

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Short discussion & experiences

1. How many of you have been conducting interviews or other field studies with potential users?
2. How many have experiences in involving patients in studies?
3. Have anyone been conducting studies that include personal health related data?

Involving potential users in design and evaluation

Why?

- **Understanding and specifying the context of use including user's need and expectations**
- **Conducting user-centred evaluation to improve the design**
- **Designing for improved user experience**

How?

- **Various methods: Interview, observation, questionnaires, user-based testing...**

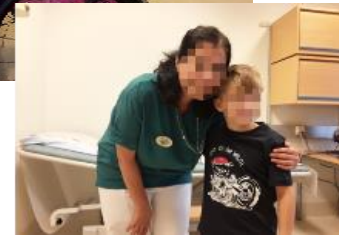
Interviewing patients: Experiences from two research projects

Lapsus:

**PATIENT-CENTRED AND
EXPERIENCE-DRIVEN
DEVELOPMENT OF
HEALTHCARE SERVICES -
Renewing Children's Hospital
for Families**

(2015-2018)

lapsus.cs.aalto.fi/



Interviewing patients: Experiences from two research projects

eHealth in Home Dialysis: Usability and Patient Experience (2020-2021)

www.cleverhealth.fi/en/development-of-home-dialysis/



eCare for Me -project consortium

- eCare for Me - project consortium
- Child with diabetes / IHAN (Sitra)
- Head area imaging analytics
- Remote monitoring of gestational diabetes
- Health Village® – Creating a common development concept
- FactAid - Distal Radius Fractures Artificial

Home dialysis

The number of patients on dialysis is constantly increasing both in Finland and elsewhere in the world. Dialysis therapy is expensive, time consuming and limiting, life-sustaining treatment.

Home dialysis is individually tailored therapy, which gives patients a better quality of life and a better prognosis. Comorbidity is lower as well. In addition, the costs of home dialysis are significantly lower than the costs of dialysis performed in a hospital. However, bringing dialysis treatment to a patient's home is burdensome and complicated for both the patient and the health care unit providing the treatment.

The CleverHealth Network home dialysis project aims to identify patients suitable for home dialysis at an early stage, and to create an application that patients can use already at the pre-dialysis stage and continue to use throughout their dialysis therapy. The application would gather monitoring data via testing equipment and sensors. The application would also facilitate communication between the patient and the staff, and management of equipment orders. The goal is to create an intelligent application to make home dialysis easy and problem-free for both the patient and professionals.

Research is part of the [eCare for Me development project](#).



eCare for Me
CleverHealth Network

Conducting Interviews with Remote Participants

Serena Hillman*, **Azadeh Forghani***, **Carolyn Pang***, **Carman Neustaedter***,
Tejinder K. Judge[#]

*School of Interactive Arts and Technology, Simon Fraser University, Surrey, BC, Canada**;
Google Inc., Mountain View, CA, USA[#]

INTRODUCTION

Interviewing is a common approach for collecting data from people in a lab environment or in the field. It is also commonly used as a data inquiry method in studies of domestic life. In fact, many of the chapters in this book discuss the use of interviews in various settings and contexts. Yet the present-day complexities of study designs and the pragmatics of conducting research mean that it may not always be possible to interview study participants in person.

First, it may not be possible to find local participants for a study, given the demographic that one is interested in. Travel to another location could be cost-prohibitive, especially if potential participants are not located in the same city or within driving distance. This could happen if one wants to interview members of the same family, but they are distributed across different cities or even countries. Second, even if participants are located in the same city, travel time may be onerous, or traffic issues may present significant travel challenges. Third, study participants may be more comfortable without a researcher present at their home, or they may not feel comfortable meeting with a researcher at another location, such as a coffee shop (Weiss 1994). Given alternative options, they may be more apt to participate in a study if they feel safe and comfortable without a stranger (the researcher) physically present. Similarly, sometimes traveling to a participant's home or another meeting place may put the researcher's safety at

