
# D9.8 Ethical assessment of data and interviews

Atefeh Bagherianzianarat, Ester Fischerova, Barbora Steinlauf, Jose Luis Guerrero Quiñones, Geoffrey Dierckxsens, Adam Houska

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## Authors in alphabetical order


| Full Name | Organisation | E-mail |
|---|---|---|
| Atefeh Bagherianziarat | IRLaB | Bagherianziarat@flu.cas.cz |
| Geoffrey Dierckxsens | IRLaB | dierckxsens@flu.cas.cz |
| Ester Fischerova | IRLaB | fischerova@flu.cas.cz |
| Jose Luis Guerrero Quiñones | IRLaB | Guerrero.quinones@flu.cas.cz |
| Adam Houska | University Hospital Královské Vinohrady | adam.houska@fnkv.cz |
| Barbora Steinlauf | IRLaB | Steinlauf@flu.cas.cz |


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# Executive Summary

This report is based on **14 in-depth qualitative interviews** (see D9.3) conducted with patients participating in the Holden Care project, all of whom experienced the installation and use of in-home RF-based monitoring technology. The interviews explored patients' everyday experiences, perceptions, reflections, and concerns related to the presence of RF monitoring in their homes.

The primary analytical aim of this report is to:

- identify and synthesise **cross-case themes and sub-themes** emerging from all 14 interviews,
- demonstrate **how these themes were constructed** from participants' lived accounts,
- and interpret them through a **multi-disciplinary lens**, integrating phenomenology, bioethics, and sociology.

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# 1. Analytical strategy: from within-case meaning to cross-case structure

## 1.1. Phenomenological orientation

The primary analytical entry point was **phenomenological**, focusing on:

- how patients *experience* RF monitoring in their everyday lives,
- how the technology becomes meaningful (or meaningless) over time,
- and how bodily presence, home space, illness, care, and monitoring are lived rather than abstractly evaluated.

Analysis attended closely to:

- patients' own language,
- concrete situations (e.g. installation, daily routines, intimate moments, illness progression),
- shifts in attention, emotion, and meaning over time.

Rather than asking whether RF monitoring is "good" or "bad," the phenomenological perspective asks:

*What is it like to live with this technology?*

*What changes, what fades, and what becomes newly salient?*

## 1.2. Within-case analysis

Each interview was first analysed **individually**, producing:

- a **case vignette**,
- a set of **preliminary codes** grounded in the participant's account,
- and an initial clustering of codes into **case-specific themes**.

At this stage, the goal was **not comparison**, but fidelity to each participant's experiential world.

## 1.3. Cross-case comparison and thematic consolidation

In a second step, themes from all 14 cases were compared to identify:

- recurring patterns,
- meaningful variations,
- tensions and contradictions across cases.

Themes were then:

- **merged, split, or refined** into cross-case categories,
- organised into **master themes and sub-themes**,
- and tested against the full dataset to ensure they captured variation without erasing difference.

Importantly, the absence of a theme in some cases was treated as **analytically meaningful**, not as a deficiency.

# 2.Multidisciplinary interpretive lenses

To reflect the interdisciplinary nature of the Holden Care project, the thematic analysis was interpreted through **three complementary perspectives**.

## 2.1. Phenomenological perspective

Focus:

- lived experience,
- embodiment,
- normalisation and attention,
- sense of safety, intrusion, or indifference.

Key question:

How is RF monitoring *experienced* in everyday life?

## 2.2. Bioethical perspective

Focus:

- autonomy,
- dignity,
- privacy,
- trust,
- consent, data use, and governance.

Key question:

What ethical values are at stake in patients' lived experiences — and how are they negotiated, protected, or put at risk?

## 2.3. Sociological perspective

Focus:

- care infrastructures,
- power relations,
- institutional trust,
- "hospital-at-home" models,
- shifting boundaries between home, clinic, and surveillance.

Key question:

How does RF monitoring reorganise care relationships, responsibilities, and institutional roles?

