The KOOLO app

A case study of self-tracking, visualization, and organizing personal moods

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Abstract — **Self-tracking refers to the regular collection of data about oneself. Smartphones and wearables have made self-tracking a pervasive activity. This paper describes the design process of a self-tracking mood functionality, which is part of the KOOLO mobile application. The purpose of the KOOLO application is to support young patients, teenagers and young adults with long-term health challenges, in the transition from child-oriented to adult-oriented healthcare. We implemented a design approach, based on a participatory design process combined with a focus on the wellbeing of the whole person, not just the diagnosis. The result was a mood tracking functionality that collects qualitative mood data in the form of color-tagged photos. The visualization of the data resulted in both a quantification of the data as well as in an interactive mood map. The organization of the color-tagged photos, in the form of a timeline and map, enables the user access to the mood data in different ways.**

Keywords — lived body, lifeworld; m-health; participatory design; qualitative self; transition; visualization, young patients.

I. INTRODUCTION

This paper presents our design research on a mood tracking functionality for a mobile phone application for young patients, who are preparing themselves for the transition to adult health care [1]. It addresses the self-tracking of the expression of moods and emotional experiences, through visualization, in a mobile phone application called KOOLO. The main aim of KOOLO is to support young patients in the transition from child-oriented healthcare to adult-oriented healthcare. This research is part of the KULU research and design project, which focuses on the design and use of interactive technologies with and for young people (15-25 years old) with chronic health challenges. KULU is a Norwegian acronym for Cool Technologies for Youth with Long-term Health Challenges (http://www.kulu.no)

Self-tracking or self-monitoring refers to the practice of collecting data about oneself on a regular basis. It "seeks to make known something that is typically not a subject of reflection, with the aim of converting previously undetected bodily reactions and behavioral clues into traceable and perceptible information" [2, p. 69].

Through the use of mobile phones and wearables, digital self-tracking has become a popular way to gather data about a wide variety of features of one's life, e.g., food, activity, sleep, health, productivity, and mood. These "everyday processes are translated into information" [2, p. 80], which can be used in generating abstract graphs and figures left to the receiver's interpretation. Self-tracking can result in qualitative as well as in quantitative data. The latter is associated with the "quantified self", a term first coined in 2007 by Gary Wolf and Kevin Kelly, which they also described as "self-knowledge through numbers" [3].

In our research and design activities, the experiences of the young patients take up a central place. This is also expressed in one of the central concept in our research, the *lived body* [4]. This notion refers to a more holistic understanding of the body. One of our design participants expressed this as follows: "the doctor should be interested in me, all of me, not just my diagnosis" [5].

Self-tracking focuses on making the features of one's life and body visible. Can we self-track the *lived body*? This paper will present some preliminary findings resulting from a design process with young people with chronic health challenges.

The contribution of this paper is as follows. It locates the design of a mobile application for young patients in the larger discussion of self-tracking. It adds to the literature in designing interactive technologies from the perspective of young people with health challenges. We present our particular design approach, which enables patients to be met as co-designers and experts of their own life and facilitates patient contributions to the design of health IT. Secondly, it contributes to understanding the life of young patients. It shows how they value moods in their life and the importance of taking a holistic perspective when tracking moods. In addition, the paper contributes to the sparse literature on the visualization of qualitative self-tracking data, by presenting a design concept that visualizes the quantification of qualitative data. Lastly, it contributes to understanding the role of technology in the life of young people in general. Teenagers and young adults' technology preferences and use are often very different from those of the researchers. Designing with the future users of a technology increases the chance that the technology reflects the values and needs of that particular user group.

The remainder of the paper is organized as follows. In Section II, we will discuss self-tracking and the use of

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visualization. We found in the literature that the self-tracking of mood is considered beneficial for both mental and physical health, but quantitative self-tracking and its visualizations can lead to a undesirable objectification of the body. We found no examples of the visualization of qualitative self-tracking. We will therefore, in Section III, explore some concepts that support a holistic patient body perspective in our design process. We also will present SHARM (Situation-based learning; Having a say; Adaptability; Respect; Mutual learning), our methodological framework, based on Participatory Design, which we used in our design activities with the young patients. In Section IV, we present the design process, the methods used, the different stages in the development of the mood tracking functionality, and the final results. In Section V, we discuss the design process and its results and in the final section, we present our concluding remarks and outline future research.

II. SELF-TRACKING

Tracking or monitoring data of different aspects of one's life is an established and persuasive activity [6]. Digital technologies, in particular mobile ones, made it possible to automate large amounts of data collection through the use of build-in sensors, such as accelerometers, gyroscopes, magnetometers, and humidity, pressure, light, and proximity sensors. Wearables, which often extend the tracking functionality of smartphones, can have other sensors, such those that measure heart rate, blood pressure, blood sugar, etc. In addition to the automated sensor-based input, data can be collected through manual user input, for example food intake, period and ovulation, and changes in skin growths, etc.

