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Knoche, Hendrik; Abdul-Rahman, Alfie; Clark, Leigh; Curcin, Vasa; Huo, Zhiqiang; Iwaya, Leonardo Horn; Lemon, Oliver; Mikulik, Robert; Neate, Timothy; Roper, Abi; Skovfoged, Milo Marsfeldt; Verdezoto, Nervo ; Wilson, Stephanie; Ziadeh, Hamzah

Identifying Challenges and Opportunities for Intelligent Data-Driven Health Interfaces to Support Ongoing Care

HENDRIK KNOCHE, Department of Architecture, Design and Media Technology, Aalborg University, Denmark

ALFIE ABDUL-RAHMAN, Department of Informatics, King's College London, UK

LEIGH CLARK, Bold Insight, UK

VASA CURCIN, School of Population Health and Environmental Sciences, King's College London, UK

ZHIQIANG HUO, Department of Population Health Science, King's College London, UK

LEONARDO HORN IWAYA, Privacy and Security (PriSec) Research Group, Department of Mathematics and Computer Science, Karlstad University, Sweden

OLIVER LEMON, Department of Computer Science at Heriot-Watt University, UK

ROBERT MIKULIK, Neurology Department of the St. Anne's University Hospital, Brno, Czech Republic

TIMOTHY NEATE, Department of Informatics, King's College London, UK

ABI ROPER, School of Health and Psychology at City, University of London, UK

MILO M SKOVFOGED, Department of Architecture, Design and Media Technology, Aalborg University, Denmark

NERVO VERDEZOTO, School of Computer Science and Informatics, Cardiff University, UK

STEPHANIE WILSON, Department of Computer Science, City University London, UK

HAMZAH ZIADEH, Department of Architecture, Design and Media Technology, Aalborg University, Denmark

This workshop will explore future work in the area of intelligent, conversational, data-driven health interfaces both from patients' and health care professionals' perspectives. We aim to bring together a diverse set of experts and stakeholders to jointly discuss the opportunities and challenges at the intersection of public health care provisioning, patient and caretaker empowerment, monitoring provisioning of health care and its quality. This will require AI-supported, conversational decision-making interfaces that adhere to ethical and privacy standards and address issues around agency, control, engagement, motivation, and accessibility. The goal of the workshop is to create a community around intelligent data-driven interfaces and create a road map for their future research.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**.

Additional Key Words and Phrases: data-driven interfaces, patient journey, data sharing, agency, trust, patient engagement, healthcare professionals, clinical settings, patient-clinician interaction, decision support, care pathways, conversational user interfaces, NLP

1 BACKGROUND

The global increase of chronic health conditions, the rise in ageing populations worldwide, and improvements in healthcare are saving the lives of more people but leaving them with varying degrees of disability. Moving forward, this will necessitate fundamental adjustments in health care provisioning. Both the management and prevention of chronic conditions requires people (supported by their carers) to take an active role in their self-care management [35]. This includes monitoring symptoms, adhering to treatments, self-rehabilitation, dealing with emotional concerns, reducing direct interactions with healthcare professionals, and gradually shifting care responsibilities to the individual [3]. Similarly, health care professionals (HCPs) need subjective, so-called patient reported outcome measures (PROM) [12] for the implementation of evidence-based treatments and to understand longer term impacts of the care provided. Currently, these processes rely on mandated or voluntary [28] use of health registries for monitoring, bench-marking, and peer comparisons between clinics, hospitals, regions, and countries.

Based on data, technology can provide many opportunities to support 1) professionals in improving health care processes and providing care and 2) people and their carers in their own self-care management as part of their everyday lives [14, 31]. For the latter, mobile and pervasive technologies for mobile (mHealth) and ubiquitous health (uHealth) systems already provide a wide range of wellness and fitness applications and clinical systems that collect objective measures. This trend is matched by needs in the medical field to pursue evidence-based treatments and data-driven individualised healthcare including recent drives to include PROMs as part of what the CHI community more commonly refers to as patient generated data (PGD) [13]. PROMs need to be provided manually by patients in, e.g., telehealth systems to gain a more comprehensive picture about efficacy and satisfaction with treatments. However, these systems should not relegate patients to passively monitoring data, e.g. without access to the data [15, 29], but should encourage mutual understanding between HCPs and patients on the extent and potential use of tracked data [32].