# 3. Cross-case phenomenological themes and sub-themes (P01-P14)

This section presents the **core results of the cross-case analysis**. It proceeds in three steps:

1. An overview **master table of themes and sub-themes** identified across all 14 interviews
2. A **theme-by-theme phenomenological synthesis**, showing how each theme is lived and articulated
3. Attention to **variation across cases**, rather than forcing uniformity

Throughout this section, patients are referred to as **P01–P14**. Quotes are paraphrased or lightly edited for clarity while preserving meaning and tone.

**Master table: cross-case themes and sub-themes**

| Master theme | Sub-themes | Observed across cases |
|---|---|---|
| **1. Presence and absence of the technology** | Forgetting / backgrounding; momentary awareness; spatial awareness | P01–P14 |
| **2. Home as a moral and experiential boundary** | Public vs private rooms; bedroom sensitivity; "head proximity"; furniture metaphor | P02, P04, P06, P08, P10, P13, P14 |
| **3. Embodiment and bodily self-relation** | Feeling monitored vs feeling unchanged; illness awareness; bodily vulnerability | P01, P03, P05, P07, P11, P13 |
| **4. Autonomy as conditional and relational** | Voluntariness; situational acceptance; future-dependent consent | P01–P14 |
| **5. Privacy, dignity, and moral thresholds** | Camera rejection; data abstraction; acceptable invisibility | P02–P14 |
| **6. Trust in institutions and actors** | Trust in science; trust in clinicians; trust in project intentions | P02, P04, P06, P09, P12, P13 |
| **7. Care, safety, and reassurance** | Emergency imaginaries; being alone; reassurance for others | P01, P05, P07, P10, P13 |
| **8. Normalisation and routinisation** | "It became furniture"; invisibility over time; habituation | P03–P14 |
| **9. Feedback, recognition, and meaning-making** | Desire for data; wish to "see results"; contribution to science | P03, P06, P09, P13, P14 |
| **10. Social mediation and visitors** | Explaining the device; curiosity; social acceptability | P02, P04, P08, P13 |
| **11. Comparison with hospital monitoring** | Non-intrusive vs invasive; tubes vs ambient presence | P01, P05, P09, P13 |
| **12. Limits and refusal points** | Bedroom refusal; camera rejection; escalation concerns | P01–P14 |

This table already indicates a key analytical finding:

**the themes are not isolated**, but **form a tightly interwoven experiential ecology**.

## 3.1. Presence and absence: "We forgot it was there"

Across all 14 interviews, participants described a rapid transition from **initial awareness** to **background presence**.

Typical expressions included:

- *"We forgot it was here"*
- *"It was just there"*
- *"It became part of the room"*

Phenomenologically, this reflects **habituation**: the technology ceases to demand attention and recedes into the background of lived experience.

Importantly, this absence was not experienced as loss or neglect. Rather, it was often described as **positive**, even reassuring:

- absence = non-intrusiveness
- absence = not being "bothered"
- absence = preservation of normal life

Yet this absence was **never total**. Awareness resurfaced:

- during cleaning,
- when navigating crowded space,
- when visitors asked questions.

This oscillation between presence and absence is central to how autonomy and intrusion are later evaluated.

| **Sub-theme** | **Illustrative quotes** | **Interpretation** |
|---|---|---|
| Initial awareness | "At first I noticed it, of course." (P04) | Early reflexive attention |
| Rapid habituation | "After a day or two, I forgot it was there." (P01) | Transition to background |
| Background presence | "It was just part of the room." (P09) | Technology becomes environment |
| Momentary reappearance | "Sometimes I'd notice it when cleaning." (P06) | Oscillating awareness |
| Positive invisibility | "The fact that I didn't notice it was actually good." (P14) | Absence as non-intrusiveness |

**Phenomenological note:**

The device moves from *object of attention* to *taken-for-granted background*, mirroring classic phenomenological accounts of tools becoming "ready-to-hand."

## 3.2. Home as a moral and experiential boundary

Patients consistently distinguished **zones within the home**, attributing different moral meanings to them.

**Living room**

- described as "public," "for guests," "shared"

- installation here was widely acceptable

**Bedroom**

- described as “private,” “intimate,” “where we rest”
- installation here often triggered hesitation or refusal

Several participants emphasised **proximity to the head during sleep** as a threshold:

- not about surveillance alone,
- but about bodily vulnerability and intimacy.

