# Designing for Self-Management of Affective Disorders from Ethics of Care Approach

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## Abstract
This paper outlines our ongoing work in the AffecTech project focusing on designing technologies for self-regulation of affect in mental ill-health. It draws from models of healthcare and ethics of care, and discusses their relevance to HCI mental health research.

## Author Keywords
Mental health; self-regulation; ethics of care; research ethics.

## ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## Introduction
The cost of healthcare provision in the UK has increased by more than 50% over the last decade, with significant social and economic implications [9]. A key contributor to this cost is the provision of mental healthcare, as mental health problems affect one in four adults each year representing also the largest single cause of disability in the UK [10]. Since such cost is unsustainable, innovative solutions to tackle it are much needed. Decentralizing mental healthcare provision, often at primary and community care levels is one solution with good indications for cost-effectiveness [12]. Other forms of decentralization include patient-centered strategies which have been shown to benefit from effective communication,

partnership, and promotion between clinician and patient [14]. A radical new approach falling under patient-centered strategies is patient self-management of one's condition and participation in one's own care [2,7,8]. Digital technologies [19] have been shown to facilitate patient-clinician communication [23], while the emergence of self-monitoring technologies offer novel approaches to healthcare based on patient' self-management.

Within this wider context, HCI research has responded with a growing interest over the last decade on emotional wellbeing and health [3,4,5,6,13,15,18, 20,22,24]. There has been however, limited focus on self-management and the concept of care in this space. AffecTech (http://www.affectech.org) is a European Commission-funded Innovative Training Network aiming to address this gap. It focuses on the design and development of low-cost, wearable technologies to support training of adaptive emotion regulation strategies to support the self-management of people living with affective disorders such as depression, anxiety or bipolar condition. Within this paper, we argue that designing such technologies should benefit from an ethics of care approach.

## Ethics of Care

Healthcare ethics argue for four key principles [1] such as autonomy, i.e., capturing the respect for the decision making ability of autonomous persons through supporting information, its understanding and consent; no-maleficence or the explicit intention of not causing harm; beneficence focusing not only on preventing harm but also on providing benefits and on balancing benefits against risks and costs; and justice which captures fair distribution of benefits, risks and costs to all people irrespectively of social class, race, gender or other forms of discrimination. Arguably, in the sensitive context of mental health research, besides the ethical guidelines of respect for autonomy, no harm, beneficence, and justice, there is a higher requirement for additional ethical concerns also common to other contexts involving vulnerable people whose risks of taking part in research may exceed their perceived benefits. For example, ways to address such risks include engaging in consultation before releasing any data which may be perceived as sensitive and further stigmatizing, or sharing data and insights with the people in order to help them build capacity [11].

Another approach is awareness of different models of care and their distinct value for empowerment and relational autonomy. For example, the prevalent Western model of care values individualism and self-determinacy and is underpinned by the assumption that dependency on others has negative moral connotations [25]. A contrasting view addressing this challenge, proposes a reciprocity-based model of care, centered on acknowledging and celebrating interdependency [26,27] and in particular relational autonomy. This concept developed in health research acknowledges that patients' decisions, rather than being left solely to them, could benefit from being open to social context and persuasion [26].

## Discussion

From the ethics of care perspective, AffecTech, which brings together mixed expertise in HCI, biomedical engineering and clinical psychology, takes a blended approach. One the one hand it follows the self-determinacy model aiming to empower vulnerable user groups, while on the other hand, in doing so, it seeks to leverage relational autonomy that people living with affective disorders could benefit from. This can take the form of family, therapist or technological interventions.

To ensure this blended approach, we have employed three specific research practices. First, as designers, we have used self-reflection [15,16,17] to better understand and address the need to sensitize the interdisciplinary design teams to the experiential challenges of affective disorders. For example, we started to developed alternative design methods leveraging first person experience of living with depression. Such methods ensure empathy in design illustrating ethics of care for end users.

Second, to ensure fair participation of the three key stakeholders: people living with affective disorders, therapists, and researchers, we made it explicit to understand and model power relations among them, and among different contributing research disciplines. For instance, we tracked different views and input into the design process, to understand at which design stages specific voices are heard more or less and why. Such approach illustrates the ethics of care towards research stakeholder for fair and equitable contribution between academics and practitioners.

Finally, within participatory design we have started working with therapists as proxy for people living with affective disorders. The next step is exploring alternative models of collaboration such as community-based participatory research bringing together academics and community members living with affective disorders as authentic partners [11] to ensure mutual transformation [7].

These approaches reflect our efforts to develop design knowledge [21] for a new class of technologies training adaptive strategies for self-regulation of affect, while ensuring authentic care for end users, practitioners, and researchers across the three disciplines that the project brings together.


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