Given the large amounts of data recorded and dimensions tracked, clinicians require support from (explainable) AI based tools [1] drawing on data visualisations, statistical analysis support, and potentially storytelling to convince management and colleagues to bring about change and support the construction of data-driven clinical pathways [4, 5]. Future patient-facing tools and services will need to motivate and support patients in their efforts to not only track and share data with the clinicians, but also provide advice [40] and facilitate sense-making and self-reflection to support care decision-making in daily life in collaboration with their carers and HCPs [9]. Patients might further be seeking consolation, encouragement, and other emotional support.

Creation of these novel services will require support and consideration from a range of interdisciplinary actors and domains: patients, health care professionals and clinicians, as well as experts in decision support systems, conversational user interfaces, natural language processing (NLP), (explainable) AI, trust, ethics, privacy, security, standardisation/interoperability, and science and technology studies. Accessibility and adaptability will be key design challenges to consider in relation to both patients and healthcare professionals. On the one hand, patients with motor, cognitive, or linguistic impairments might find it difficult to engage with standardised self-care technologies at home, and the motivational and persuasive aspects future health interfaces will need to address will necessitate new accessibility considerations and insights. On the other hand, healthcare professionals might face challenges not only engaging with poorly designed data collection tools but also processing and securely using clinical information as well as other socio-technical challenges [8].

To address the aforementioned challenges and enhance the active participation of patients and healthcare professionals in the design of these intelligent data-driven health interfaces, service designers will need a better understanding of

these stakeholders, their contexts, and their goals. More research is needed to create appropriate design tools and methods to support this process. For example, while some laudable efforts have been made towards publishing, e.g., for older adults in general [44] with heart failure [16], accessibility needs [30] and users of online health communities [17], there is still a long way to go for having contextually situated morbidity-specific personas. In addition, previous research has highlighted the opportunities to use large scale data [20, 41, 44] to define personas grouping them by similarities in goals and attitudes or using hybrid approaches, or how personas might be co-designed with end-user communities with access and health needs [30]. Personas should be particularly helpful in designing conversational [23] or autonomous agents [6] and their personalities, e.g. when emulating supportive peers with similar impairments but should be morbidity-specific for attitudes and advice to be of use to patients [40].

1.1 Related Workshops

This workshop builds conceptually upon prior successful workshops at CHI and CSCW, which have explored: human-data interaction [36] (CHI 2021), supporting transitions from health technology dependence to independence [37] (CHI 2021), self-care design [42] (CSCW 2014), the future of care work [21] (CSCW 2021), infrastructuring work of patients and cargivers [10] (CHI 2019), conversational agents in healthcare [24] (CHI 2020), the ethics of conversational user interfaces [26] (CHI 2022), individual differences in privacy [43] (CHI 2021) and its design for vulnerable populations [27] (CHI 2020). Two workshops are particularly pertinent to the current propsal. The first is Ongwere et al. [33]'s CHI 2022 workshop (including co-organiser Verdezoto Dias), which explored how we might address the management of complex health needs through the lens of technological ecosystems – e.g., a range of technologies to support user needs (c.f. [7], CHI 2020). The second focused on realizing AI in healthcare [34] (CHI 2021). Our workshop adds to this discourse by specifically focusing on the increasingly important role of data – its collection, its presentation, and data-supported decision making – in health interfaces for patients and health care professionals.

2 CHALLENGES AND RESEARCH QUESTIONS

This section details a non-exhaustive list of potential topics to be discussed using the scenarios in the user journeys of HCPs and patients depicted in Figure 1 as individual lenses.

