MAPPING THE JOURNEYS OF ATRIAL FIBRILLATION PATIENTS AND CITIZENS USING WEARABLE DEVICES FOR REMOTE CARDIAC MONITORING

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ABSTRACT

Atrial Fibrillation (AF) is one of the most prevalent cardiac diseases in the world. How might we design patient journeys improving quality of life using wearable cardiac devices for continuous out of hospital monitoring and support? Most of the studies to date have emphasised the technical aspects of implementing such devices with less focus on human factors. As such, remote cardiac monitoring appears to be burdened by poor patient adherence. This research study proposed a journey map based on Roger's technology adoption model to understand the challenges faced by AF patients and non/asymptomatic patients in using wearable devices to monitor their health. Data from semi-structured interviews conducted in Denmark with 12 participants aged 24 to 65 years was used. Interview results show that citizens prefer tracking heart activity only in conjunction with other measures such as steps or sleep and do not feel motivated to track their heart activity on a daily basis. Patients view wearables as a valuable tool to check if their health is all right, although apprehension that devices can cause unnecessary worry can lead to their rejection. Finally, recommendations for the design of patient journeys when using wearables were made.

Keywords: User centred design, Biomedical design, Inclusive design, Remote patient monitoring, Healthcare

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1 INTRODUCTION

Design engineers have an important role to play in solving complex problems. One such issue where there is a dire need for innovative solutions is heart disease, which is the leading cause of death in today's world. Atrial Fibrillation (AF) is a highly prevalent heart disease that is associated with higher mortality and poorer quality of life. It affects around 0.51% of the total global population (Lippi et al., 2021). A large proportion of cases are initially asymptomatic and episodic in nature, and patients need to be monitored continuously and outside hospitals and typical care environments (Savelieva and Camm, 2000). Nowadays, there are several 'smart' wearable and portable devices including smartwatches and patch electrodes that can remotely monitor heart rate and rhythm using sensors, and automatically diagnose AF in its nascent stages using different algorithms (Egan et al., 2022). These include commercially available devices such as Apple Watch, Fitbit, Zio patch, etc., which have received regulatory approval for their widespread use in different health systems, as well as customised systems such as KardiaMobile (Kumar et al., 2022). Such devices along with their concomitant software applications allow users to observe their heart rate and rhythm in real time, which can empower them in making informed decisions. However, most of the studies to-date have focused on the technological aspects of these devices such as technical implementation, feasibility evaluation, sensitivity and specificity leaving a niche to study in what way we might enhance insights into human factors influencing acceptance, adoption, and experience more widely. As such, it becomes necessary to analyse the entire user journey to understand the different challenges that determine adoption and rejection of such health interventions.

In this paper, we propose the following. Firstly, a literature review on journey maps that explored the processes and measures that have been analysed to-date. Secondly, a novel user-journey map of cardiac wearable devices based on Rogers's technology adoption model (Rogers, 2003), and based on the results, recommendations for the redesign of health interventions using wearable devices. Data from semi-structured interviews conducted on atrial fibrillation patients and other citizens in Denmark was used to develop the journey map. The remainder of the paper is arranged as follows. Section 2 details the literature review on clinical pathways and journey maps. Section 3 and 4 present the methods used and results of the study respectively. The paper concludes in section 5 with a summary, by stating limitations of the study, and by proposing future directions for research.

2 LITERATURE REVIEW

2.1 Clinical pathways vs user journeys: The need for journey maps in remote cardiac monitoring

Traditional clinical practice has to-date focused more on the detection and management of diseases (Perry et al., 2021) with a need to also focus on patients' different needs, motivations, and actions. Healthcare services are delivered through 'clinical pathways' that consist of a set of medical procedures. They do not explicitly account for what patients go through in their daily lives, i.e., their unique journeys. Patient uptake and adoption of interventions is highly influenced by the emotions and feelings patients experience in their journeys (Pal et al., 2018). Remote cardiac monitoring is burdened by a poor patient adherence rate, and thus, few programmes have transitioned from the pilot phase to long-term health interventions. Furthermore, several wearables, especially the more commercially available devices such as smartwatches and fitness bands, are not specifically targeted towards AF or other cardiovascular disease patients. They are also used by healthy individuals and citizens to track their general health and fitness. These citizens may also represent asymptomatic patients, whose arrhythmia can progress to more serious and symptomatic forms. Hence, the differences in the journeys of patients and citizens using wearable devices, which are not captured by current health systems, also need to be ascertained to design more personalised interventions. Healthcare design seeks to empathise and engage more with patients and other stakeholders in the delivery of more personalised health services, and thus, aims to bridge the gap between clinical pathways and patient journeys (Krolikowski et al., 2022). In this context, a journey map as a design tool that visually represents users' experiences and interactions with a product or a service (Howard, 2014) is promising. A journey map depicts the progression of different measures across a period or process. Journey mapping as activity has been proposed as particularly suitable for eliciting experiences and