One participant noted that even **non-recording technology** felt different in the bedroom:

*“We like to keep technology away when we sleep.”*

This suggests that **privacy is not only informational**, but deeply **spatial and embodied**.

**Theme 2: Home as moral space and boundary**

| Spatial distinction | Illustrative quotes | Moral meaning |
|---|---|---|
| Living room | “This is where guests come, so it’s fine.” (P02) | Semi-public |
| Bedroom hesitation | “In the bedroom it would feel different.” (P08) | Intimacy |
| Head proximity | “Near the head while sleeping — that’s more sensitive.” (P06) | Bodily vulnerability |
| Bathroom acceptance | “The bathroom actually makes sense, people fall there.” (P14) | Risk-based justification |
| Design blending | “If it looked like a vase or painting, even better.” (P14) | Aesthetic domestication |

**Key insight:**

Privacy is *spatial and embodied*, not only informational.

## 3.3. Embodiment and bodily self-relation

For most participants, RF monitoring did **not** heighten bodily self-surveillance:

- they did not feel “watched”,
- they did not change behaviour,
- they did not become more illness-focused.

However, in cases of advanced illness or frailty, bodily awareness entered indirectly:

- through imagining emergencies,
- through fear of falling or passing out,
- through concern about being alone.

Here, monitoring was not experienced as control, but as a **potential extension of bodily safety**.

**Theme 3: Embodiment, illness, and bodily self-relation**

| Sub-theme | Illustrative quotes | Interpretation |
|---|---|---|
| No bodily change | "I didn't feel different in my body." (P03) | Non-intrusive embodiment |
| No behaviour change | "I didn't move differently." (P07) | Lack of performativity |
| Illness awareness | "It reminded me that I'm fragile, but in a calm way." (P11) | Gentle bodily attunement |
| Emergency imaginaries | "I thought about falling or fainting." (P05) | Anticipatory vulnerability |

**Interpretive point:**

The technology rarely produced self-surveillance; instead, it supported *latent bodily reassurance*.

## 3.4. Autonomy as conditional and relational

Rather than a fixed principle, autonomy appeared as **situational and negotiated**.

Participants often expressed:

- autonomy *now*, but uncertainty *later*
- acceptance *under certain conditions*
- refusal *under others*

Typical formulations:

- *"It depends"*
- *"If my condition got worse"*
- *"If I were alone"*
- *"If it became more intrusive"*

Autonomy was therefore:

- **temporal** (changing over time),
- **relational** (linked to partner presence, care networks),
- **technologically contingent** (scope of monitoring mattered).

**Theme 4: Autonomy as conditional, temporal, and relational**

| Dimension | Illustrative quotes | Meaning |
|---|---|---|
| Voluntariness | "I could say no at any time." (P01) | Perceived control |
| Conditional acceptance | "As long as it stays like this." (P10) | Technological limits |
| Temporal flexibility | "Now it's fine, later I don't know." (P06) | Future uncertainty |
| Relational context | "If I were alone, I'd want it more." (P13) | Dependence on care network |

**Cross-case finding:**

Autonomy is lived as *situational freedom*, not abstract independence.

## 3.5. Privacy, dignity, and moral thresholds

Across all cases, a **clear moral boundary** emerged:

- RF monitoring without cameras = acceptable
- Camera-based monitoring = unacceptable

Participants did not frame this primarily in legal terms, but in terms of **dignity**:

- *"We want privacy"*
- *"That would be different"*
- *"I don't see how you could do that"*

Interestingly, many were open to **heart rate or breathing monitoring**, as long as:

- it remained non-visual,
- abstracted,
- and purposive.

This indicates that dignity is tied less to **what is known**, and more to **how it is known**.

**Theme 5: Privacy, dignity, and moral thresholds**

| Boundary | Illustrative quotes | Ethical meaning |
|---|---|---|
| Camera rejection | "If it were a camera, absolutely not." (P14) | Visual dignity |
| Data abstraction | "Dots are fine, not images." (P07) | De-personalisation |
| Purpose limitation | "Only if it helps medically." (P05) | Moral justification |
| Doctor access | "The doctor should see it." (P02) | Legitimate authority |
| Family access | "Family already knows everything." (P14) | Relational transparency |

**Key distinction:**

Patients differentiate sharply between *monitoring* and *surveillance*.