Agency and control: Ethical and regulatory standards are high for decision-making that directly impacts patients' health and care (patient-facing) or indirectly impact them through changes in health care provisioning (HCP-facing). For clinician-facing intelligent interfaces we draw on concerns raised by Correll on automated analyses, machine learning, and provenance as starting points [11]. How much guidance should intelligent interfaces provide for HCPs trying to find causes for poor care provisioning? To what degree should these interfaces restrict actions likely to lead to spurious conclusions akin to p-hacking? To our knowledge, current health registries do not provide HCPs with guidance to analyse data statistically or understand findings from complex machine learning models. How, and how many insights requiring human follow-up should intelligent dashboards present to users? What roles should auditing and logging interactions play? How should conversational user interfaces integrate with data dashboards, visualisations and draw on tools such as data storytelling?

Engagement and motivation: Participation of patients in user-centred design has the potential to improve individualised healthcare decisions by better meeting user needs. Engagement among patients may be low if they do not perceive the technology as beneficial to their health and well-being. While previous research highlights the importance of understanding people's motivation to perform self-care activities and use self-monitoring technologies [15], motivating people to engage in self-care is hard and little is known about attitudes towards and potential barriers to patient

engagement with design [38]. How do we, intrinsically or extrinsically, motivate patients with different outlooks, e.g. those who are not interested in taking a more active stance in their health care? How does motivation depend on other aspects? Do we need to motivate clinicians entering and analysing data and if so, how? How to best motivate patients to participate in data-driven technology development and evaluation, particularly for elderly and disabled patient groups? What are the cost-effective incentives to improve patient engagement as well as the utilisation of the developed technology? How can we nudge users despite the asymmetry between patients and clinicians that currently impedes the sharing and reviewing of recorded data [32]?

Accessibility and understanding: How easily can the processes for data entry and review be understood and undertaken by novice users who may have cognitive, communicative, sensory and/or mobility disabilities? How can systems accommodate the needs of users with existing, newly acquired, or degenerative conditions over time? In cases of severe impairments, how can design support users to engage in data collection and reflection activities? Ethical and regulatory standards are high for decision-making that directly impacts patients' health and care (patient-facing) or indirectly impacts patients through changes in health care provisioning (HCP-facing). How do we best onboard patients and clinicians? How can we make complex, AI-supported, decision support tools more transparent and accessible to patients and caretakers (c.f. [2])? How might we provide insights from decision support tools, which are actionable for people to manage their health [25].

Trust and data veracity: How do we address shortcomings in conversational ability of intelligent interfaces that might erode trust in the provided insights and advice? How should advice dispensed by automated decision making systems be validated and who bears responsibility when the individual profile data providing the basis for the advice is inaccurate? How should systems structure interactions to assess and cross-check entered data to ensure high veracity that does not burden HCPs (c.f. [40])?

Privacy: How do we effectively employ data minimisation strategies to ensure privacy and, at the same time, create rich repositories and registries of data? Data-driven projects may want to collect data for unforeseen purposes e.g. to avoid Simpson's paradox [39], combine data-sets, or even create "data lakes". This becomes a privacy issue, since there can be significant expansion of user profiling activities, inference of new data, etc. How do we create friendly consent interfaces that do not impede on-boarding processes and still meet their purpose? How can patient and user consent be managed dynamically? For example, when users change their minds, or are asked for consent for additional data and processing purposes [19, 22]. How do we effectively return control of data to users? How can we enable transparency and the ability to intervene in systems so that users know what data has been collected, how it is processed and who has been accessing the data? This must specifically allow users to exercise various privacy rights [18] such as access, correction, deletion and object processing whenever possible in the healthcare context.

3 ORGANIZERS

- **Alfie Abdul-Rahman** is a Lecturer at the Department of Informatics, King's College London. Her research interests include information visualisation, visual analytics, computer graphics, and digital humanities.
- **Leigh Clark** is a Senior UX Researcher at Bold Insight UK. His research focuses on the domain of conversational user interfaces (CUIs) and how they can be made more inclusive and trustworthy.
- **Vasa Curcin** is a Professor of Health Informatics at King's College London and leads the Biomedical Informatics Group focusing on learning health systems, including guideline-based decision support systems, application of machine learning methods to novel data sources, such as social networks, and standardising big data analytics.