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pain points with services (Clatworthy et al., 2011) such as remote cardiac monitoring. Patient journey mapping helps in identifying information that has to be shared with patients and guides patients on actions they are recommended to take (Patient Journey App, n.d.).

2.2 The current state of journey maps

A literature review on user journey maps was conducted, firstly, to check whether similar studies on Atrial Fibrillation (AF) have been conducted, and secondly, to formulate a process for building the proposed maps. The following notable Design and Human Cmputer Interaction (HCI) journals and peer-reviewed international conferences were searched using the keywords 'journey' and 'map': For journals, the search included the following, listed in alphabetical order: Artificial Intelligence for Engineering Design, Analysis and Manufacturing (AI EDAM), CoDesign - International Journal of CoCreation in Design and the Arts, Journal of Design Science, Computers in Human Behaviour, IEEE Transactions on Human-Machine Systems, Journal of Ambient Intelligence and Humanized Computing, Journal of Design Creativity, Journal of Engineering Design, Journal of Mechanical Design, Journal of the ACM, Pervasive and Mobile Computing, Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies, Research in Engineering Design, and Design Studies. For peer-reviewed design conferences, the search function on the worldwide Design Society website was used, with the pool of publications including conference proceedings such as ICED, DESIGN, DfX, DSM, E&PDE, NordDesign, and ICDC as well as the search function on the Design Research Society (DRS) website for conference proceedings including those of the DRS, Nordes, Learn X, and Pluriversal Design. The proceedings of the Conference on Human Factors in Computing Systems (CHI) were also searched on the ACM digital library.

The results are summarised in table 1. While journey maps and journey mapping have been used in a wide variety of contexts, we could not find published work on eliciting experiences along user journeys when monitoring Atrial Fibrillation or other cardiovascular diseases using wearable devices. Journey maps have been used to visualise a wide range of processes, from the morning routines of individual participants (Scharoun et al., 2019) to complete industrial design processes (Wodehouse et al., 2020), and public services (Lallemand et al.) consisting of several participants and/or stakeholders. Similarly, maps for healthcare applications have been formulated for multi-stakeholder clinical services (Elizarova and Kahn, 2018) as well as for a single user's experience (Hussein and Sanders, 2012). Hence, journey maps can be tailored to suit different levels of a complex socio-technical system (Moray, 2000; Flin et al., 2009). In considering healthcare as a socio-technical system, the people consisting of patients and carers would be at the centre, and their immediate level of interaction will be with equipment and devices, followed by tasks, workspace, environment, and finally, the organisation and its overarching policies (Norris, 2009). In the case of remote cardiac monitoring, patients would interact first with the equipment consisting of the wearable devices and concomitant digital systems, followed by the different tasks and instructions given by their doctors, their environment consisting of hospitals, homes, etc., and finally, the policies and government regulations covering monitoring. A systems approach to healthcare, or in this case, cardiovascular care, can be seen as an ensemble of patients, physicians, and journeys of other people interacting with different levels of the health system (Thuesen et al., 2022; Komashie et al., 2021). The progression of different measures has been assessed in journey maps. In Bowen et al., (2013) and Hussein and Sanders (2012), participants tracked their positive and negative emotions themselves through self-mapping exercises. Heiss and Kokshagina (2021) analysed the cultural, social, political, and systemic pain points or barriers in the journeys of patients in complex healthcare systems. In Elizarova and (2018), the touchpoints such as phone and mail where a user came into contact with an insurer for a diabetic dental care program were recorded. For data collection, studies on simpler processes have utilised interviews and self-mapping exercises, in which participants themselves lay out their emotions, activities and other measures on the map. However, for more complex processes higher up in the hierarchy of system involving multiple interactions and stakeholders such as complete clinical services, observation studies would be required to overcome the limitations of recalling experiences (Cooney et al., 2018; Heiss and Kokshagina, 2021).

