D9.9 Ethical evaluation of patient autonomy

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Executive Summary

This report synthesises the experiences of 14 patients to evaluate how passive RF-sensing and monitoring impact personal autonomy. The analysis reveals that autonomy is not a singular concept but is experienced in four distinct modes:

1. **Scaffolded Autonomy:** Technology extends the patient's ability to live independently.
2. **Autonomy as Refusal:** Agency is exercised by rejecting or limiting the use of technology.
3. **Passive Autonomy:** Autonomy is preserved through indifference or 'forgetting'.
4. **Autonomy Eclipsed by Illness:** Severe physical suffering renders the technology irrelevant to the patient's sense of agency.

The findings suggest that for many patients, the RF system does not threaten autonomy but rather changes its nature from "independence" (doing things alone) to "supported certainty" (knowing help is available).

The report is divided into three main parts that represent the relevant phenomenological aspects of a patient's experience of autonomy in the context of home palliative care, where the RF-sensing device has been introduced.

The first part focuses on the experience of autonomy in relation to the device itself and related aspects such as aesthetics, invasiveness, privacy, sense of security and others. This section covers the first three modes of autonomy indicated above.

The second part addresses autonomy from the point of view of the patient's experience of themselves as an embodied being and relevant aspects that are related to that (sense of health, freedom of movement, experience of surroundings). This section covers the final mode of autonomy indicated above.

Finally, the report will provide ethical guidelines for the future development of the HOLDEN RF-sensing device based on the analysis of this report.

Table of Contents

Abbreviations

Abbreviation	Description
AI	Artificial intelligence
HCP	Healthcare practitioners
HOLDEN	Ethical design of holography in dense wireless networks
RF	Radio Frequency
WP	Work Package

1. Introduction

The purpose of this report is to assess the ethical aspects of the RF-sensing technology that is developed in the HOLDEN project. Specifically, the report focuses on autonomy. It addresses the following question: does the RF-sensing device improve patient autonomy, and to what extent? In order to address the question, the IRLaB research team has completed a case study in palliative care. In this study, we have set up the RF-sensing device in the homes of 14 patients in palliative care who have volunteered to share their user experiences after a test period of 10-14 days (detailed information about the prototype system and the data collected can be found in deliverables 9.5 and 9.6). We have focused on patient experience of autonomy and related experiences living with the radars and having their movements tracked.

Autonomy is one of the key principles in bioethics, understood in the sense of healthcare ethics [1]. However, traditionally, autonomy is safeguarded in healthcare as a principle, that is, as a guideline for healthcare providers to be implemented in their care tasks. Often overlooked is whether patients actually *feel* or *experience* autonomy when they go into healthcare systems. In our case study, we have focused on the experience of autonomy understood in this sense. The advantage of this approach is that it gives a better understanding of whether and to what extent aspects of healthcare actually improve patient autonomy. In our case, we have focused on the palliative care patient home setting, and we have placed the RF-sensing device in that setting. Important to note is that the device has not been used for medical purposes itself. It only measured the movements of the patients, their family members and visitors (we have isolated the movements of the patients).

Following the test runs of the RF-sensing device, we have conducted so-called phenomenological interviews with the patients. These interviews are open-ended, specifically designed to get an understanding of the patient's experiences. The interviews (see annexe on deliverable 9.8) have been recorded, translated from Czech to English, and transcribed. Finally, they have been subject to a semi-structured sociological analysis (please see deliverable 9.8). The current report is based on this analysis and provides a phenomenological interpretation of it.

2. Experience with the device

2.1. Aesthetics

By *aesthetics,* we mean the way the device looks as it was set up in the case study, as well as *how* it was set (as connected to several cables and a mini-PC that was used to collect the data. We have found that patients' experience of the device itself, how it looks and is set up, potentially restricts their autonomy. In the case of patient 01, the radar was installed in the patient's home unexposed, which was a problem for the patient's comfort. The radar created a sense of unsafe exposure to frequencies, and the radar's light was bothering them. In the cases of patients 02 to 14, the radar was covered by a plastic casing. However, patient 04 also reported being bothered by the radars blinking lights.

"[I]t lights up at night. That sometimes at night it goes crazy, it lights up and feels like we can't sleep. Sometimes. It's not constant, but sometimes you look, and it is on, and it is very unpleasant." - Patient 04.

- **Interference with surroundings:** The way the device looks and where it is placed in the room has a potential impact on how the patient experiences the surroundings they are familiar with.

"Well, since it's actually a pilot, I was just noticing the diodes. That, actually, as you weren't used to it, the way the diodes were glowing around here, I mean, in the evening]...] - Patient 01.