- **Nervo Verdezoto Dias** is a Senior Lecturer at Cardiff University. He has investigated how people use self-monitoring technologies in their everyday life and how these shape their everyday practices, clinical encounters and decision making. His recent work investigates healthcare infrastructures in the Global South and how socio-technical and cultural practices influence maternal and child health practices and pregnancy complications.
- **Zhiqiang Huo** is a Research Associate at the Department of Population Health Science, King's College London. His research lies in applying data to improve patients' healthcare and outcomes, including designing and developing patient-centred dashboards and applying AI to improve clinical decision-making.
- **Leonardo Horn Iwaya** is an Associate Senior Lecturer at the Department of Mathematics and Computer Science, Karlstad University. His work focuses on the privacy and security aspects of digital health, especially mobile health (mHealth) and ubiquitous health (uHealth) systems.
- **Hendrik Knoche** is an associate professor at the Faculty of IT and Design at Aalborg University. His research focuses on human computer interaction in the health domain on creating accessible and engaging data-driven experiences for patients to support their recovery and rehabilitation efforts.
- **Oliver Lemon** is a Professor in the Department of Computer Science at Heriot-Watt University, Edinburgh. His research focuses on conversational AI, Natural Language Processing (NLP), and Human-Robot Interaction (HRI), with applications in healthcare systems.
- **Robert Mikulik** is a professor at the Department of Neurology at St. Ann's Hospital in Brno. His main research and professional interests are diagnostics, treatment and prevention of acute stroke, and stroke care organization and its quality. For the latter, he founded the stroke registry RES-Q currently used by 1700+ hospitals worldwide.
- **Timothy Neate** is a Lecturer at the Department of Informatics, King's College London. His work considers human-computer interaction and accessibility, focusing on interaction techniques to support communication and creativity.
- **Abi Roper** is a Research Fellow at the School of Health and Psychology at City, University of London. She is a qualified speech and language therapist and her work focuses on supporting and promoting access to technology for people with communication disabilities.
- **Milo M. Skovfoged** is a PhD student at the Faculty of IT and Design at Aalborg University. His research on focuses using human-computer interactions to motivate patients to continuously collect health data.
- **Stephanie Wilson** is Professor of Human-Computer Interaction at City, University of London. Her research focuses on human-computer interaction for digital health, and inclusive interaction design for people with communication impairments.
- **Hamzah Ziadeh** is a PhD student at the Faculty of IT and Design at Aalborg University. His research focuses on human-computer interactions between healthcare clinicians and exploratory data dashboards to improve the quality of care provided to patients.

4 WORKSHOP LOGISTICS

4.1 Presence

A workshop website will be the central point for communication before and after the workshop. It will contain the details of the call for participation, submission instructions including deadlines, participant submissions, the workshop agenda, and relevant media on the topics of discussion and if called for the links to all virtual attendance and collaboration tools.

Should it not be possible to run the workshop physically due to, e.g., Covid restrictions, we will rely on the following fall-back plan. The workshop will run over Zoom, Remo or similar platforms for forum discussions and breakout rooms. Collaborative work during the session will be supported through collaborative tools such as Miro, and communication through Discord channels or similar. In case of a hybrid event, we will follow the above approach for the online participants.

4.2 Attendees

We will welcome 20-25 attendees interested in the workshop topics coming from different interdisciplinary backgrounds including patients, patient advocacy groups, health care professionals, care managers, researchers from social sciences, health science, science and technology, and HCI backgrounds, as well as regional professional groups for a diverse and complimentary audience. Solicitation will include, targeted emails to authors of cited references, online channels like social media and mailing lists, and professional networks, e.g., relevant COST actions. Prospective attendees will submit a one-page position paper or other format containing a mini-bio and their ongoing, past, or planned work.
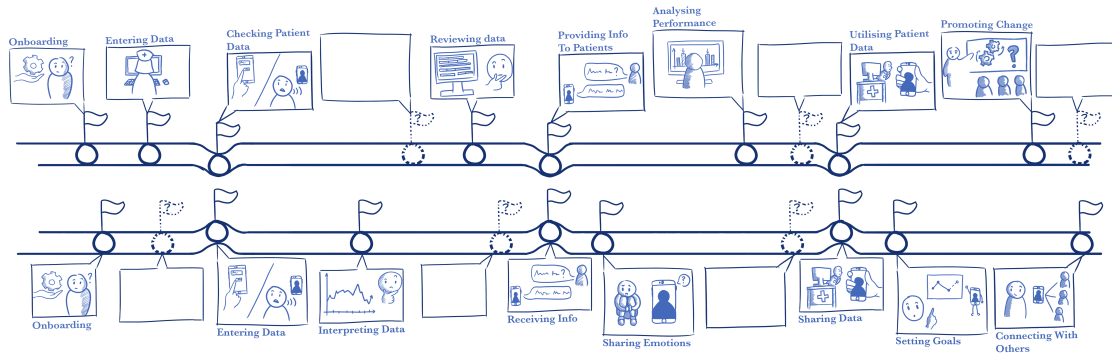

