In Proceedings of the Workshop on Envisioning a Research Agenda for Input Visualization. IEEE VIS 2025. Vienna, Austria.

Input as Translation: Bridging Chronic Pain Experience and Clinical Understanding Through Visualization

Michael Oppermann[1]* Beatrix Wais-Zechmann[1]† Diotima Bertel[1,2]‡

[1]AIT Austrian Institute of Technology, Center for Technology Experience, Vienna, Austria
[2]University of Salzburg, Austria

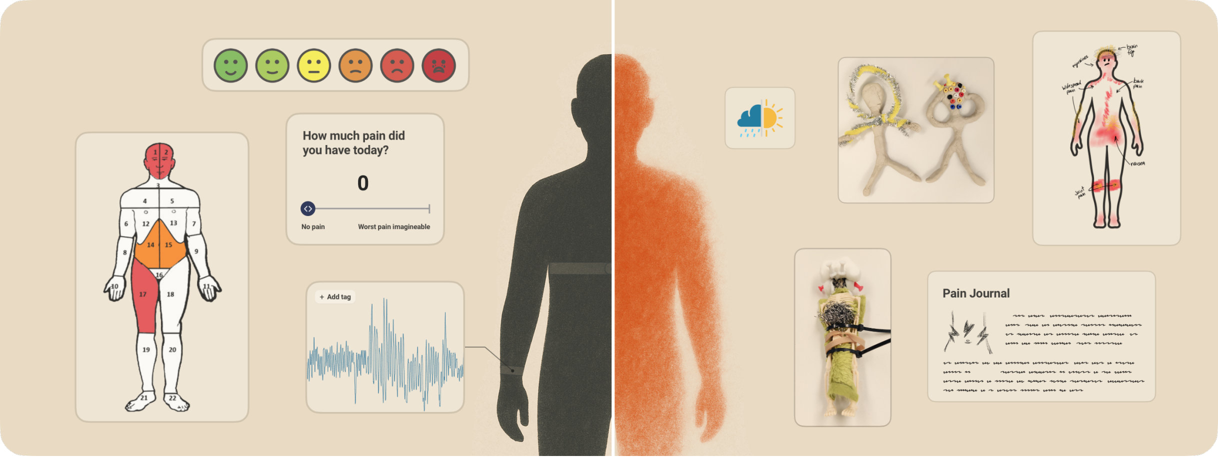

Figure 1: Illustration of the tension between clinical documentation practices, which often reduce pain to quantifiable scales, scores, and discrete categories, and alternative approaches that aim to capture subjective, embodied experiences. While current tracking tools emphasize measurable aspects such as intensity, location, and type (*left*), input visualizations can also support the articulation of more ambiguous, metaphorical, and experiential data (*right*).

ABSTRACT

This position paper investigates how input visualizations can mediate between subjective experiences of chronic pain and clinical documentation practices. Drawing on participatory research, we explore how patients use metaphors, analogies, and embodied representations to articulate pain. We discuss design tensions in creating input visualizations that support expressive, personalized input while remaining clinically interpretable. Our aim is to inspire a research agenda that recognizes the role of non-standardized formats in enriching and augmenting clinical data collection to foster empathy and recognition of diverse symptoms.

1 INTRODUCTION

Chronic pain is a complex, multifaceted condition that is challenging to communicate and capture in uniform formats. In clinical practice, pain is routinely compressed into reductive inputs such as quantifiable scales [29], symptom checklists, or brief free-text notes. These formats prioritize efficiency and comparability but obscure people's lived experiences and situatedness [9]. Pain scales have changed repeatedly over time, while the differences in the social and cultural acceptance of pain and distress were often neglected in quantitative studies of subjective responses [26]. As a result, patient accounts of pain may be underrepresented, misinterpreted, or dismissed. The empathy and credibility a patient receives from medical staff and other people largely depend on their ability to communicate symptoms and on sociodemographic factors. Research has shown that phenomena such as medical gaslighting disproportionately affect women [10], and that age, ethnicity, and other characteristics influence how pain is perceived, diagnosed, and treated [19].

In recent years, mobile apps, smartphone-based pain manikins [2], wearables [3], tangible user interfaces [1], and other digital tools have been introduced to support pain tracking and reporting. These tools may offer useful data by standardizing input, enabling more frequent symptom tracking, and facilitating remote self-reporting. However, while clinically efficient, many of these systems build upon those quantifiable scales, embed normative assumptions about what constitutes valid or actionable data, and often lack accessibility for individuals with diverse communication needs or non-standard pain experiences [11]. Such limitations risk reinforcing existing epistemic biases, especially when designed without an in-depth incorporation of patient perspectives.