Patient 03 reinforced their autonomy based on the way the device appeared to them. He jokingly told visitors that the device was used by the government or intelligence services to monitor private and secure information. This case is illustrative of the phenomenon of scaffolded autonomy, where the technology reinforces patient agency. They reported in the interview that he was suspicious of the device and that only his trust in their doctor (Adam Houska) had convinced them to participate: "Yeah, they [the visitors] asked me that, they scared me that it was connected to the intelligence services" (patient 03). At same time, patient 03 reported that the device was almost invisible. To them, it felt as if it were not there at all. Patient 05 mentioned that it would be easier to move around when the device were "smaller and more stable." Patient 14 mentioned that if the device were to be installed for a longer period, it would be good if it looked like a daily home object.

"that if it were long-term, say two or three years that somebody would need it, that it might have a better effect on someone if it were designed like a vase, a painting, anything, so that it wouldn't remind people so much of a device that is watching them." - Patient 14.

It is significant that the technology is experienced as allowing a maximum amount of autonomy when it looks like an object that is integrated in the home environment, that is, as if it was part of the furniture or decorations, as well as an object that does not intrude in private spaces.

In sum, with the exception of patient 03, the majority of the patients gained autonomy through the aesthetics of the technology. The experience of the device being discreet and "in the background", was helpful fo the patients to be able to adapt to its presence in their homes. This happened on three different levels. In the majority of the cases, patients gained *passive autonomy*, experiencing more independence when the monitoring device was almost unnoticeable in the background, "as if it was not there." In other

cases, patients were disturbed by the technology but maintained their autonomy by refusing the technology, either by ignoring it or (as in one case) switching it off. As mentioned, patient 03 used the looks of the technology – its obvious but somewhat unidentifiable way of monitoring – the gain scaffolded autonomy by integrating the RF-sensing device into a narrative to entertain friends and relatives.

2.2. Enhancement

For a subset of patients, the RF technology was not seen as a restriction on their freedom, but as a tool that actively supported their independence. These patients viewed the monitoring as a "safety net" that allowed them to remain at home rather than facing hospitalisation.

- **The "Extension" of Care**: Patient 01 serves as the archetype here. He did not feel monitored in a restrictive sense; instead, he felt his care was "multiplied". For them, autonomy was extended by the machine, which offered continuous vigilance that human caregivers could not provide. Patient 04 reported that they could see potential in the device to become a signalling or alerting device that has the potential to improve home care, for example by alerting neigbors or family when the patient would fall.

  "It multiplies the care... The machine monitors 24 hours a day." — Patient 01

Patient 01 generally expressed enthusiasm for technology in the interview and in the interactions with the healthcare providers. Patient 14 reports that they do not like technology in general, especially monitoring technology such as video cameras. However, when used for medical purposes they agreed to support technology and expresses enthusiasm about the potential future medical use of RF-sensing.

- **Autonomy as Certainty**: Patient 14 reframed autonomy not as "independence" in the traditional sense, but as relief from the anxiety of the unknown. For them, the device provided the certainty that someone would respond to a crisis, which was more valuable than abstract privacy.

  "Not independence, but rather the certainty that someone will arrive on time." — Patient 14

In the majority of the cases autonomy is enhanced either *passively* by forgetting about or adapting to the presence of the RF-sensing device in the home environment, or, in creating *a specific relation* with the technology. The case study shows that this relation can take various forms and is not pre-given but dependent on the patient's first-person experience of the device. For example, some patients have created a trust relation with the monitoring device, whether or not mediated by institutions or other people (care institutions or Dr. Houska). Other cases showed an independence relation, in which a patient still felt "in control" by ignoring or accepting the presence of the device. In other cases still, a caring relation is experienced, to the extent that patients feel that the RF-sensing device may contribute to people's health in the future and to their independence in the sense of being able to spend more time at home instead of in the hospital.

2.3. Refusal and boundary setting

For some patients, autonomy was demonstrated not by accepting the technology, but by asserting control *over* it—deciding where it goes, when it stays, or when it leaves.

- **The Right to Withdraw:** Patient 06 illustrates the strongest exercise of autonomy through refusal. Their experience of bodily distress (twitching, nausea) led them to reject the technology despite their

initial willingness. Autonomy was reclaimed by asserting that their bodily sensations mattered more than the scientific protocol.

"I'm not going to push it... It just doesn't make sense." — Patient 06

- **Spatial Sovereignty:** Patient 13 and Patient 02 exercised autonomy by enforcing strict spatial boundaries. While they accepted the device in "public" areas of the home (living room), they drew a hard line at the bedroom, preserving a zone of intimacy.