Fig. 1. Poster for: Two user journeys 1. *Improving health care provisioning* (health care professionals, top) and *Moving towards self-care* (patients, bottom) serve as a starting point for guiding the collaborative brainstorming and discussions around the challenges and research questions. Placeholders signify the opportunity for attendees to add scenarios anywhere in the timelines during the cafés and the workshop.

5 WORKSHOP STRUCTURE

5.1 Call for Participation

Drawing on the themes, challenges, and research questions detailed in Section 2, we will invite authors to submit a position paper of up to one page (ACM single-column format) detailing their interest, past, current, and future work in the topic. Position papers in PDF-format are due by February 14, 2023. We will elicit position papers from a variety of perspectives using our channels. We will reach out to our immediate 'HCI' audience through channels such as CHI meta and the SIGCHI mailing lists. We will also aim to invite and bring people from outside the traditional CHI audience to the session – e.g., clinicians, patients, patient advocacy groups, industrial partners. We will target these through our established networks and patient-participation involvement (PPI) groups. Submissions will be reviewed by the workshop organisers. Acceptance will be based on relevance and the potential of the position paper and its authors to generate discussions at the workshop. At least one author of an accepted position paper must attend the workshop;

registering for at least one day of the conference. For more detailed information they can visit the workshop website: https://iddhi2022.create.aau.dk/.

5.2 Pre-Workshop Activities

We will hold two online cafés over Zoom with support from a Miro board amending a poster of user journeys and scenarios as a starting poing (see Figure 1) to refine and elicit further scenarios and design tensions for discussion at the workshop.

5.3 Workshop Design

The workshop will start with a brief welcome of the organisers and introduction of the agenda and goals of the workshop. This includes two motivational video vignettes one of a patient one from an HCP, which we will produce upon acceptance of the workshop.

Activity	Duration
Welcome and agenda	20 minutes
Icebreaker and participant introductions	45 minutes
Coffee break	15 minutes
Interactive exercise I	120 minutes
Group lunch	60 minutes
Sharing of exercise I work (show and tell)	60 minutes
Reshuffled interactive exercise II	60 minutes
Coffee break	15 minutes
Summary from exercise II	45 minutes
Wrap-up and next step planning	20 minutes

Table 1. Workshop timeline: To be updated based on the number of registered attendees.

Ice-breaker activities will include participant introductions, eliciting their expectations, and affinity mapping of their interests based on their workshop submissions. A coffee break will provide some mingling before the first interactive exercise facilitated by the organisers based on the user journey scenarios poster depicted in Figure 1. Current scenarios include on-boarding, data entry, data checking, interpreting and reviewing data, providing/receiving advice and information, sharing emotions and data, utilising collected data, settings goals, connecting with others, and promoting change. The participants will elaborate on challenges and opportunities for the different scenarios vis-a-vis and drawing on the design tensions to identify themes and document them on the poster through post-its. After lunch, the break-out groups will share summaries of their deliberations based on the posters and then re-shuffle for a follow-up elaboration and reflection exercise to work on gaps, differences, and contradictions identified during the sharing round. A second coffee break will precede the final presentations from the second break-out round. The workshop will wrap up with discussions and details on the post workshop plan.