Working in an environment with young adults, who all have a smartphone, we implemented a scoping survey among our students to understand the occurrence of self-tracking apps. We approached 50 students and received 45 responses (23 male and 22 female students). Twenty-five students used one or more apps (13 male and 12 female students). The most popular functionalities were tracking of activity, such as steps (19 respondents), pulse (10 respondents), sleep (7 respondents); food intake or calories (6 respondents) and menstruation (4 respondents). Non-users often had particular ideas about self-tracking apps: "Apps do not measure in an appropriate way, for example blood pressure" (f/22) or "I do not trust health apps. They can measure wrongly" (f/19). Two respondents pointed to possible negative side-effects of such apps. One used a fitness app, but not other health apps because "It is easy to get too much involved; this can result in a negative self-image (f/20). Another student mentioned "self-tracking apps can make you too self-centered (f/19).

A. Typology of self-tracking

Lupton has developed a typology of self-tracking: private, pushed, communal, imposed, and exploited self-tracking [7]. According to Lupton, the aim of *private* self-tracking is self-awareness and improvements in particular aspects of one's life, such as better sleep and better health or control over mood swings. Data collection is self-motivated and for personal reasons; they are not shared or shared with selected others. In contrast, *pushed* self-tracking is motivated by others. External encouragement for self-tracking, such as in the workplace or as part of a health care program, results in data that may benefit both the promotor of self-tracking and the individual doing the tracking. The collected data is often shared with particular others (health care professionals, employers, insurance companies, etc.).

A third category in Lupton's typology is *communal* self-tracking, in which the individualistic behavior of self-tracking is perceived as part of a larger community of trackers. Data are shared, via especially designed social media platforms, "to further one's own interests and goals". In contrast, *imposed* self-tracking is solely for the benefit of others, such as forced productivity self-tacking in the workplace and monitoring of location, alcohol, and drug use by authorities.

Exploited self-tracking is private, pushed, communal or imposed self-tracking, in which the data collection is used for the mainly commercial interests of a third party. The self-tracker may not always be aware of this exploitation.

One line of investigation in the self-tracking literature focuses on the body that is being tracked. In the context of the phenomenological distinction between the *objective body* and the *subjective, lived body*, Pritz mentions that self-tracking focuses on the objective body and thus replaces experiences of the subjective body, which cannot be trusted [8]. Wiederman [9], on the other hand, found no conflicts between the objective and subjective body, but argues that the body can never be reduced to calculations that produce data.

Ruckenstein [2] explores the concept of *data double*, first described as the result of surveillance data [10]; the process in which a person is first divided up in different data streams, as a result of monitoring, and then these data streams are put together in the form of a data profile that is stored on computers in different places. Ruckenstein describes the process of assembling self-tracking data as a re-assembly of the body; a new way of having access to the body, "giving a new kind of value to their personal realities and everyday doings" [p. 81-82]

B. Quantified and qualified self-tracking

The majority of self-tracking apps and technologies collect quantitative data. Aspects of one's life are measured in the form of time, speed, weight, location, inputs, states (e.g., mood or blood sugar level), number of events, etc. The "quantified self" is becoming a global phenomenon, with self-trackers meeting each other in cities around the world to compare data and discuss tracking technologies [11].

Qualitative self-tracking can be defined as "*using mobile technology to recurrently record qualities of experience or environment, as well as reflections upon them, with the intention of archiving aspects of personal life that would otherwise be lost, in a way susceptible to future review and revision of concerns, commitments and practices in light of such a review* [12].

Several researchers argue against maintaining a strict division between qualified and quantified self-tracking [7][13][14]. For example, Davis argues that the quantified

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self has a qualitative component, which is "key in mediating between raw numbers and identity meanings. If self-quantifiers are seeking self-knowledge through numbers, then narratives and subjective interpretations are the mechanisms by which data morphs into selves. Self-quantifiers do not just use data to learn about themselves, but rather, use data to construct the stories that they tell themselves about themselves."

C. *Visualization of self-tracking data*

The collection of data is often invisible, especially when sensors are used. Data visualization tools are then used to organize and present the data in a meaningful manner, often in the form of graphs, colors, and quantities (e.g., Figures 1 and 2).