## 3.6. Trust in institutions and actors

Trust functioned as a **background condition** enabling acceptance.

Trust was placed in:

- scientific institutions,
- medical professionals,
- the stated aims of the project.

Few participants articulated strong data-use anxieties. Instead, trust was expressed as:

- *"They know what they're doing"*
- *"It's for research"*
- *"It's to help people*"

This trust, however, was **personal and contextual**, not abstract or unconditional.

**Theme 6: Trust in institutions, science, and professionals**

| Object of trust | Illustrative quotes | Function |
|---|---|---|
| Research | "It's serious research, not nonsense." (P09) | Legitimacy |
| Clinicians | "Doctors are there to help." (P04) | Moral authority |
| System | "It wouldn't cost so much if it didn't make sense." (P14) | Rational trust |
| Team | "You explained everything clearly." (P12) | Procedural trust |

**Important nuance:**

Trust is **contextual and relational**, not blind.

# 3.7. Care, safety, and reassurance

Monitoring was frequently imagined in **hypothetical emergency scenarios**:

- falling,
- fainting,
- sudden deterioration.

Notably, this benefit was often framed as:

- reassurance for others (partners, clinicians),
- rather than constant reassurance for the self.

Care was understood as:

- responsiveness,
- availability,
- *possibility* of help — not continuous intervention.

**Theme 7: Care, safety, and reassurance**

| Sub-theme | Illustrative quotes | Interpretation |
|---|---|---|
| Emergency framing | "If something happened, someone would know." (P07) | Timely intervention |
| Reassurance for others | "My partner would be calmer." (P10) | Relational benefit |
| Being alone | "If I lived alone, it's very important." (P01) | Social vulnerability |
| Certainty | "It gives peace of mind." (P14) | Emotional security |

**Interpretive insight:**

Care is understood as *availability*, not constant presence.

# 3.8. Normalisation and routinisation

Over time, the technology:

- became "part of the furniture,"
- lost salience,
- blended into daily routines.

This normalisation was often welcomed. However, it also laid the groundwork for later ethical tensions, discussed in the conclusion

**Theme 8: Normalisation and routinisation**

| Aspect | Illustrative quotes | Implication |
|---|---|---|
| Furniture metaphor | "Like a lamp, it's just there." (P03) | Domestic integration |
| Loss of salience | "I didn't think about it anymore." (P08) | Ethical invisibility |
| Positive normalisation | "That's why it's acceptable." (P05) | Reduced burden |

**Foreshadowing:**
This theme becomes ethically ambivalent in the conclusion.

## 3.9. Feedback, recognition, and meaning-making

Several participants expressed a desire for:

- feedback,
- aggregated results,
- comparison with others.

This was not framed as entitlement, but as:

- curiosity,
- wish for recognition,
- desire to feel that participation was meaningful.

**Theme 9: Feedback, recognition, and contribution**

| Desire | Illustrative quotes | Meaning |
|---|---|---|
| Feedback | "It would be nice to know what you found." (P06) | Recognition |
| Comparison | "How am I compared to others?" (P09) | Social positioning |
| Contribution | "If it helps future patients, good." (P14) | Altruistic framing |

## 3.10.Social mediation and visitors

When noticed or explained, the device often became:

- a conversation starter,
- an object of curiosity,
- a symbol of scientific participation.

Visitors were generally described as:

- interested,
- educated,
- supportive.

**Theme 10: Social mediation and visitors**

| Situation | Illustrative quotes | Effect |
|---|---|---|
| Visitor curiosity | "They asked what it was." (P02) | Conversation |
| Normalisation | "Nobody reacted strangely." (P08) | Social acceptability |
| Explanation | "I just told them it's research." (P13) | Identity as participant |

## 3.11. Comparison with hospital monitoring

Hospital monitoring was consistently described as:

- invasive,
- bodily intrusive,
- restrictive.

By contrast, RF monitoring was framed as:

- ambient,
- non-restrictive,
- compatible with everyday life.

This comparison reinforced acceptance.