5.4 Post-Workshop Plans

We will keep the website as an online repository of the position papers and a starting point for people who want to reach out to currently interested parties in the domain. Based on the created artefacts, discussions, and analysis we propose to prepare an article in a special interest magazine (e.g. ACM Interactions), which would hopefully lead to a

roadmap or white paper on the topic in e.g. IJHCS, Interacting with Computers. In case of sufficient interest from the participants, we will form a team to submit a proposal for a follow-up Dagstuhl seminar to explore the topic in more depth, and potentially work on larger (e.g. EU-funded) bids with our new topic alignment.

ACKNOWLEDGMENTS

REFERENCES

[1] Ashraf Abdul, Jo Vermeulen, Danding Wang, Brian Y. Lim, and Mohan Kankanhalli. 2018. Trends and Trajectories for Explainable, Accountable and Intelligible Systems: An HCI Research Agenda. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. Association for Computing Machinery, New York, NY, USA, 1–18. https://doi.org/10.1145/3173574.3174156

[2] Panos Balatsoukas, Talya Porat, Isabel Sassoon, Kai Essers, Nadin Kokciyan, Martin Chapman, Archie Drake, Sanjay Modgil, Mark Ashworth, Elizabeth Sklar, Simon Parsons, and Vasa Curcin. 2019. User Involvement in the Design of a Data-Driven Self-Management Decision Support Tool for Stroke Survivors. In *IEEE EUROCON 2019 -18th International Conference on Smart Technologies*. IEEE, Novi Sad, Serbia, 1–6. https://doi.org/10.1109/EUROCON.2019.8861812

[3] Julie Barlow, Chris Wright, Janice Sheasby, Andy Turner, and Jenny Hainsworth. 2002 Oct -Nov. Self-Management Approaches for People with Chronic Conditions: A Review. *Patient Education and Counseling* 48, 2 (2002 Oct -Nov), 177–187. https://doi.org/10.1016/s0738-3991(02)00032-0

[4] Emma Beede, Elizabeth Baylor, Fred Hersch, Anna Iurchenko, Lauren Wilcox, Paisan Ruamviboonsuk, and Laura M. Vardoulakis. 2020. A Human-Centered Evaluation of a Deep Learning System Deployed in Clinics for the Detection of Diabetic Retinopathy. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*. Association for Computing Machinery, New York, NY, USA, 1–12. https://doi.org/10.1145/3313831.3376718

[5] Joao H. Bettencourt-Silva, Jeremy Clark, Colin S. Cooper, Robert Mills, Victor J. Rayward-Smith, and Beatriz de la Iglesia. 2015. Building Data-Driven Pathways From Routinely Collected Hospital Data: A Case Study on Prostate Cancer. *JMIR Medical Informatics* 3, 3 (July 2015), e4221. https://doi.org/10.2196/medinform.4221

[6] Alexandru Bundea and Peter Forbrig. 2022. Patient and Therapist Model Attributes for Social Robot Stroke Therapies Based on Implicit Knowledge from Expert Interviews. In *Human Centred Intelligent Systems (Smart Innovation, Systems and Technologies)*, Alfred Zimmermann, Robert J. Howlett, and Lakhmi C. Jain (Eds.). Springer Nature, Singapore, 41–51. https://doi.org/10.1007/978-981-19-3455-1_4

[7] Eleanor R. Burgess, Alice Renwen Zhang, Jessica L. Feuston, Madhu C. Reddy, Sindhu Kiranmai Ernala, Munmun De Choudhury, Stephen Schueller, Adrian Aguilera, and Mary Czerwinski. 2020. Technology Ecosystems: Rethinking Resources for Mental Health. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) *(CHI EA '20)*. Association for Computing Machinery, New York, NY, USA, 1–8. https://doi.org/10.1145/3334480.3375166

[8] Federico Cabitza, Andrea Campagner, and Clara Balsano. 2020. Bridging the "Last Mile" Gap between AI Implementation and Operation: "Data Awareness" That Matters. *Annals of Translational Medicine* 8, 7 (April 2020), 501. https://doi.org/10.21037/atm.2020.03.63

[9] Carrie J. Cai, Samantha Winter, David Steiner, Lauren Wilcox, and Michael Terry. 2019. "Hello AI": Uncovering the Onboarding Needs of Medical Practitioners for Human-AI Collaborative Decision-Making. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (Nov. 2019), 104:1–104:24. https://doi.org/10.1145/3359206