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Table 1. Results of the literature review on journey maps

Paper	Processes	Measures	Data extraction methods
How was it for you? Experiences of participatory design in the UK health service (Bowen et al., 2013)	Outpatient Service and the touchpoints with the service	Emotional maps of healthcare workers and patients Positive and negative emotions	Participant self -mapping in interviews
Fusion of horizons: Co-designing with Cambodian children who have prosthetic legs, using generative design tools (Hussein and Sanders, 2012)	A day in participants' lives	Positive and negative emotions	Participant self -mapping in interviews
Learning histories as an ethnographic method for designing teamwork in healthcare (Kleinsmann et al., 2020)	Personal timelines of staff and patients for a day/shift	Emotions, communication momen ts, medical decisions.	Observations and interviews
Designing healthy futures: involving primary school children in the co-design of a health report card (Scharoun et al., 2019)	Morning routine	Breakfast meals, commute to school, etc.	Self-mapping of activities
The configuration and experience mapping of an accessible VR environment for effective design reviews (Wodehouse et al., 2020)	Complete design process involving clients and designers: Initiation, Presentation, Exploration, Reflection.	Logistical: Workflow and actors Interface: Interactions and spaces used	Observation, Interviews, and Questionnaires
Representational artefacts in social problem solving: A study from occupational rehabilitation (Cooney et al., 2018)	Occupational Rehabilitation Process	Thoughts and feelings of stakeholders in their interactions with each other.	Semistructured interviews, observations, workplace documents
Tactile co-design tools for complex interdisciplinary problem exploration in healthcare settings (Heiss and Kokshagina, 2021)	5 different healthcare cases inculding cancer care, old-age home experience, etc.	Tiles/cards representing: Blocks, Workarounds, Emphathy, Pathways (Connectors), Stakeholders	Interviews and observation
Seamless Journeys to Work: A multifaceted approach to exploring daily journey to work experiences of young people with disabilities (Chamorro-Koc et al., 2020)	Disabled people's journey to work	Challenges encountered while using modes of transport and applications.	Interviews and self-reported observations.
Filling in the gaps: Navigating the human experience of COVID-19 (Rice et al., 2022)	Patient COVID-19 experience from pre-illness to recovery	People involved in recovery Resources used Symptoms Emotions Patient-identified gaps	Interviews
Align and Combine, Customer Journey Mapping and COM-B Analysis to Aid Decision-Making During the Design Process (Elizarova and Kahn, 2018)	Different phases of a preventative diabetic dental care program	The states of patients, insurers, touchpoints, and actors.	Interviews
Physical Journey Maps: Staging Users' Experiences to Increase Stakeholders' Empathy towards Users (Lallemand et al., 2022)	Railway passengers' experiences	Painpoints and feelings	Quantitative and qualitative user research data
Journey Mapping: The Integration of Marketing and User Experience through Customer Driven Narratives (Dove et al., 2016)	MathWorks Hardware support package installation	User self-reported milestones	Interviews

3 RESEARCH METHODS

We decided to focus on the most immediate interactions of patients in socio-technical health and care systems, i.e., those interactions with technology, which in this case consists of the wearable devices. Furthermore, data from semi-structured interviews only would not suffice to support the formulation of higher-order maps, as mentioned in the previous section. The Rogers' user-technology adoption model, which examines the interaction of people with a piece of technology, was selected as the process of the proposed map. It considers the five stages a user goes through when interacting with any piece of technology: Awareness/Knowledge, Persuasion/Interest, Decision/Evaluation, Implementation/Trial, and Adoption/Confirmation. The emotions and thoughts were selected as measures for the map to evaluate the interaction of users with wearable devices. The emotions were broadly classified based on the Russell's circumplex model (Russell, 1980). While current studies have only examined the valence of emotions, i.e., the extent of nature of an emotion that can be negative or positive, as shown in table 1, the circumplex model also considers arousal, which is the intensity of an emotion that can be high or low. This helped us assess both the nature and impact of the interactions with wearables in a user's journey.