Emerging work in *input visualization* [6]—visual representations designed to elicit and structure user-generated data—offers new possibilities for expressing multifaceted embodied experiences (illustrated in Fig. 1). These encompass the diverse sensory, affective, cognitive, and behavioural dimensions through which individuals perceive pain and other symptoms, reflecting the modern biopsychosocial model in healthcare [12].

The input visualization paradigm builds on earlier notions of *constructive visualization* [27], and aligns with the principles of *data humanism* [18], advocating for a more personal approach to how data is captured, analyzed, and visualized. For instance, Jang et

---

*e-mail: michael.oppermann@ait.ac.at
†e-mail: beatrix.wais-zechmann@ait.ac.at
‡e-mail: diotima.bertel@ait.ac.at

al. [16] found that patients felt more confident using drawings to communicate pain than written descriptions, a preference that was similarly reflected among medical professionals. Rajabiyazdi et al. [21, 22] studied patient-generated data visualizations and how they support patients and healthcare providers with presenting and reviewing healthcare data. Their findings underscore the importance of designing for the individual patient while considering their interactions with healthcare providers. In a more general context, *DataSelfie* [17] allows people to design personalized visuals as survey responses and thereby combines a familiar survey authoring interface with free-form drawing. Techniques involving forming materials, positioned within the broader domain of data physicalization [14], have been shown to support freeform and expressive input [15]. As such, expressive input visualizations hold the potential for personal reflection [4, 7] but also as translational tools to augment communication between patients and healthcare providers.

This position paper draws on participatory engagements with people living with chronic pain to explore how they make sense of and communicate their subjective experiences; often through creative analogies and metaphors [8]. We build on prior work by Rajabiyazdi et al. [21, 22] and discuss how our insights can inform the design of input visualizations that complement clinical documentation practices. Our aim is to contribute to a research agenda for input visualization by articulating design tensions and opportunities for integration in healthcare contexts, with the goal of supporting more nuanced and equitable forms of clinical communication.

2 PARTICIPATORY ENGAGEMENTS WITH PEOPLE LIVING WITH CHRONIC PAIN

This work is informed by a broader research project that explores how individuals living with chronic pain make sense of and communicate their experiences. We conducted two co-creation workshops with a total of eleven participants (4 in the first workshop, 6 in the second) and eleven problem-centred interviews to examine how people articulate their pain across different temporalities, bodily sensations, and individual contexts. Our interlocutors lived with a range of chronic symptoms, from migraines and cluster headaches to chronic back pain to endometriosis. We deliberately included various pain sensations to shift focus to the pain experience rather than the disease. Out of our 22 participants, three identified as male and 19 as female, despite our efforts to achieve gender balance. Participants' age ranged from 22 to 87 years, with an average age of 43 years. In the interviews, we aimed to understand the experiences of people with chronic diseases, such as their illness narrative, communication aspects and the impact of both. The co-design workshops focused on investigating how patients create haptic body representations and the potential of these forms for expressing embodied experience. Selected examples of the patient-generated artefacts are shown in Fig. 2.

Although some participants initially expressed hesitation about visualizing their symptoms using materials like clay, wire, or fabric, all ultimately engaged with the task and developed individual ways to represent their sensations. Participants frequently employed metaphors, analogies, and narrative framings to externalize their pain, expressing, for example, that they felt shackled by their pain, that their pain felt stinging like needles, flaming hot and like an explosion, or like a lighting bolt. They also used colors (e.g., red for hot pain, blue for cool pain) and symbols (e.g., lightning bolts, needles, hooks) to describe their pain. Many emphasized the inadequacy of standardized input systems, such as numeric pain scales or checklists, to represent these multifaceted experiences. They did, however, appreciate the potential of quantifiable analysis that comes with measurability.

A cross-cutting theme was the spatial and directional character of sensations. Participants articulated five recurring categories of perception: pain perceived as **entering** the body (e.g., a needle or electric jolt), pain **exiting** the body (e.g., pressure or an explosion), pain located on the body's **surface**, pain deep **within** the body, and pain perceived **around** the body (e.g., like a fog around the head or aura). These categories reflect not just physical conditions but also participants' interpretive framing of pain and accompanying symptoms. About temporality, we found that chronic pain was often experienced as recurring in cycles or phases, especially in women who often experienced recurring symptoms according to their hormonal cycle.