**Theme 11: Comparison with hospital monitoring**

| Comparison | Illustrative quotes | Meaning |
|---|---|---|
| Hospital | "Wires, beeping, discomfort." (P05) | Invasive |
| Home RF | "Silent, elegant." (P14) | Ambient |
| Freedom | "I don't have to go to hospital." (P09) | Autonomy-supporting |

## 3.12. Limits and refusal points

Despite overall acceptance, **limits were clearly articulated**:

- cameras,
- bedroom installation,
- excessive physiological detail,
- automation without explanation.

These limits form crucial **ethical boundary markers**, not rejections of technology as such.

**Theme 12: Limits, refusals, and red lines**

| Red line | Illustrative quotes | Ethical boundary |
|---|---|---|
| Cameras | "That would violate dignity." (P01) | Absolute |
| Bedroom | "I'd refuse that." (P10) | Spatial |
| Automation | "I want a human decision." (P07) | Governance |
| Expansion | "Not more without asking." (P06) | Consent renewal |

# 4.Bioethical analysis: autonomy, dignity and governance

## 4.1.Reframing autonomy: from consent to lived self-determination

Across the fourteen interviews, autonomy does not appear primarily as a question of *initial informed consent*, but as a **lived, ongoing condition** shaped by everyday experience, trust, and the perceived reversibility of monitoring.

Most participants reported that agreeing to the installation felt autonomous not because they fully understood the technical details, but because they experienced:

- the possibility to refuse,
- the ability to withdraw,
- and the sense that the technology did not impose itself on their daily lives.

Autonomy here is therefore **procedural but also experiential**. Patients repeatedly emphasised statements such as:

*"I could say no at any time,"*

*"As long as it stays like this,"*

*"If it changed, I'd think about it again."*

These formulations reveal autonomy as **conditional and revisable**, rather than absolute. Importantly, this condition was not perceived as a weakness but as a source of reassurance: autonomy was maintained through *continued moral control*, not through constant decision-making.

This challenges narrow bioethical models that equate autonomy solely with information provision and rational choice at a single moment. Instead, the data support a **relational and temporal conception of autonomy**, in which autonomy is sustained through:

- trust relationships,
- institutional credibility,
- and the ongoing felt compatibility between the technology and one's sense of self.

## 4.2. Autonomy under conditions of vulnerability

Illness plays a decisive role in shaping how autonomy is understood and valued. Many participants explicitly linked their acceptance of monitoring to anticipated or experienced vulnerability:

- fear of falling,
- cognitive disorientation,
- sudden deterioration,
- living alone.

Rather than framing monitoring as a loss of independence, participants often described it as a **means of preserving autonomy under fragile conditions**:

"If something happened, someone would know."

"It allows me to stay at home."

“It gives certainty, not control.”

From a bioethical perspective, this reframes autonomy not as *freedom from interference*, but as **the capacity to remain oneself while ill**. Monitoring was accepted insofar as it:

- supported remaining at home,
- reduced the need for constant human supervision,
- and delayed or avoided institutionalisation.

This aligns with ethical accounts of **supported autonomy**, in which technologies act as scaffolding rather than constraints. Importantly, none of the participants described feeling pressured, coerced, or morally obligated to accept the technology—even when acknowledging potential benefits.

## 4.3. Dignity beyond privacy: abstraction, non-visuality, and moral distance

A striking ethical finding across cases is that **dignity was not equated with privacy in the narrow informational sense**, but with *how the body is represented*.

Participants drew a sharp moral boundary between:

- abstract, non-visual data (“dots,” “movement,” “graphs”), and
- visual capture (cameras, images, recordings).

Repeatedly, patients stated:

“If it were a camera, absolutely not.”

“Dots are fine.”

“It’s anonymous.”

From a bioethical standpoint, this suggests that dignity is preserved not merely through data protection, but through **ontological abstraction**: the technology does not present the patient as a visible, inspectable body. Instead, it maintains moral distance between the person and their representation.

This distinction is ethically significant because it explains why many participants accepted monitoring even in traditionally sensitive spaces (bedroom, bathroom), while simultaneously rejecting other forms of surveillance (phones, street cameras, tracking apps). Dignity, in this context, is tied to **not being seen as an object**, rather than to absolute control over information.