Figure 1. Visualizing self-tracking data I (https://zapier.com/blog/best-fitness-tracking-apps/)

Figure 2. Visualizing self-tracking data II (http://www.healthviewx.com/solutions/patient-tracking/)

Personal analytics, personal visualization, and personal visual analytics [15][16], are some of the terms that are used to refer to this particular type of data visualization. According to Few, good data visualization "encodes information in a manner that our eyes can discern and our brains can understand" [17]. A good visualization:

- Clearly indicates how the values relate to one another, e.g., a part-to-whole relationship.
- Represents the quantities accurately.
- Makes it easy to compare the quantities.
- Makes it easy to see the ranked order of values.
- Makes obvious how people should use the information - what they should use it to accomplish - and encourages them to do this.

We did not find literature that discusses the visualization of qualitative self-tracking data.

In the context of self-tracking for people with health challenges, it is important to stress the reliability and accuracy of the self-tracking technologies collecting data for the visualizations. Among others, [18] and [19] report some inaccuracy in commercial wearables and smartphone applications measuring activity levels. While the authors argue that this is acceptable in cases of healthy users wanting to improve their physical health and lifestyle, these inaccuracies contribute to the limited use of mass-marketed self-tracking technologies in clinical studies and healthcare practices [20].

D. *Tracking moods and emotions*

Moods are often differentiated from acute emotional states, such as being angry, sad or happy. They last longer and are often not related to an immediate trigger: "mood state appears to be an integrative function of the organism's acute emotional experiences over time" [21]. In the field of IT health, e-health, and m-health (health IT), this differentiation disappears when describing or designing mood technology. This becomes for example clear in [22], which categorizes mood technologies into *Technology that measures mood*; *Technology that expresses user mood*; *Technology that adapts to user mood*; and *Technology that influences user mood*. Another categorization of mood technology is diagnosis-based versus general mood. For example, mood apps can address specific mood disorders, such as bipolar disorder [23], anxiety disorders [24], and depression [25], or have a more general approach, such as happy apps [26]. According to Matthews et al. [27], mood tracking, in the form of mood monitoring or mood charting, is widely used in mental health.

In a scoping study, Seko et al. [28] found that mobile phones are an appropriate way to engage youth in therapeutic activities and that "the ability of mobile phones to offer personal space is also considered to increase levels of perceived autonomy, control, and self-esteem in young users" which can strengthen their mental health. The participation and adherence rate to treatment was higher for mobile phone apps than on paper [27], [29], rating mood was seen as most useful [30]. Young people with chronic physical health challenges are more likely to have mood-related issues, ranging from emotional problems to mood disorders [31], [32]. Nevertheless, mobile phone applications still depend on additional therapy in order to be effective, they play a supportive role rather than being able to replace professional treatment.

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Self-tracking of moods is also relevant in the context of physical health. Moods and emotions are central components of the *subjective well-being* (SWB) concept. In an extensive review of evidence indicating a positive relation between SWB and health and longevity, Diener and Chan [33] argue that moods and emotions are not only a result of people's life and health situation. The authors present research indicating that "positive moods such as joy, happiness, and energy […] were associated with reduced risk of mortality in healthy populations, and predicted longevity, controlling for negative states" [p.3]. Despite the controversy surrounding causality explanations between positive SWB and better life expectancy among cancer patients, the authors argue "patients in the low range for SWB would experience better health if their SWB could be raised" [p.33]. Diener and Chan [33] also suggest adding SWB to public health goals and place the responsibility for increasing SWB at a societal level.

In *Making Emotions Count: The Self-Tracking of Feelings*, Pritz [8, p. 184] argues that the self-tracking of moods and emotions can be understood within two opposing views on the social regulation of feelings in modern Western societies: the view that supports the hypothesis of the domestication, disciplining, and instrumental objectification of emotion, and the view that supports the hypothesis of informalization of emotion. Self-tracking brings the two together, as "emotions are treated as phenomena that can be ordered, regulated and normalized" and at the same time "treated as "personal resources for self-knowledge and self-fulfillment".

III. CONCEPTUAL FRAMEWORK

A conceptual framework consisting of three main components guided our research and design activities with teenagers and young adults with chronic health challenges :

a) The lived body

Our research participants made clear that they want to be met as young people, not as patients. Their wish to push their 'patientness', the quality of being a patient, to the background is also confirmed in the literature [34]–[36]. Young patients use the terms *normal* and *regular* to express how they want to be perceived and treated by the world around them [35], [36]. They acknowledge their illness, but want to have lives like their peers and they do not want their caregivers to see only their diagnosed bodies [5].