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3.1 Data acquisition: Semi-structured interviews with patients and citizens

Data from virtual and in-person semi-structured interviews of 30 to 60 minutes in duration conducted on 5 Atrial Fibrillation (AF) patients in Denmark, aged between 30 and 65 years, and 7 citizens in Denmark, aged between 24 and 33 were used in this study. The participants consisted of both males and females. A combination of snowball and convenience sampling was used to collect data, where participants nominated others for interviews. Participants used smartwatches such as an Apple watch, Garmin watch, and Fitbit, except for one individual who used a simple pulse-oximeter. The interviews investigated different areas including patient pathways, acceptance of new technology, and health prevention. To enrich the information from the interviews, patients were also asked to complete a template detailing the periods of their life before developing symptoms and after treatment. Consent to the anonymised use of their data was obtained from all participants.

3.2 Analysis: Combining interview data with the technology adoption model

The Technology Adoption Model used in this study is described below:

1. Awareness/Knowledge: An individual becomes aware of a piece of technology and its features, i.e., the wearable devices and their sensors and algorithms.
2. Interest/Persuasion: They develop an active interest/disinterest in the device due to different reasons.
3. Evaluation/Decision: They start to mentally envisage different use cases and evaluate the advantages and disadvantages of each case.
4. Trial/Implementation: They actually use the device in different scenarios.
5. Adoption/Confirmation: They decide to keep or stop using the device.

A thematic analysis was performed, where a deductive coding approach was used to broadly split the data in each interview into the 5 themes mentioned above (Fereday and Muir-Cochrane, 2006). 'Adopters' and 'Rejecters' were defined as those participants that adopted and rejected the devices of their own volition. The thoughts, emotions, and pain points of participants were inductively coded. The evaluation and trial stages were combined to facilitate easier comparison between adopters and rejecters of wearables in the study, as most of the people in latter group did not conduct a trial before rejecting the device. Also for adopters, most of the interview questions asked about potential use cases on self-tracking and data use. A case-based analysis was conducted to compare the journeys of patients and citizens.

4 RESULTS AND DISCUSSION

Mapping user experiences elicited through interview with the Technology Adoption Model in mind as well as the underlying elicitation of emotions (Russell, 1980), a characterisation of adopters and rejecters by both patients and citizens were discerned, capturing the following thoughts and emotions and exemplified with interview quotes (see figure 1).

4.1 Patients

Looking at Rogers' stages, awareness of patient users appears unclear. Only 2 patients mentioned the electrocardiogram (ECG) sensors of smartwatches that are responsible for collecting cardiac data. The primary driver for patient interest appears to be anxiousness about their health status. Adopters of wearables desire a tool that can inform them whether everything is all right or that they need to seek immediate medical help. One patient remarked that they were *"left in the dark"*, and that the wearables were the only way to see what was happening to them. They felt that a pacemaker capable of remote monitoring is inadequate as they want to see the results for themselves. The sole rejecter felt that these devices can create unnecessary worry and that they would misdiagnose them and make them go to the hospital for no reason. They took the advice of their doctor to not buy wearables; they said that they trusted their medical doctor more than any device as they have access to their complete medical history and were in a better position to help them. They also stated that they would deactivate the AF tracking feature should they ever decide to acquire a wearable. This directly contradicts the thoughts of an adopter who was a married mother of a young child who felt that remote monitoring can help reduce the number of visits to the hospital. The adopter also recounted that their device would occasionally measure their heart rates incorrectly, which can lead to undesired visits to the hospital.

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All the patients showed a willingness to share their data with health systems and wearable device companies, while some stated that they would only do so with reputed organisations that they trust. The adopters stated that they would track their heart rate and rhythm every day, with some of them doing so during or after intense physical activity such as biking and other exercises.