## 4.4. Trust as an ethical infrastructure

Autonomy and dignity were consistently mediated by **trust**:

- trust in clinicians,
- trust in researchers,
- trust in the healthcare system.

Participants did not describe engaging in detailed risk-benefit calculations. Instead, ethical acceptance relied on:

- the perceived seriousness of the project,
- the institutional legitimacy of healthcare,
- and the moral intention attributed to caregivers and researchers.

For example:

“Doctors are there to save lives.”

“This wouldn’t exist if it didn’t make sense.”

“It’s research for the future.”

From a governance perspective, this trust functions as an **ethical infrastructure** that enables acceptance. However, this also introduces ethical responsibility: when autonomy is grounded in trust rather than comprehension, institutions must ensure that this trust is not misplaced or exploited.

Ethically, this calls for **reflexive governance**, in which:

- transparency is ongoing, not one-off,
- consent is revisitable,
- and expansion of functionality is accompanied by renewed ethical engagement.

## 4.5. Normalisation as an ethical risk

One of the most subtle ethical risks identified in the analysis is the **very success of normalisation**.

Participants consistently framed the technology’s acceptability in terms of its invisibility:

“I didn’t notice it anymore.”

“It was just part of the room.”

“Like a lamp.”

While this experiential invisibility preserves dignity and reduces burden, it introduces a structural ethical tension:

when monitoring becomes ordinary, it may become **harder to question, resist, or renegotiate**.

Ethics reviewers should note the paradox that:

- what feels non-intrusive today,
- may become difficult to contest tomorrow.

This is particularly relevant if monitoring:

- expands in scope,
- becomes standard rather than exceptional,
- or is integrated with automated decision-making or AI-based alerts.

In such scenarios, autonomy may remain experientially intact while becoming **structurally fragile**. The ethical challenge is therefore not only to protect autonomy as currently lived, but to prevent its gradual erosion through routinisation.

## 4.6. Governance implications: limits, red lines, and conditional legitimacy

Finally, the interviews reveal that acceptance is **not unconditional**. Participants articulated clear ethical limits:

- absolute rejection of cameras,
- discomfort with expanded data use without consent,

- insistence on human oversight in decision-making.

These boundaries form an implicit **moral contract** between patients and the system:

"As long as it stays like this."

From a bioethical governance perspective, this implies that legitimacy depends on:

- purpose limitation,
- proportionality,
- and the preservation of human judgment.

Crossing these boundaries without renewed consent would not merely raise technical concerns—it would constitute a **moral breach** of the conditions under which autonomy was granted.

In this section we showed that autonomy in RF-based monitoring is:

- lived rather than abstract,
- supported rather than diminished,
- and ethically contingent rather than unconditional.

In **section 6**, the analysis will shift to a **sociological perspective**, examining how these ethical meanings are embedded in broader transformations of care infrastructures, domestic space, and the emerging "hospital-at-home" model.

# 5. Sociological analysis: autonomy, care infrastructures, and "hospital-at-home"

## 5.1. From individual experience to care infrastructure

While Parts II and III examined autonomy as lived experience and ethical condition, a sociological perspective situates these experiences within **broader transformations of care**. Across the fourteen interviews, RF-based monitoring is not perceived as an isolated device but as part of an emerging **reconfiguration of healthcare delivery**, particularly the shift from institutional to domestic care settings.

Participants consistently framed the technology in relation to:

- hospitals,
- intensive care units,
- home nursing,
- and the burden placed on family caregivers.

Rather than interpreting monitoring as surveillance, patients described it as **infrastructural care**—a background system that supports safety without requiring constant human presence. This framing is sociologically significant because it reveals how autonomy is produced *through systems*, not only through individual choice.

## 5.2. The home as a hybrid care space

Across cases, the home emerges as a **hybrid space**—simultaneously private, domestic, and medical.

Patients did not describe the installation as "medicalising" their home in a negative sense. Instead, many welcomed the transformation:

"It's better than being in the hospital."

"You can stay at home and still be monitored."

"It's more comfortable."

This suggests a redefinition of autonomy in spatial terms. Autonomy is not about keeping medicine out of the home, but about **keeping the patient out of institutions**. RF monitoring enables what participants repeatedly described as:

- comfort,
- peace of mind,
- and continuity of everyday life.