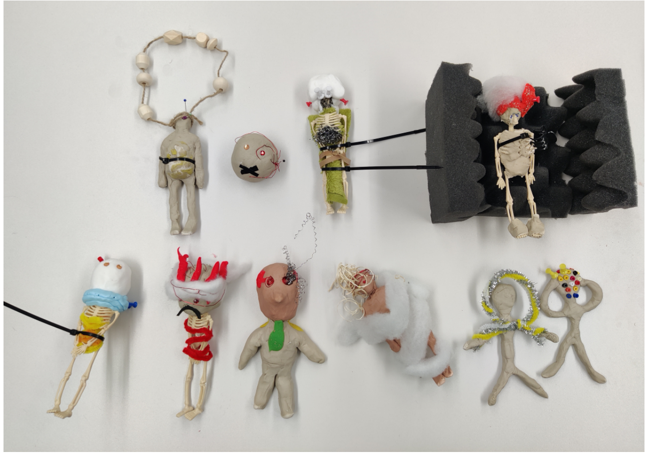

Figure 2: Examples of patient-generated artefacts from co-creation workshops, used by participants to reflect on and articulate their pain.

Findings from these participatory engagements illustrate the situated and embodied aspects of chronic pain and underscore the complexity of designing input visualizations. Such visualizations must account for multidimensional pain expressions, which vary across intensity, location, directionality, temporality, and individual context.

3 INPUT VISUALIZATIONS AS TRANSLATIONAL TOOLS IN PAIN CARE

Input visualizations enable modes of communication that are often constrained by conventional documentation formats. In our workshops, participants created haptic body representations that more closely reflected how they experience and make sense of chronic pain, highlighting their potential to support personal reflection and sense-making [27].

However, expressive input alone is insufficient when the goal extends beyond personal insight. Within healthcare settings, patient-generated data must also support clinical interpretation and actionability. Current tools and processes prioritize efficiency, comparability, and standardization—principles that often conflict with open-ended, individualized representations. Consequently, richly expressive input formats may remain peripheral to clinical workflows if they cannot be interpreted reliably or quickly by healthcare providers. This tension raises a critical research direction for the visualization community: to develop reference models, design guidelines, techniques, and tools that support patient-centered expression without compromising clinical utility.

Addressing this gap is not simply a matter of translating data into a more readable format. It requires rethinking how input visualizations can serve as interfaces between lived experience and institutional processes of documentation, communication, and care practices. A further challenge lies in determining how complex, individual symptoms can be condensed in ways that enable clinical comparability without erasing meaningful differences or marginalizing specific population groups.

We propose this as a central research question for the future of input visualization in the context of chronic pain care:

> *How can input visualizations preserve expressive richness while producing data that clinicians can meaningfully interpret and act on?*

In the following section, we outline key challenges and opportunities that emerge from this question and may inspire future research directions.

4 DESIGNING TRANSLATIONAL INPUT VISUALIZATIONS: CHALLENGES AND OPPORTUNITIES

We outline four interrelated areas of design tension that arise in supporting patient-centered input while ensuring that the resulting data remains interpretable and usable in clinical contexts. Similar challenges and opportunities have been discussed in the literature on data physicalization and quantified self practices (e.g., [5, 7, 15, 27]). Here, we revisit these themes through the lens of chronic pain and examine how input visualizations can function as translational tools.

Representing ambiguity and subjectivity. Input visualizations in the medical field often rely on structured formats that facilitate comparison and standardization, but are misaligned with the inherently fuzzy, subjective and ambiguous nature of chronic pain. Patients feel comfortable using metaphors, narratives, and embodied expressions that may not be reduced to fixed categories or scores. Addressing this requires moving from discrete encoding toward designs that support interpretive input. Building on prior work [22], future research could explore layered input visualizations that combine quantitative and qualitative elements, and, for instance, develop multimodal approaches that incorporate haptic, visual, and voice-based input. Such approaches could also include icons that reflect culturally prevalent pain metaphors, such as lightning bolts, needles, or weather-related symbols, to support intuitive input. Recent work on AI-assisted conversational journaling also highlights the potential to incorporate narrative aspects to augment patient-generated health data collection [25].

Balancing personalization and consistency. Allowing patients to describe their experiences in personally meaningful ways can capture important nuances [21], but also leads to challenges for maintaining consistency and comparability across inputs. One direction is to augment structured formats with optional freeform layers, enabling patients to choose between multiple input modes based on personal relevance. Future research might investigate adaptive interfaces [30] that dynamically balance personalization with consistency, and preserve the ability to analyze data across individuals and contexts.