  "Bedroom is a private place. Living room is for guests and friends." — Patient 13

- **Political Resistance:** Patient 03 framed their autonomy as a "soloist" standing against institutional pressure. They maintained their agency by viewing the project through a lens of suspicion, albeit potentially meant jokingly (fearing intelligence services) and asserting that he would refuse if they did not personally trust the doctor.

The test cases demonstrate that the device – although objectively harmless in its design – has nonetheless the potential to be experienced as a threat or at least something to be wary about. The nature of the threat differs, however, whether it is a potential health threat (harm to the body), a security threat (monitoring sensitive information), or a privacy threat (invading into private spaces). It is remarkable that it shows from the interviews that several patients were still unfamiliar with how the device works exactly, even though they have been explained in detail before the testing period commenced. We have identified different factors that may help to mitigate the experience of the device as a threat. These include environmental factors, such as a comparison with hospital monitoring devices that are more invasive (tubes, wearables, monitors, sonars, etc.). Mitigating factors also include social factors such as being able to establish a good relation with the doctor and healthcare providers more generally and having a detailed explanation of the workings of the device. Other mitigating factors are technical, as a good understanding of the workings of the technology, seeing the data and results and receiving positive feedback proofed to be all relevant for the patients.

2.4. Passive autonomy and 'non-interference'

A significant number of patients preserved their autonomy through a strategy of **minimisation** or **indifference**. They did not engage with the device; they simply rendered it "phenomenologically inert." As long as the device did not disrupt their routine, their sense of autonomy remained intact.

- **Autonomy as Non-Event:** Patients 08, 09, and 12 largely ignored the device. Their autonomy was neither threatened nor enhanced; it was simply unaffected because they refused to grant the object any significance.

  "I absolutely didn't mind... I forgot about it immediately." — Patient 12

- **Relational Commitment:** Patient 02 showed a form of "committed autonomy." Once they agreed to the project, they felt they "must accept the conditions". Their autonomy was expressed through loyalty to their word and trust in the medical staff, rather than ongoing negotiation. Patient 01 went even further stating explicitly that they are "very comfortable with technology" and making sure that the sensing signals were optimally received by the device by being careful not to put objects in front of the radars or to obscure them.

Throughout the testing period patients have exercised their autonomy by "protecting their home environment. They have done this in different ways, in a large part *passively*, by ignoring the technology or by refusing it to interfere with their daily routine. In some case, patients express

autonomy by setting bounderies, such as allowing the technology only in certain "more public" spaces and not in more private ones (e.g. toilet or bedroom). Another way of setting boundaries that we observed was that patients expressed the need to set certain specific conditions for allowing the technology in their homes: only because it does not record images, if they can somehow "see" the data, only because it will help science and future healthcare, because I trust Dr. Houska.

3. Embodiment

As the test cases have shown, patient autonomy is essentially an embodied autonomy in two ways. First of all, in the specific case of palliative care, patient autonomy is highly dependent on the experience of pain, as the patient are terminally ill and several of them experience high levels of pain. Secondly, patient autonomy is essentially intersubjective. By this we mean that patient autonomy is mediated by interaction with other embodied persons (not just with the non-embodied technical sensing device). These interactions include physical care, conversations, body movement and others.

3.1.Experience of health

For the most critical patients, the debate about technological autonomy was rendered moot by the overwhelming reality of physical suffering. Pain and illness stripped away their agency far more effectively than any surveillance device could.

- **The Dominance of Pain:** Patient 05 and Patient 10 were so saturated by pain and fatigue that they had no energy to care about being watched. The technology became invisible not because it was seamless, but because their world had shrunk to the immediate management of their suffering.
  "When I'm in pain, I don't enjoy even talking with people... I don't think about it." — Patient 05

- **Pragmatic Survival:** Patient 12 explicitly stated that when life is at stake, concerns about dignity or privacy "go aside". In this mode, autonomy is subordinated to the biological imperative of survival.
  "When something serious happens, everything else goes aside." — Patient 12

3.2. Intersubjectivity

During the testing period of the RF-sensing technology there were several interactions between the patient and other parties that were impacted by the technology or the result of the placement of the technology in the patient's home:

- **Interactions with the technician:** Interactions between the patient and the technician, I.e. the computer engineer that installed the technology in the homes, was required. More specifically the technician asked the patients to briefly move around in front of the radar so that the sensing device could be properly set up. There are no signs or reports of any discomfort by patients.
- **Interactions with healthcare providers and interviewer:** Before the testing phase, patients were informed by interviewers about the working of the device prior to the installation of the technology in their homes and a healthcare provider (Dr. Adam Houska recruited the patients on voluntary basis, although small financial compensations where provided (5000CZK). Normal interactions between healthcare providers and patients were maintained during the testing period. The healthcare providers do regular check-ups of the patient in order to ensure proper medical care. Patient 14 states that they believe the technology would improve the trust relation between patient and healthcare provider in that it would provide more accurate data for correct diagnosis.