4.2 Citizens

Unlike patients, some of the citizens did have a technical background and were aware of the sensors and algorithms used in smartwatches. The adopters were primarily interested in a gadget that could record their heart rate during physical activity in conjunction with other measures such as steps or sleep. One adopter stated that they *"do not pay attention"* to the heart rates in their watch and another felt that an irregular heart rhythm notification would not motivate them to contact a doctor. The rejecters, similar to patients, felt that devices cannot replace doctors. Both adopters and rejecters see daily self-tracking as a tedious process and feel it is unnecessary since they are not ill. They would only do so on the advice of their physicians. In comparing the personas of patient and citizen rejecters, it can be seen that the negative emotions of the former have more intensity compared to those of the latter. This indicates that the pain points in patient journeys caused more aggravation and had a profound impact on the quality of their life. However, among adopters, patients' emotions associated with self-tracking were higher in both arousal and valence, which shows that they have more enthusiasm for monitoring.

4.3 Design directions for wearable device interventions

4.3.1 A behaviour based approach to address user need/anxiousness

As discussed above, patient and citizen journeys appear different. To ensure adoption, wearables need to be pervasive enough to help relieve patients' anxiousness through health monitoring, but not so much as to make them apprehensive about their future through 'over-monitoring'. Citizens desire monitoring to be even less pervasive, which can be problematic if they are actually asymptomatic patients, as AF cases can get undiagnosed. The current commercial nature of 'smart' wearables pushes these devices to notify users of their heart rate and rhythm repeatedly; usually a number of times every day. Design for human behaviour in a systemic world considers the nuances of human behaviour in developing interventions (Maier and Cash, 2022), which can be broadly classified into behaviour change interventions, which aim at modifying user behaviour and behaviour driven interventions, which collect behavioural data from patients to act accordingly (Ciccone et al., 2019). The former is more suitable for citizens and asymptomatic patients who need to be nudged to participate in more pervasive monitoring, while the latter is appropriate for diagnosed patients, whose anxiousness and concerns need to be addressed in the design of interventions.

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User Journey | **Patient Adopter**

	Awareness	Interest	Evaluation & Trial	Adoption
Thoughts	Aware of wearable sensors and Telemedicine. Detailed knowledge of sensors and regulatory status unclear.	Worries about their heart condition and wants to see the results of monitoring themselves.	Interested to self-track and share data with doctors and reputed organizations.	Tracks heart rate if they feel symptoms.
Quotes	*"These apps can "ring the bell" to the patients. In other words, they can show them some indications for the status of their heart and health."* Source: Patient Interview C	*"It is nice to see if it everything ok or if something is wrong."* Source: Patient Interview A	*"It (data sharing) depends again on which company it is, how much I am trusting this company. I want someone to handle my data in a good way."* Source: Patient Interview A	*"If I have a high or low pulse I would call to the doctor. The watch is the only way for me to see how my heart is going."* Source: Patient Interview B
Emotions	unsure	anxious about health	Unconcerned about data privacy	interest in self-tracking

User Journey | **Patient Rejecter**

	Awareness	Interest	Evaluation & Trial	Adoption
Thoughts	Aware of the ECG sensors and the new AF tracking algorithm of the Apple watch. Researched to check for FDA approval.	Monitoring will create unnecessary worry.	Would deactivate AF feature if using the watch.	
Quotes	*"I researched and I found that atrial fibrillation is supported by a new feature in the Apple watch. I have read extensively the reports."* Source: Patient Interview E	*"Even if you do not have any type of arrhythmia and you are healthy, it will monitor any arrhythmia and you will go to the hospital for no reason."* Source: Patient Interview E	*"You need to discuss with your doctor and do not see it technologically. So, if I buy anApple watch, I would deactivate the AF feature."* Source: Patient Interview E	
Emotions	aware	anxious	anxious	

User Journey | **Citizen Adopter**

	Awareness	Interest	Evaluation & Trial	Adoption
Thoughts	Aware of wearable sensors based on occupation and job experience.	Does not pay much attention to the heart rate feature. Does not feel 'irregular' heart rhythm notification would motivate them to seek medical attention.	Will self-track on the advice of physicians and/or if they are ill.	Tracks heart rate during physical activity in conjunction with other features such as steps and calories.
Quotes	*"I was working with sensors so it is easy for me to detect some errors. One thing to concern me is the bugs. It influences the accuracy."* Source: Citizen Interview E	*"I am not sure if I would be motivated enough to really look into it and analyze the data."* Source: Citizen Interview C	*"If the doctor told me to track and share my data with him/her I would share it. If I had a health issue and I knew that I would benefit from tracking it, I would track myself."* Source: Citizen Interview C	*"It is much easier to know how to progress and control your workout if you are tracking yourself."* Source: Citizen Interview E
Emotions	confident of knowledge	uninterested in tracking heart	trust Physicians	uninterested in self-tracking