This particular positioning by the young patients can be explained with the notion of the *lived body*, the body as experienced by the self and as being-in-the-world, as described in phenomenology [37], [38]. The concept that encompasses both the lived body and its experiences in the world is the notion of lifeworld. Lifeworld can be described as "the world of lived experience or the beginning pace-flow from which we divide up our experiences into more abstract categories and names" [39]. Lifeworld theory describes five intertwined dimensions in which these experiences become meaningful: temporality, spatiality, intersubjectivity, embodiment, and mood [39]. Mood, in this context, is described as a "messenger of the meaning of our situation" or our being-in-the-world, "mood is complex and often more than words can say" [39].

b) Lifeworld-led care

Lifeworld-led care is a particular perspective on healthcare, which focuses on the wellbeing of the whole person, not just the illness or diagnosis [40], [41]. This perspective is both a deepening of the understanding of patient-centered care and a critique on the dehumanisation and depersonalization of care, not the least through the use of technology [41]. The aim of a lifeworld-led design approach is to let the young patients' *lived experiences* of everyday life, diagnosis, and technology use, guide the design of new technology that supports them in living their everyday life with their health challenges [41].

c) SHARM approach

In order to provide an enabling environment in which young patients can build forth on their lived experiences, KULU implements its design activities within a participatory methodology called SHARM, which is based on Participatory Design [42][43]. The participation of young people as co-designers of their own healthcare technologies enables a design space in which the young participants can position themselves in the way they perceive themselves and how they want to be perceived by others. The SHARM approach is based on five principles [44]: 1) *Situation-based action* locates the design activities in the lifeworld and relationships of the participants; 2) *Having a say* is about creating real opportunities for participants to share the decision-making power; 3) *Adaptability* is about applying tools and methods in the design activities that can easily adapt to the participants' changing physical or emotional state; 4) *Respect* is about treating the young participants as experts on their own life and body; and 5) *Mutual learning* refers to choosing methods and tools that enable the participants to lean as much from the researcher/designers as the researcher/designers do from the participants.

This framework was applied in a research and design project with the Youth Council of the Akershus University Hospital (AHUS), in Norway. The Youth Council had made a wish list of issues and technologies they wanted to use in the design project with KULU. The transition to adult healthcare was one of the main concerns of the Council and they wanted to explore how a mobile phone application (app) could support them in the transition process.

This paper reports in particular on the design of the mood tracker functionality for a multifunctional transition app. The design process consisted of four workshops and an online prototype evaluation. The workshops took place in two large meeting rooms and were attended on average by seven Youth Council members. In total, ten young patients participated, five male and five female participants, who were between 14 and 21 years old. They had a variety of chronic diagnoses. The project was evaluated and approved by the data authority for universities in Norway and the privacy officer of AHUS. All participants had given their consent to participate. Additional consent was sought from the legal guardians of the participants that were younger than 16 years old. Further details of the design process can be

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found in [44], which we describe the larger design context, with multiple design projects, in which the design research described in this paper took place.

IV. Results from the Design Process

A. Identifying functionality

During the first workshop, the functionality of the KOOLO transition app was explored with a brainstorming technique [45], resulting in two lists: *Cool-to-have* and *Must-have* [46]. The *Must-have* list consisted of functionalities that the app needs in order to be used, such as calendar for doctor appointments, alarm for taking medicines, checklists, and *recording of the general state* of the user (e.g., mood, energy level), but also attributes, such as *colors* and *privacy*. Color preferences were perceived as very personal and one of the participants proposed that colors could be used to personalize the app [47]. A password or pass code was suggested to keep the content of the app separate from other apps [46]. The *Cool-to-have* list mentioned aspects and functionalities that made the app extra attractive for young people, such as an 'Instagram'-like environment, music play-list (similar to 'Spotify'), and film and television program tips [46]. An analysis of the group discussion of all proposals resulted in the identification of three categories: to have an *overview* (medicines, appointments, routines); strengthen *autonomy* (recording the general state, checklists); and *entertainment* (music, tips).

Figure 3. Design proposals for registering the general state: 1) using a humor-energy ax, 2) rating feeling healthy, energy, and control, and 3) using images.

B. General State

During the second workshop, the *recording of the general state* was one of several functionalities further explored. In a collaborative prototyping session, three design proposals (Figure 3) were presented in the form of both paper-based and digital prototypes. Collaborative prototyping enables the translation of values and needs into design requirements [48][49]. The three proposals reflected different ways of mapping the patients' energy levels and mood. The recording of the general state through images was perceived as more creative and personal. In the discussion that followed, the difference between taking your own photos and finding images on the net was explored, with one participant expressing the concern that finding and uploading images from the net needed focus and energy, which was not always available. Another participant mentioned:

> *When you are really down, we all have our ups and downs, when you are in a bad period, you can go back and see, 'OK, I had a bad January but see how good my February was'. And to see different photos and that there is one, for example, that makes you happy. For example, when you are admitted to the hospital, you can go back and look for what gives you energy, and look at the photos* [46].