[10] Yunan Chen, Nervo Verdezoto, Xinning Gui, Xiaojuan Ma, Claus Bossen, Naveen Bagalkot, Valeria Herskovic, and Bernd Ploderer. 2019. Unpacking the Infrastructuring Work of Patients and Caregivers around the World. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems (CHI EA '19)*. Association for Computing Machinery, New York, NY, USA, 1–8. https://doi.org/10.1145/3290607.3299021

[11] Michael Correll. 2019. Ethical Dimensions of Visualization Research. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland UK) *(CHI '19)*. Association for Computing Machinery, New York, NY, USA, 1–13. https://doi.org/10.1145/3290605.3300418

[12] Prasanna R. Deshpande, Surulivel Rajan, B. Lakshmi Sudeepthi, and CP Abdul Nazir. 2011. Patient-Reported Outcomes: A New Era in Clinical Research. *Perspectives in clinical research* 2, 4 (2011), 137. https://doi.org/10.4103/2229-3485.86879

[13] Mayara Costa Figueiredo and Yunan Chen. 2020. Patient-Generated Health Data: Dimensions, Challenges, and Open Questions. *Foundations and Trends® in Human–Computer Interaction* 13, 3 (April 2020), 165–297. https://doi.org/10.1561/1100000080

[14] Geraldine Fitzpatrick and Gunnar Ellingsen. 2013. A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. *Computer Supported Cooperative Work (CSCW)* 22, 4 (Aug. 2013), 609–665. https://doi.org/10.1007/s10606-012-9168-0

[15] Erik Grönvall and Nervo Verdezoto. 2013. Beyond Self-Monitoring: Understanding Non-Functional Aspects of Home-Based Healthcare Technology. In *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '13)*. Association for Computing Machinery, New York, NY, USA, 587–596. https://doi.org/10.1145/2493432.2493495

[16] Richard J. Holden, Anand Kulanthaivel, Saptarshi Purkayastha, Kathryn M. Goggins, and Sunil Kripalani. 2017. Know Thy eHealth User: Development of Biopsychosocial Personas from a Study of Older Adults with Heart Failure. *International Journal of Medical Informatics* 108 (Dec. 2017), 158–167. https://doi.org/10.1016/j.ijmedinf.2017.10.006

[17] Jina Huh, Bum Chul Kwon, Sung-Hee Kim, Sukwon Lee, Jaegul Choo, Jihoon Kim, Min-Je Choi, and Ji Soo Yi. 2016. Personas in Online Health Communities. *Journal of Biomedical Informatics* 63, C (oct 2016), 212–225. https://doi.org/10.1016/j.jbi.2016.08.019

[18] Leonardo H Iwaya, Simone Fischer-Hübner, Rose-Mharie Åhlfeldt, and Leonardo A Martucci. 2018. mhealth: A privacy threat analysis for public health surveillance systems. In *2018 IEEE 31st International Symposium on Computer-Based Medical Systems (CBMS)*. IEEE, Karlstad, Sweden, 42–47. https://doi.org/10.1109/CBMS.2018.00015

[19] Leonardo H Iwaya, Jane Li, Simone Fischer-Hübner, Rose-Mharie Åhlfeldt, and Leonardo A Martucci. 2019. E-consent for data privacy: consent management for mobile health technologies in public health surveys and disease surveillance. In *17th World Congress of Medical and Health Informatics (MEDINFO), 25 to 30 August 2019*, Vol. 264. IOS Press, Lyon, France, 1223–1227. https://doi.org/10.3233/shti190421

[20] Ramesh Jain, Laleh Jalali, and Mingming Fan. 2013. From Health-Persona to Societal Health. In *Proceedings of the 22nd International Conference on World Wide Web* (Rio de Janeiro, Brazil) *(WWW '13 Companion)*. Association for Computing Machinery, New York, NY, USA, 1329–1334. https://doi.org/10.1145/2487788.2488171