Capturing temporal and symptom-specific variation. Chronic pain varies across time, context, and treatment. Participants in our study described changes in intensity, location, and sensation that emerged over hours, days, or weeks, with pain experiences often reoccurring in a cyclical or wave-like way. Personalized and subjective input formats, when used in isolation or alongside patient journals and standardized forms, increase the risk of capturing only snapshots of experience, particularly peak moments of high pain intensity. Input visualizations must therefore account for temporality and variations across pain conditions, such as recovery progression [24], to avoid oversimplifying complex experiences. Visualization research could investigate how input systems can elicit temporal patterns and variations of symptoms to enhance the analysis and communication of chronic conditions.

Embedding input visualizations in clinical workflows. Despite growing interest in patient-generated health data, the integration of such input into clinical decision-making remains difficult [20]. Prior research highlights concerns among clinicians regarding the accuracy, completeness, and relevance of such data, as well as the time required to interpret it [13, 23, 28]. These challenges are amplified when input includes unfamiliar, metaphorical, and subjective self-reporting. Besides the technical compatibility, designing input visualizations for clinical uptake requires formats that support mutual understanding between patients and healthcare professionals [23]. This includes reexamining clinical authority and the extent to which patients are given an active role in the process. One promising direction is to develop visualizations for shared use within consultations, which can function as conversational anchors. Future work could explore how a phased introduction might allow these tools to gradually support richer, more patient-centered communication without disrupting established routines.

5 CONCLUSION

Input visualization offers a promising direction for enhancing clinical communication by supporting the interpretation and articulation of lived experiences of chronic pain. In this paper, we have outlined opportunities and future directions for visualization research in this domain. We advocate for a research agenda that systematically explores input visualization modalities, evaluates their integration into clinical contexts, and derives design principles for expressive and inclusive systems.

ACKNOWLEDGMENTS

This research has been conducted under the project *Embodied Perceptions*, funded by the Austrian Research Promotion Agency under the funding programme FEMtech 2023 (GA No. FO999913010), and under the III.Lab (Intelligent Interfaces Innovation) funded by AIT Austrian Institute of Technology, University of Salzburg and Land Salzburg (GA No. 20102/F2300416-KZP).

REFERENCES

[1] A. T. Adams, E. L. Murnane, P. Adams, M. Elfenbein, P. F. Chang, S. Sannon, G. Gay, and T. Choudhury. Keppi: A tangible user interface for self-reporting pain. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1–13, 2018.

[2] S. M. Ali, W. J. Lau, J. McBeth, W. G. Dixon, and S. N. van der Veer. Digital manikins to self-report pain on a smartphone: A systematic review of mobile apps. *European Journal of Pain*, 25(2):327–338, 2021.

[3] F. R. Avila, C. J. McLeod, M. T. Huayllani, D. Boczar, D. Giardi, C. J. Bruce, R. E. Carter, and A. J. Forte. Wearable electronic devices for chronic pain intensity assessment: A systematic review. *Pain Practice*, 21(8):955–965, 2021.

[4] A. Ayobi, T. Sonne, P. Marshall, and A. L. Cox. Flexible and mindful self-tracking: Design implications from paper bullet journals. In *Proc. Conf. on human factors in computing systems (CHI)*, pp. 1–14, 2018.

[5] S. S. Bae, D. A. Szafir, and E. Y.-L. Do. Exploring the benefits and challenges of data physicalization. *Proc. of ETIS*, 2022.

[6] N. Bressa, J. Louis, W. Willett, and S. Huron. Input visualization: Collecting and modifying data with visual representations. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1–18, 2024.

[7] E. K. Choe, N. B. Lee, B. Lee, W. Pratt, and J. A. Kientz. Understanding quantified-selfers' practices in collecting and exploring personal data. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1143–1152, 2014.

[8] R. Coakley and N. Schechter. Chronic pain is like... the clinical use of analogy and metaphor in the treatment of chronic pain in children. *Pediatric Pain Letter*, 15(1):1–8, 2013.

[9] A. Deptula. One size does not fit all: How clinical pain assessment scales and tools mask crip narratives of chronicity. *Journal of Technical Writing and Communication*, p. 00472816251325229, 2025.

[10] S. Durbhakula and A. H. Fortin. Turning down the flame on medical gaslighting. *Journal of General Internal Medicine*, 38(15):3426–3427, 2023.

[11] D. A. Epstein, N. B. Lee, J. H. Kang, E. Agapie, J. Schroeder, L. R. Pina, J. Fogarty, J. A. Kientz, and S. Munson. Examining menstrual tracking to inform the design of personal informatics tools. In *Proc.*

Conf. on Human Factors in Computing Systems (CHI), pp. 6876–6888, 2017.