User Journey | **Citizen Rejecter**

	Awareness	Interest	Evaluation & Trial	Adoption
Thoughts	Aware of wearable sensors and the technology behind them.	Considers self-tracking a time-consuming task.	Would not track ECG data every 24 hours as they are not ill.	
Quotes	*"I do not really trust them (wearable sensors). I can say that the state of research and development is not enough."* Source: Citizen Interview A	*"Self-tracking is a tedious task that requires investing time and yourself in it."* Source: Citizen Interview B	*"I do not have a heart related disease I would not track my ECG 24 hours per day, I would spend my money elsewhere."* Source: Citizen Interview A	
Emotions	unsure	uninterested	uninterested	

High arousal/high valence; Low arousal/high valence; High arousal/low valence; Low arousal/low valence

Figure 1. The journey maps of 4 different users: patient adopter, patient rejecter, citizen adopter and citizen rejecter

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4.3.2 Co-design to include physicians in the monitoring process

Both patients and citizens seem to give a lot of importance to their relationships with their doctors. In the interviews it was observed that there was a lack of clinical integrability with wearables. Patients should not be forced to choose between their devices and their doctors. At the most immediate level of a health system, physicians need to use these devices in a similar fashion to other more 'standard' medical devices such as stethoscopes and x-ray machines. This is possible only through co-design, i.e., the involvement of doctors along with other stakeholders in the design of interventions (Mrklas et al., 2020). Health systems across the world have started to consider the importance of co-designing interventions with stakeholders. For example, standard 8 of the evidence standards framework (ESF) of the United Kingdom's National Institute for Health and Care Excellence (NICE) states that healthcare professionals need to be involved in the design, development, and testing of digital health intervention or must support its deployment (NICE UK, 2022). Wearable devices generate a huge amount of data, of which not all is useful to physicians and can cause 'information overload' (Alpert et al., 2020), calling also for training in visual literacy. Visual literacy is defined as the ability to decode and interpret visual information, which in this case are the recordings, metrics, and notifications from a wearable device (Metros, 2008). The device outputs need to be streamlined to ensure that healthcare professionals also find them discernible.

5 CONCLUSION AND FUTURE WORK

The study proposed, firstly, a literature review of patient journey maps to date including an analysis of their use in examining interactions with different levels of socio-technical systems in the context of Atrial Fibrillation (AF) monitoring and secondly, a journey map utilising the technology adoption model (Rogers, 2003) combined with the circumplex model of emotions (Russell, 1980) to understand the needs and expectations of users of cardiac wearables. It highlighted and illustrated the differences in the journeys of AF patients and citizens or asymptomatic patients. In the interviews, participants displayed a full spectrum of emotions across the different stages of the journey map (awareness, interest, evaluation & trial, and adoption). The implications for the design of health interventions using wearable devices, namely, the need to understand user behaviour, and the use of co-design to involve physicians in the design process, were discussed. However, the study did have some limitations. Firstly, some of the interviewed citizens had a technical background and were more aware of wearables and sensors compared to patient interviewees. This could have been a confounding variable. Secondly, the device type was not treated as an independent variable. As mentioned above, there are different kinds of wearable devices, and the study did not consider patch electrodes and implantable loop recorders. Thirdly, several questions, especially those examining the 'evaluation & trial' stage of the map relied on participants' recollection of their experiences, which may have been subject to recall bias. This also meant that the exact nature of transition between the stages could not be determined. Future studies should utilise observations to alleviate these issues. Fourthly, there was a stark difference between the ages of the patients and citizens, which may have also influenced the results of the study. Finally, the sample size of 12 is not representative of the wider population. However, this work can be regarded as an exploratory study that can direct future research towards journey mapping for cardiac wearables. To conclude, we believe that remote AF monitoring interventions utilising 'smart' wearables need to be redesigned to become smarter and more inclusive in supporting user journeys.

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