C. Mood

The discussions of the three prototypes evolved around the use of photos, colors, and mood. The next iteration of the function for mapping the user's general state focused on these three aspects and consisted of three low-fidelity digital prototypes, which were also produced as plasticized paper printouts. In the ensuing discussions, a new iteration emerged, consisting of a photo tagged with a colored frame, which would be an expression of the mood associated with the photo. Inspired by Snapchat, the popular image messaging and multimedia mobile application, the snapshots take within the KOOL app were named *MoodSnaps*. In order to enable the user to "go back" in time, we used the concept of the *timeline* as an organizing principle for the photos: each photo would be tagged with a date, creating a *MoodLine* (see Figures 4 and 5). During the third workshop the different prototypes were explored and discussed (Figure 4). The participants preferred the option to scroll up and down through the list of photos. Secondly, they preferred photos of the same size to the option to have different sizes, because this gave a better overview of the photos in the timeline. The timeline itself should depend on the date, not on photos, so it would be clear to them on which days they were too tired or sick to add a photo to the timeline.

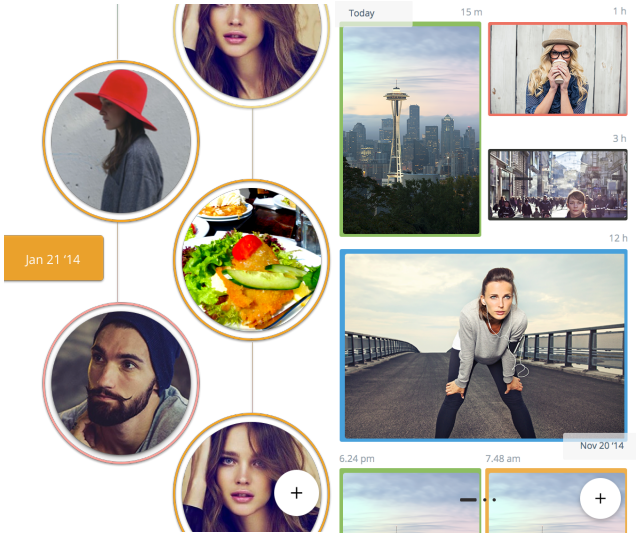

Figure 4. Prototypes of the *MoodLine* explored in the 3rd workshop.

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The timeline of the *MoodSnaps*, photos with different color-tags, inspired a discussion of what they could do with the colors. One participant proposed to add a new option to the mood tracker, namely the possibility to see only photos tagged with one color, similar to Instagram. For example, on a difficult day, the user could scroll through photos tagged with the color-tag *happy* (e.g., yellow), in order to get through the day and inspire or motivate oneself with photos that presented better times or moods. We also explored different options for personalization through colors [47]. The option to allow the user to configure the colors' associated mood meanings was chosen over option to use colors with a default set of moods (See Figure 6). The combination of images and colors enabled a focus on tracking their mood, not on taking pretty pictures. This option also expresses the wide variety of color associations found among the participants, which were the result of age, gender, and personal preferences [47].

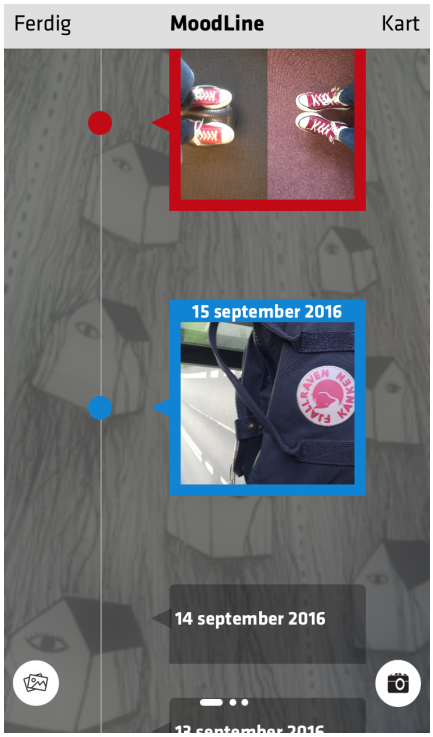

Figure 5. The *MoodLine* (KOOLO app)

D. Final iteration

The final iteration of the mood function was produced in InVision, an online prototyping software for clickable, high-resolution prototypes. During the last workshop, our co-designers were invited to access what was now named the KOOLO app in Invision, in order to click through the different options, such tagging colors with a mood, adding a photo, color-tagging the photo, scrolling through photos, and accessing the mood map to select a collection of photos tagged with the same color. All the participants received information on how to access the online prototype and an invitation to use and evaluate the prototype.