Sociologically, this reflects the logic of *hospital-at-home*: care is distributed into domestic space while attempting to preserve the symbolic meaning of "home" as non-institutional.

## 5.3. "Multiplying care": technology as relational amplifier

A recurring theme across interviews is that RF monitoring does not replace human care but **"multiplies" it**.

Participants contrasted:

- intermittent visits by nurses or doctors,
- with continuous, passive monitoring.

Rather than seeing this as depersonalisation, they understood it as **augmentation**:

“The nurse can’t be here all the time.”

“This watches when no one else can.”

“It helps them know when to come.”

This framing is sociologically important because it challenges simplistic narratives of technological substitution. The technology is understood as a *relational amplifier*—it enables human actors (doctors, nurses, caregivers) to intervene at the “right moment,” rather than constantly or blindly.

Autonomy here is relational: the patient remains autonomous precisely because care is **targeted and responsive**, not omnipresent.

## 5.4. Trust, expertise, and institutional legitimacy

Trust, already discussed ethically, has a distinct sociological dimension. Participants often justified acceptance by invoking:

- medical expertise,
- research investment,
- and institutional seriousness.

For example:

“This wouldn’t exist if it didn’t make sense.”

“It cost a lot, so it must be useful.”

“Doctors rely on machines already.”

These statements reveal how **institutional legitimacy** substitutes for technical understanding. Patients position themselves as laypersons within a system of expert knowledge, accepting monitoring not because they master it, but because they trust the social institutions behind it.

Autonomy here is **delegated autonomy**: patients retain control by choosing *whom* to trust, rather than by controlling every technical detail.

## 5.5. Technology, inequality, and imagined users

Although most participants focused on their own situation, many spoke reflexively about “other people”:

- older patients,
- those living alone,
- people unfamiliar with technology,
- or those with cognitive decline.

This comparative imagining serves a sociological function: it positions the speaker as competent and autonomous while recognising broader inequalities in technological engagement.

At the same time, several participants emphasised:

- simplicity,
- invisibility,
- and non-interactivity

as key design features—precisely because these reduce barriers for less tech-savvy users. Sociologically, this highlights how design choices shape **who can remain autonomous** under technological care regimes.

# 6.Tensions, ambivalences, and boundary conditions

This section examines situations in which RF-based home monitoring becomes ethically fragile—where autonomy is strained, negotiated, or withdrawn. Rather than outliers, these cases reveal the **limits of acceptability** and define the boundary conditions for responsible deployment.

## 6.1.Conditional and reversible autonomy

Across all interviews, autonomy was never unconditional. Even supportive participants described acceptance as **temporary, situational, and revocable**. Autonomy emerged as a practice rather than a fixed position, dependent on bodily experience, spatial arrangements, trust in care systems, and time.

## 6.2. Bodily distress and withdrawal (Patient 06)

Patient 06 represents the clearest limit case. Although initially supportive of research and unconcerned about monitoring itself, she experienced escalating physical discomfort (twitches, nausea, unusual menstruation) that she associated with the device. Repeated cycles of deactivation and reactivation led her to permanently turn it off.

This case demonstrates a fundamental ethical boundary:

**when technology is experienced as bodily threatening, subjective experience overrides technical assurances**. Autonomy here is enacted through withdrawal, not endurance.

## 6.3. Spatial intrusion and material burden (Patients 06 & 07)

Both patients highlighted how the physical presence of the system—cables, size, visibility—produced discomfort independent of data concerns. For Patient 06, the device intensified feelings of spatial overcrowding; for Patient 07, irritation and vigilance increased over time.

These accounts show that autonomy is shaped by **material and environmental factors**, making design and installation ethically consequential.

## 6.4. Feeling watched despite non-visual monitoring (Patient 07)

Patient 07 experienced a growing sense of being watched, particularly in the bedroom, even though she understood the system was non-visual. This affected intimate practices such as changing clothes.

This tension illustrates that **cognitive understanding does not necessarily resolve affective unease**. Ethical non-invasiveness must therefore be assessed phenomenologically, not only technically.