Interviewing patients about sensitive health related topics – things to consider

- **Adequately prepare for a interview**
 - Particularly when conducting interviews with remote participants
- **Building rapport and trust is important**
 - But is more difficult when conducting interviews with remote participants
- **Noticing and reacting on participant's emotional struggles can be difficult**
 - Particularly when conducting interviews with remote participants

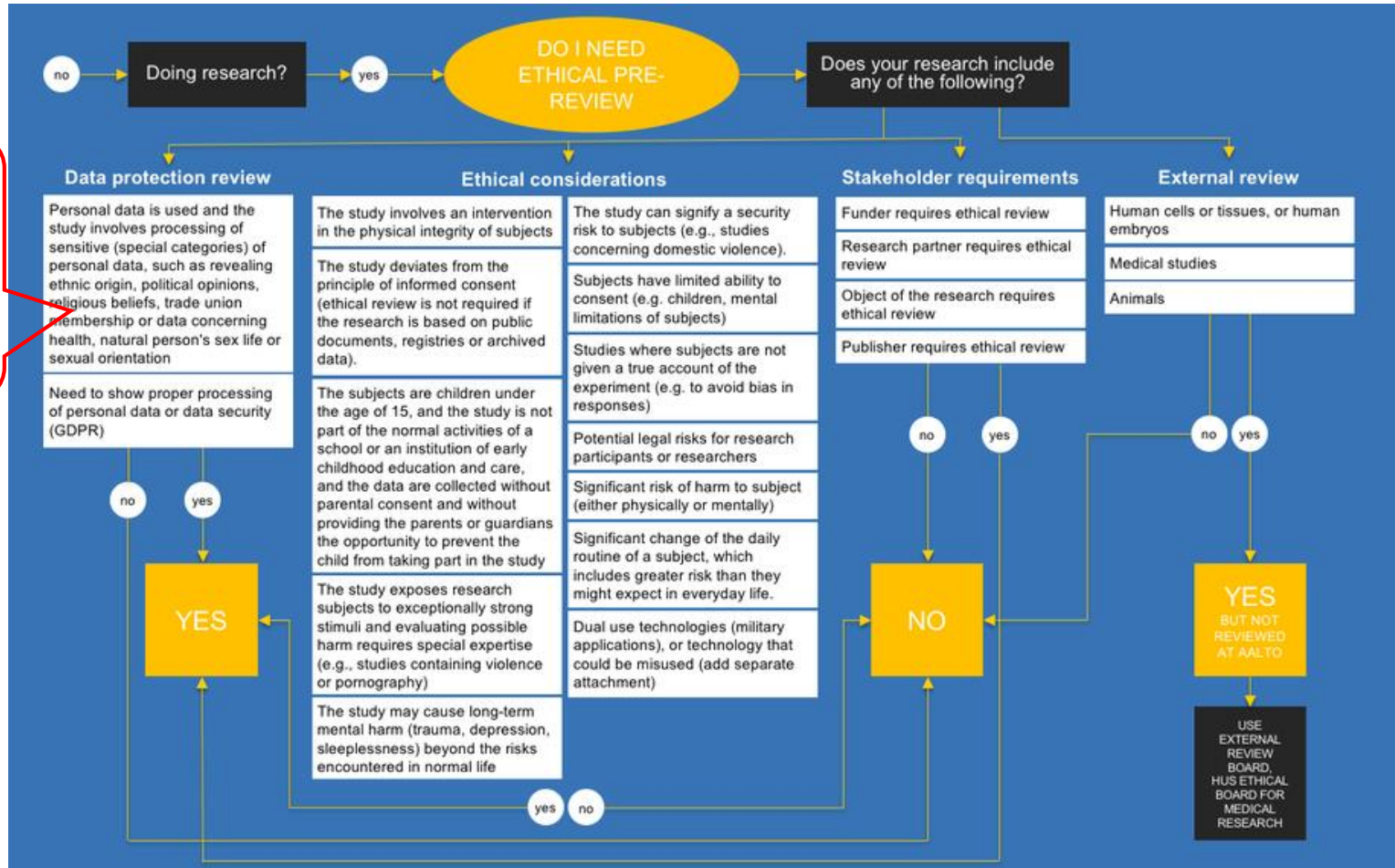
Interviewing patients about sensitive health related topics – things to consider