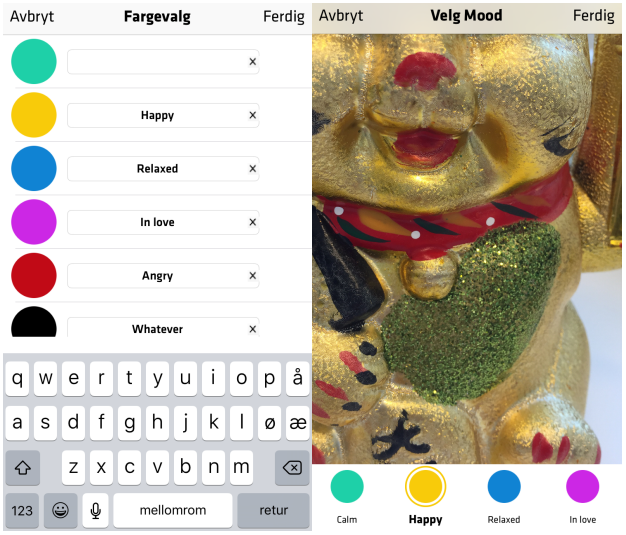

Figure 6. Changing the tags associated with the colors (left) and tagging a *MoodSnap* with a color (KOOLO app).

V. Discussion

"*Lived experience is coloured by mood*" [39]

A systematic review of apps supporting adolescents' personal management of chronic and long-term physical conditions [50] shows that the lack of large-scale studies makes it difficult to find empirical evidence of their benefit, but that engaging the adolescents contributes to changes in the mobile intervention's design. The use of the KOOLO app hasn't been studied yet, but we did find that the engagement of young patients as co-designers did have a tremendous effect on the design of the KOOLO app in terms of it functionality and the particular design aspects within each functionality.

The KOOLO app now has three main functionalities: i) mood tracking, ii) a calendar to keep track of health-related appointments and events the users wish to keep separated from the native calendar app of the phone, and iii) interactive transition checklists, which are based on the paper-based checklists developed and implemented by the Royal Children's Hospital Melbourne [3], the MYHealth Three Sentences Summary of Sick Kids Toronto[4], and Akershus University Hospital[5]. In particular in the mood tracker, the co-designers' preferences and needs form the core of the design (see summary in Table I).

[3] http://www.rch.org.au/transition/factsheets_and_tools/transition_checklists/

[4] http://www.sickkids.ca/Good2Go/For-Youth-and-Families/Transition-Tools/MyHealth-3-Sentence-Summary/Index.html

[5] http://www.ungdomsmedisin.no/resources/

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TABLE I. IMPLEMENTATION OF DESIGN SPECIFICATIONS FOR THE MOOD TRACKER

Requirement	Implementation
1. Recording the general state	Photos in an 'Instagram'-like environment, framed by a mood color
2. Time as organizing principle	A*MoodLine* organized by dates, including dates without photos
3. Color as organising principle	No default settings for tags
	Can be used for personalization of the whole app
	The photos can be organized by color via the *MoodMap* option
4. Privacy	Photos are stored in the app, which is password/code protected

A. *Recording of the general state*

In the discussions on *recording the general state*, the co-designers included their existing experiences with apps, such as that it was easier to take a photo in an app than to find a photo on the web and to import it into the app. They also knew they were often experiencing a lack of energy and had to find the most energy-efficient way to record the state they were in.

Instagram, the popular online photo- and video sharing app, was used by all participants. Their knowledge of how to collect and share data in Instagram, played a central role in how they envisioned the recording of their general state in the app.

The combination of image and color, in the form of a photo framed by a color representing a mood, enables the users to register or track their mood in meaningful way. It enables a bi-directly meaning-making process. The mood color provides context to the image and the image provides context to the color. The fact that the color-framed images are organized by time, enables a third layer of meaning-making, as the date of the color-framed image can be linked to the calendar, another functionality in the transition app (See Figure 7).

B. *Time as organizing principle*

The concept of the timeline evolved very early in the design process into an image-based mood functionality. The *MoodLine* could use the existing functionality of the mobile phone (the native photo app) as input and the participants perceived this as an intuitive, easy, and personal way to track one's mood. Also, the shape of the images reflected the participants' existing app use: square shape of the images was preferred over round-shaped ones, because of its similarity with square-shaped images of the popular Instagram app (see Figures 4 and 5).

Our co-designers also made clear that they wanted to track both positive and negative moods and did not want to favor one type of mood over the other by presenting them in different formats or styles. As an example they mentioned that a day with a negative mood could be a very important day, but that this could get lost in a design that would present positive mood images larger than negative mood images.