## 6.5. Endurance, obligation, and "soft coercion"

Patient 07 continued participation largely out of commitment *("I promised ten days"*), despite discomfort. While formal withdrawal was always possible, social obligation and moral reliability made withdrawal harder.

This raises a bioethical concern: **consent may shift into endurance**, especially in research contexts. Autonomy depends not only on the right to withdraw, but on how easy it feels to exercise that right.

## 6.6. Institutional trust as a condition of acceptance (Patient 07)

Patient 07 expressed scepticism toward healthcare responsiveness, questioning who would actually respond to alerts. Her reluctance toward long-term monitoring stemmed less from privacy concerns than from distrust in care infrastructures.

This highlights a sociological boundary condition: **monitoring without reliable response systems risks producing false reassurance rather than care**.

## 6.7. Refusal cases as ethical boundary markers

Patients who declined participation cited discomfort, desire to keep the home private, or feeling overwhelmed by illness. These refusals were clear, immediate, and principled.

Refusal cases function as ethical signals, reminding the project that:

- not all patients desire monitoring,
- refusal is an active form of autonomy,
- and acceptability cannot be presumed or normalised.

## 6.8. Summary

Together, these cases show that autonomy can:

- **hold** (conditional acceptance),
- **bend** (endurance),
- or **break** (withdrawal or refusal).

Recognising these boundary conditions is essential for ethically robust design, consent procedures, and governance—setting the stage for the project-level implications discussed in **section 5**.

# 7. Conclusion

This cross-case analysis of fourteen patient interviews demonstrates that RF-based in-home monitoring does not have a single, uniform impact on patients' autonomy, privacy, or experience of care. Instead, its ethical and experiential meaning emerges through lived bodily experience, spatial arrangements, trust relations, and institutional contexts. Autonomy, across cases, is neither simply preserved nor undermined by the technology; it is **actively negotiated**, situational, and reversible.

From a **phenomenological perspective**, most participants experienced the technology along a spectrum ranging from rapid normalisation to persistent awareness and discomfort. For some, the system faded into the background and became part of the taken-for-granted home environment; for others, especially in intimate or bodily vulnerable situations, it remained salient and intrusive. Crucially, several cases show that acceptance can shift over time, and that discomfort may only emerge after days of exposure. These findings underline that ethical evaluation cannot rely solely on first impressions or initial consent but must attend to the temporal dynamics of lived experience.

From a **bioethical perspective**, the interviews highlight autonomy as a practice rather than a static principle. Patients exercised autonomy not only by consenting, but also by setting limits, temporarily enduring, withdrawing, or refusing participation altogether. Refusal cases and early withdrawals should not be interpreted as failures of the technology, but as ethically meaningful expressions of self-determination. At the same time, cases of endurance reveal a subtle ethical risk: even when withdrawal is formally possible, social obligation, politeness, or commitment to research can make it psychologically difficult to exercise. This calls for consent procedures that actively normalise withdrawal and re-consent throughout deployment.

From a **sociological perspective**, acceptance of RF monitoring was inseparable from broader care infrastructures. Patients evaluated the technology not only in terms of privacy, but in relation to trust in healthcare systems, responsiveness to alerts, and the perceived reliability of institutional actors. For some, monitoring promised safety and continuity of care at home; for others, it risked producing surveillance without support. These findings underscore that home monitoring cannot be ethically assessed in isolation from the systems of care to which it is connected.

Across all perspectives, one key ethical insight emerges: **the success of normalisation is itself ethically ambivalent**. While invisibility and non-intrusiveness can support comfort and autonomy, they may also reduce patients' ongoing awareness and capacity to question, renegotiate, or refuse monitoring over time. Ethical deployment therefore requires not only protecting current autonomy, but safeguarding against its gradual erosion through routinisation.

In conclusion, the Holden Care project demonstrates strong potential to enhance care at home—but only if its development remains attentive to experiential diversity, boundary conditions, and refusal as a legitimate outcome. Ethical robustness will depend on designing technologies and governance structures that accommodate heterogeneity, support ongoing choice, and embed monitoring within trustworthy and responsive care systems. Autonomy, in this context, should be understood not as a one-time decision, but as an ongoing, supported capability.