[12] R. J. Gatchel, Y. B. Peng, M. L. Peters, P. N. Fuchs, and D. C. Turk. The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychological bulletin*, 133(4):581, 2007.

[13] S. Guardado, M. Karampela, M. Isomursu, and C. Grundstrom. Use of patient-generated health data from consumer-grade devices by health care professionals in the clinic: systematic review. *Journal of Medical Internet Research*, 26:e49320, 2024.

[14] E. Hornecker, T. Hogan, U. Hinrichs, and R. Van Koningsbruggen. A design vocabulary for data physicalization. *ACM Trans. on Computer-Human Interaction*, 31(1):1–62, 2023.

[15] S. Huron, T. Nagel, L. Oehlberg, and W. Willett. *Making with data: Physical design and craft in a data-driven world.* CRC Press, 2022.

[16] A. Jang, D. L. MacLean, and J. Heer. Bodydiagrams: improving communication of pain symptoms through drawing. In *Proc. Conf. on human factors in computing systems (CHI)*, pp. 1153–1162, 2014.

[17] N. W. Kim, H. Im, N. Henry Riche, A. Wang, K. Gajos, and H. Pfister. DataSelfie: Empowering people to design personalized visuals to represent their data. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1–12, 2019.

[18] G. Lupi. Data humanism, the revolution will be visualized. `https://printmag.com/article/data-humanism-future-of-data-visualization/`, 2017. PrintMag.

[19] V. A. Mathur, Z. Trost, M. O. Ezenwa, J. A. Sturgeon, and A. M. Hood. Mechanisms of injustice: what we (do not) know about racialized disparities in pain. *Pain*, 163(6):999–1005, 2022.

[20] C. Y. Oh, Y. Luo, B. St. Jean, and E. K. Choe. Patients waiting for cues: information asymmetries and challenges in sharing patient-generated data in the clinic. *Proc. Conf. on Human Factors in Computing Systems (CHI)*, 6:1–23, 2022.

[21] F. Rajabiyazdi, C. Perin, L. Oehlberg, and S. Carpendale. Exploring the design of patient-generated data visualizations. In *Graphics Interface Conference (GI)*. Canadian Information Processing Society, 2020.

[22] F. Rajabiyazdi, C. Perin, L. Oehlberg, and S. Carpendale. Communicating patient health data: A wicked problem. *IEEE Computer Graphics and Applications (CGA)*, 41(6):179–186, 2021.

[23] F. Rajabiyazdi, C. Perin, J. Vermeulen, H. MacLeod, D. Gromala, and S. Carpendale. Differences that matter: In-clinic communication challenges. In *Proc. EAI Int. Conf. on Pervasive Computing Technologies for Healthcare*, pp. 251–260, 2017.

[24] S. H. Ramesh, A. Ouskine, E. Khorasani, M. Ebrahimipour, H. Finestone, A. D. Chan, and F. Rajabiyazdi. A data visualization tool for patients and healthcare providers to communicate during inpatient stroke rehabilitation. In *Proc. Graphics Interface Conference*, pp. 1–14, 2024.

[25] M. Rashik, S. Sweth, N. Agrawal, S. Kochar, K. M. Smith, F. Rajabiyazdi, V. Setlur, N. Mahyar, and A. Sarvghad. Ai-enabled conversational journaling for advancing parkinson's disease symptom tracking. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1–23, 2025.

[26] F. W. Stahnisch. Objectifying "pain" in the modern neurosciences: A historical account of the visualization technologies used in the development of an "algesiogenic pathology", 1850 to 2000. *Brain Sciences*, 5(4):521–545, 2015.

[27] A. Thudt, U. Hinrichs, S. Huron, and S. Carpendale. Self-reflection and personal physicalization construction. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1–13, 2018.

[28] P. West, M. Van Kleek, R. Giordano, M. J. Weal, and N. Shadbolt. Common barriers to the use of patient-generated data across clinical settings. In *Proc. Conf. on Human Factors in Computing Systems (CHI)*, pp. 1–13, 2018.

[29] A. Williamson and B. Hoggart. Pain: a review of three commonly used pain rating scales. *Journal of Clinical Nursing*, 14(7):798–804, 2005.

[30] F. Yanez, C. Conati, A. Ottley, and C. Nobre. The state of the art in user-adaptive visualizations. In *Computer Graphics Forum*, vol. 44, p. e15271, 2025.