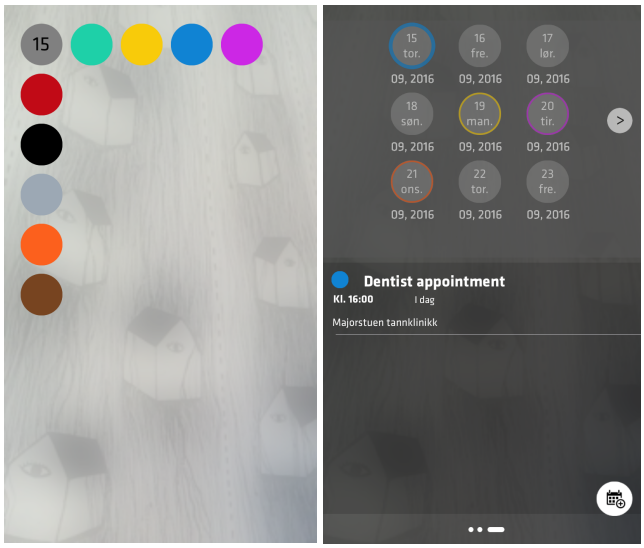

Figure 7. Tagging the date in the calendar with a color (left) and dates tagged with a color in the calendar view (KOOLO app).

This example makes clear that the co-designers were able to find and explore connections between their *lifeworlds* and the specifications of the mood functionality. That they wanted to track their mood in relation to their lived experiences became also clear in the design of the timeline and the application of mood colors to other functionalities in the app. They preferred the *MoodLine* to track all days, not only the days in which a user added a photo. This way, a day without a photo has meaning as well, by evoking reflection on the reason for not adding a *MoodSnap* to the *MoodLine*, such as being too tired or too sick.

Inspired by the color tags of the *MoodLine*, they proposed to use color tags in other functionalities of the app, such as the dates in the calendar functionality of the app. A date tagged with a color thus became a meaningful way to highlight days with doctor appointments or test results (Figure 7).

C. *Color as organizing principle*

The idea for the *MoodMap* (Figure 8) came up in a discussion about keeping an *overview* of things. The larger the MoodLine would become over time, the more difficult it would be to find patterns that were meaningful in the user's life. The proposal for a *MoodMap* was inspired by the Instagram photomap, which geographically maps where a user has taken a photo and shows all photos taken on that same location. Once proposed by one of the members of the AHUS Youth Council, all participants perceived this as a fun and intuitive way of organizing their mood images. The *MoodMap* gives an indication of how many photos are tagged by a particular color. Selecting one color in the *MoodMap* results in a *MoodLine* with only images tagged with the selected color (see Figure 9).

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Figure 8. The *MoodMap* (KOOLO app).

The *MoodMap* visualizes the data tracked in the *MoodLine* in the form of an overview of how many times a particular mood has been tracked in the *MoodLine*. This quantification of mood should not be understood as fixing emotions with a symbol systems [51], but rather it provides i) a new level of meaning to the experienced moods, ii) a new way of accessing moods, and iii) a possibility to influence a mood.

The young patients can use the mood functionality to keep an overview of their moods over time as well as per mood. In addition, they can use mood colors in other functionalities of the app, such as calendar and date functionality. This can give them an understanding of the context in which their moods appear. Keeping an overview and looking for meaning are related to mastery, the experience of emerging stronger from a very stressful health condition [52]. The experience of mastery increases when young patients can participate in a meaningful way in decisions that affect their life. The *MoodMap* allows the user to focus on one particular emotional state, which may affect motivation, inspiration, learning, and change.

D. Privacy

Lastly, the *privacy* specification: the co-designers proposed a strict division on their mobile phone between general apps and an app focusing on their diagnosis or health challenges. The design of the mood functionality, and the KOOLO transition app as a whole, are designed according to *Privacy by Design* principles [53]. Privacy is default, as well as integrated to the system, without diminishing functionality. There is very limited communication between this app and the other apps stored on the mobile phone - data produced in the app, calendar events, photos, and checklist entries are stored within the app – and there is no communication with a website or with third parties. The source code is open and available for investigation.

Figure 9. The view of the *MoodLine* when selecting only one color in the *MoodMap* (KOOLO app)

E. Visualization

Ruckenstein [2], reporting from an empirical self-monitoring study of heart-rate variations, discussed how visualizations enable, promote or intensify emotional attachments between people and their data. It became clear that visualizations represent data that are only a partial presentation of the empirical world [p.76-77]. Ruckenstein concludes that self-tracking technologies have the "ability to reimagining the present" [p.81]. It is this reimagining that is enabled in the KOOLO mood-tracking functionality. For example, in the *MoodLine*, dates without data (a date without a color-framed photo), can be made visible. They can be meaningful, in terms of days, or a whole period, in which the user was too tired or ill to take a picture.