"It should be able to tell if the patient is a hypochondriac or not [...] And at the same time, the patient wouldn't misuse by calling a doctor because of the flu." - Patien 14.

- **Interactions with family and visitors:** Interactions with family members and visitors were impacted by the presence of the device in several cases. Patient 03 reported that their visitors asked about the purpose of the technology and whether it related to any "secret services" (see 2.1). Patient 04 reported that their visitors encouraged them "to walk more." Patient 05 mentioned that the presence of the device made them joke with their kids.

"The kids just laughed at me, saying that the aliens would be watching me and I wouldn't know they were watching me. Just signs, like the Chinese and stuff, you know." - Patient 05.

4.Key insights for HOLDEN

The "Active vs. Passive" Tension

A recurring friction in the interviews is the difference between **passive sensing** (being watched) and **active control** (calling for help).

- Patient 07 and Patient 11 expressed a clear preference for active technologies (buttons, wearables) over passive radar.
- **Implication:** Autonomy is often felt most strongly when the user can *initiate* an action (pressing a button) rather than merely being the subject of data collection.

"I would rather have something I press." — Patient 07

Trust as the Proxy for Autonomy

For patients who did not understand the technology (e.g., Patient 02, Patient 10, Patient 11), autonomy was outsourced to **trust**. They felt safe not because they controlled the data, but because they trusted the specific humans (doctors/researchers) behind the system.

- **Implication:** If trust in the medical provider is broken, the sense of autonomous consent collapses immediately.

Feeling at home in one's body

Patients generally felt most at ease and autonomous with the technology when they were able to integrate it physically and mentally in their home environment, so that it does not disrupt their daily lifes. Several factors are at play here. Significant factors include the aesthetics of the device, it being user friendly and not disturbing (noise and flashing lights). Another important factor that influences patient feeling comfortable with the technology in their homes is they experience being in control, that is know what it is sensing and can turn it off at all times.

- **Implication:** a potential significant factor that impacts the ethical design of the technology depends on the aesthetical design and its user friendliness.

Toward progressive science and healthcare

It is evident and was also apparent from the case study that the success of potential use of the RF-sensing device in the context of palliative care will greatly depend on it being tailored for good healthcare. Although the tests have been conducted with a prototype that did not have any actual medical functions or purposes, several patients have expressed that their willingness to participate in the study was conditioned by the fact that it will contribute to scientific progress and improved future healthcare.

- **Implication:** medical development of the device will determine its ethical use in healthcare.

5. Recommendations

Based on this analysis, the following actions are recommended to respect and support patient autonomy:

1. **Implement "Spatial Consent":** Move away from a binary "yes/no" for the whole house, and make sure that patients can decide where in the house they want the radars to be installed. For example, allowing patients to explicitly accept the device in the living room while rejecting it in the bedroom (as per Patient 13 and Patient 02).
2. **Clarify the "Refusal" Protocol:** Ensure patients know that withdrawing (like Patient 06) is a valid and respected exercise of their autonomy, not a failure of the experiment.
3. **Bridge the Gap with Active Tools:** Consider pairing the passive RF radar with an active "SOS" button or feature. This addresses the desire for control expressed by Patient 07 and Patient 05.
4. **Acknowledge the "Illness Eclipse":** Be aware that patients in severe pain (P05, P10) may accept the device simply because they are too exhausted to object. This requires a higher ethical standard of care from the research team to ensure their passive consent is not exploitation. This standard will remain relevant in the future, when the technology will be further developed for actual use, beyond the research phase.
5. **Design an “appealing” tool:** Several patients (.g. 01 and 04) have expressed the importance of the aesthetics of the device for its use. It should look non-invasive and be easy to integrate into the home environment.

6.Conclusion

This report provides a phenomenological interpretation of how patient autonomy is impacted by RF-sensing technology based on the test case in palliative care conducted by IRLaB (WP9). From the test case, we conclude that multiple factors may impact patient autonomy, meaning that there is no unidirectional way in which RF-sensing impacts user autonomy (either decreases or increases). Factors that have impact on patient autonomy where RF-sensing is applied include (1.) aspects of its design and functionality, (2.) environmental factors such as the way in which the technology is installed, location and other factors, (3.) intersubjective relations between patients, healthcare providers, family members and other parties, and (4.) the experience of the patient's own body. Based on our findings we recommend that future development of the HOLDEN technology takes into account these impact factors, in particular when in view of its potential use in healthcare as a medical device.

References

[1] Beauchamp, T. L., & Childress, J. F. (2009). Principles of biomedical ethics (7th ed.). Oxford University Press.