Interviewing patients remotely

- **Participants may feel less committed to participate to remote sessions**
- **Participants may feel anxious when using videoconferencing arrangements**
- **Preparing for possible distractions**
- **Conducting interviews remotely introduces new concerns**
 - These should be carefully addressed already when planning the study and before requiring the participants

Aalto: Research Ethics Committee

<https://www.aalto.fi/en/services/research-ethics-committee>



Personal data
...concerning health

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Clinicians' perspective on health information technology and eHealth services

- eHealth services have the potential to support patient empowerment, self-care, and management
- Healthcare professionals may perceived such services and patients' more active role as threat to professional autonomy
- Professionals are concerned about patients' willingness and capabilities to use eHealth services
- Health professionals are in a key role in supporting and engaging patients in use of new eHealth services

Ref: Kujala, S., Hörhammer, I., Kaipio, J. and Heponiemi, T., 2018. Health professionals' expectations of a national patient portal for self-management. International journal of medical informatics, 117, pp.82-87. DOI: <https://doi.org/10.1016/j.ijmedinf.2018.06.005>

Clinicians' perspective on health information technology and eHealth services

- **Clinicians have negative experiences with their currently used health information systems**
- **Clinicians use tens of information systems, lack of integration between the systems is a challenges and causes additional work**
- **Usability problems of health information systems (HIS) hamper the efficient use and clinical work**

Kaipio, J., Kuusisto, A., Hyppönen, H., Heponiemi, T. and Lääveri, T., 2020. Physicians' and nurses' experiences on EHR usability: Comparison between the professional groups by employment sector and system brand. *International Journal of Medical Informatics*, 134, p.104018. DOI: <https://doi.org/10.1016/j.ijmedinf.2019.104018>

Viitanen, J., Hyppönen, H., Lääveri, T., Vänskä, J., Reponen, J., Winblad I. 2011. National questionnaire study on clinical ICT systems proofs: physicians suffer from poor usability. *International Journal of Medical Informatics*, 80 (10) (2011), pp. 708-725

Conclusions

- **User experience (UX), patient experience (PX), customer experience (CX)...**
 - What are the special characteristics of the potential users and how to take those into account in design?
- **Conducting user experience research with patients**
 - Studies require careful planning
 - Challenges related to remote interviews
 - How to discuss about personal and sensitive health related topics?
- **When designing new eHealth solutions, it is important to take into account clinician's viewpoint as well**

Readings

- International Organization for Standardization (2019). ISO 9241 standard -- Part 210: Human-centred design for interactive systems, Ergonomics of human-system interaction.
- Wolf, J. A., Niederhauser, V., Marshburn, D., LaVela, S. L. (2014) Defining Patient Experience. Patient Experience Journal, 1(1), Article 3. <https://pxjournal.org/journal/vol1/iss1/3/>
- Torpie, K. (2014). “Customer service vs. patient care” Patient Experience Journal, 1(2), 6-8. <https://pxjournal.org/journal/vol1/iss2/3/>
- Hillman, S., Forghani, A., Pang, C., Neustaeder, C. and Judge, T.K., 2014. Conducting interviews with remote participants. Studying and Designing Technology for Domestic Life, pp.11-53. (book available online: <https://books.google.fi/books?id=hWdzAwAAQBAJ&printsec=frontcover#v=onepage&q&f=false>)
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Thank you!

Questions and comments?

This Thursday:

Data-Driven Approaches to Healthcare Research during the COVID-19 Pandemic

Miika Leminen

*Head of Analytics and AI Development
at Helsinki University Hospital (HUS)*



Aalto University
School of Science



Participatory Workshop on Friday June 26, 10am - 12pm

*Rethinking Human-Centred Research and Design for
Potential Projects in Crisis*

Prof. Nitin Sawhney

Department of Computer Science, Aalto University

Dr. Salu Ylirisku

Design Teacher (Senior University Lecturer) at Aalto University



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