This stands in contrast with many other self-tracking apps, which depend on a daily and structured data input to produce meaningful visualizations. In empirical research on the use of one of those apps [54], we found that the push notifications to the users' phones, prompting them to log the status of their health, were experienced as clashing with their lived bodies. The participants in our study did not continue

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to use the app because it became too intrusive in their symptom-free periods, when they did not identify themselves as patients. This indicated that they only wanted to track their health when they felt like 'patients' (i.e., had symptoms or were involved in activities that brought out their patientness). This provides an important implication for the design of self-tracking devices for young patients.

The *MoodMap*, which visualizes the data of the *MoodLine*, adds another level of meaning. It quantifies the qualitative self-tracking data of the MoodLine, but at the same time offers an esthetical visualization of moods that can be used to *zoom in* into one mood, creating a *MoodLine* of only one mood. The *MoodMap* enables user-initiated ordering and re-ordering of all self-tracked data: mood data as well as non-data, in the form of date tags without mood data (see Figure 5).

F. The SHARM approach

The five principles of the SHARM approach played a central role in creating a *lifeworld-led design process* with the co-designers, the young people with long-term health challenges. The design workshops took place in the hospital, enabling a safe place for reflecting on their experiences and needs as young patients (situation-based action). The iterative approach, in which the design preferences, ideas, and results from the previous workshop were presented in a more developed manner in the following workshop, provided the co-designers the opportunity to see the results of their participation.

The methods we used in the workshops enabled a mutual learning process that was at the one hand explorative and inspiring, and on the other hand based on research and experience. The participants brought in their existing experiences with using apps to discuss options for mood tracking. They were all Instagram users and could bring this experience, in particular the ease of adding a photo and ways of organizing photos, into discussions on the design of the mood tracker.

The SHARM approach extended beyond the design process itself, as the *Adaptability* principle which concerned itself with adapting to the participants' changing physical or emotional state was translated into the MoodLine functionality and availability of visualizing the non-data. Further, the *Adaptability* principle resulted in increased focus on facilitating user appropriation of the features in the KOOLO app. The option to assign moods to colors used in *MoodSnaps* and Calendar allows users to track other values than moods if they choose to do it. In addition, while the design assumes that the main value and information comes from the color tag on the images in the *MoodLine*, we have included a zoom-in functionality in case the users want the images to be the primary source of information.

The KOOLO app has now been fully developed for both the Android and iOS platform. It was launched in a public event with the Youth Council of AHUS, representatives of healthcare organizations, and the design and development team. The Youth Council members expressed their appreciation for being able to participate in a complete design process and to see their ideas and contributions materialized in the application.

VI. CONCLUSIONS

Our study confirms that the participation of young people with health challenges in the design of their own interactive technologies can result in creative and important contributions to the design process. A participatory and *lifeworld*-led design process, based on collaborative methods and an iterative approach, allows young patients to explore mood-related needs and values in a more holistic and relational manner. This resulted in very specific design requirements that were closely related to the young persons' everyday experiences with technology. The popular Instagram app was an important inspiration in the design process. Secondly, it resulted in a more meaningful mood tracking and mapping practice, such as personalizing the use of self-selected colors and self-produced images (*MoodSnaps*); the equal importance of positive and negative moods and days with and without images (*MoodLine*); and the organization of photos by mood (*MoodMap*).

The young patients were met as co-designers and experts of their own life, which enabled them to be heard as well as to have a say in the design process. This allowed them to make important contributions to the design of health IT. In turn, this enabled the researchers to learn more about the young patients' lived bodies, their *lifeworlds*, and the role of technology in their life. SHARM, our design approach, enabled a lifeworld-led design process. As a result, methodology, methods, and design specifications transformed into a holistic process. This became especially clear in the methodological principle of *Adaptability*, which was translated into the design of the mood tracking functionality.

The design of the mood tracking functionality resulted in two new design concepts for organizing mood data, the *MoodLine* and the *MoodMap*. The use of photos, framed with colors representing self-assigned emotional states, enabled a meaningful recording of the young persons' mood in a visually pleasant manner (*MoodLine*) and in a meaningfully organized way (*MoodMap*). The visualization of qualitative self-tracking data is an unexplored topic. In this context, the *MoodMap* provides a simple example of how visualization enables meaning-making as well as providing opportunities for support and change.

The literature mainly discusses self-tracking in the context of quantitative data gathering and the objectification of the human body. We found that it is possible to self-track the lived body, when the self-tracking technology focuses on data that is meaningful to the user and that enables the user to create visualizations.

Future work consists of making the transition app, including the mood functionality, available to a group of test users, with and without a diagnosis, followed by qualitative interviews with the users as well as health personnel. We will also explore what other means of qualitative self-tracking can be added to the mood-tracking functionality of the KOOLO app.

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