[21] Naveena Karusala, Azra Ismail, Karthik S Bhat, Aakash Gautam, Sachin R Pendse, Neha Kumar, Richard Anderson, Madeline Balaam, Shaowen Bardzell, Nicola J Bidwell, Melissa Densmore, Elizabeth Kaziunas, Anne Marie Piper, Noopur Raval, Pushpendra Singh, Austin Toombs, Nervo Verdezoto, and Ding Wang. 2021. The Future of Care Work: Towards a Radical Politics of Care in CSCW Research and Practice. In *Companion Publication of the 2021 Conference on Computer Supported Cooperative Work and Social Computing (CSCW '21)*. Association for Computing Machinery, New York, NY, USA, 338–342. https://doi.org/10.1145/3462204.3481734

[22] Jane Kaye, Edgar A Whitley, David Lund, Michael Morrison, Harriet Teare, and Karen Melham. 2015. Dynamic consent: a patient interface for twenty-first century research networks. *European journal of human genetics* 23, 2 (2015), 141–146. https://doi.org/10.1038/ejhg.2014.71

[23] Hankyung Kim, Dong Yoon Koh, Gaeun Lee, Jung-Mi Park, and Youn-kyung Lim. 2019. Designing Personalities of Conversational Agents. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland Uk) *(CHI EA '19)*. Association for Computing Machinery, New York, NY, USA, 1–6. https://doi.org/10.1145/3290607.3312887

[24] A. Baki Kocaballi, Juan C. Quiroz, Liliana Laranjo, Dana Rezazadegan, Rafal Kocielnik, Leigh Clark, Q. Vera Liao, Sun Young Park, Robert J. Moore, and Adam Miner. 2020. Conversational Agents for Health and Wellbeing. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) *(CHI EA '20)*. Association for Computing Machinery, New York, NY, USA, 1–8. https://doi.org/10.1145/3334480.3375154

[25] Nadin Kokciyan, Martin Chapman, Panagiotis Balatsoukas, Isabel Sassoon, Kai Essers, Mark Ashworth, Vasa Curcin, Sanjay Modgil, Simon Parsons, and Elizabeth I Sklar. 2019. A collaborative decision support tool for managing chronic conditions. In *The 17th World Congress of Medical and Health Informatics*. he 17th World Congress of Medical and Health Informatics, Lyon, France, 5 pages. https://doi.org/10.3233/SHTI190302

[26] Minha Lee, Jaisie Sin, Guy Laban, Matthias Kraus, Leigh Clark, Martin Porcheron, Benjamin R. Cowan, Asbjørn Følstad, Cosmin Munteanu, and Heloisa Candello. 2022. Ethics of Conversational User Interfaces. In *Extended Abstracts of the 2022 CHI Conference on Human Factors in Computing Systems* (New Orleans, LA, USA) *(CHI EA '22)*. Association for Computing Machinery, New York, NY, USA, Article 80, 7 pages. https://doi.org/10.1145/3491101.3503699

[27] Nora McDonald, Karla Badillo-Urquiola, Morgan G. Ames, Nicola Dell, Elizabeth Keneski, Manya Sleeper, and Pamela J. Wisniewski. 2020. Privacy and Power: Acknowledging the Importance of Privacy Research and Design for Vulnerable Populations. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems (CHI EA '20)*. Association for Computing Machinery, New York, NY, USA, 1–8. https://doi.org/10.1145/3334480.3375174

[28] R. Mikulik, M. Bar, A. Grecu, R. Herzig, J. Neumann, D. Sanak, O. Skoda, D. Skoloudik, V. Svobodova, A. Tomek, and D. Vaclavik. 2017. The Registry of Stroke Care Quality (RES-Q): The First Nation-Wide Data on Stroke Care Quality. *Journal of the Neurological Sciences* 381 (Oct. 2017), 91. https://doi.org/10.1016/j.jns.2017.08.302

[29] Stephanie Githa Nadarajah, Peder Walz Pedersen, Bastian Ilsø Hougaard, and Hendrik Knoche. 2019. Am I Coughing More than Usual? Patient Reflections and User Needs on Tracking COPD Data in a Telehealth System. In *Proc of HealthMedia'19* (healthmedia '19 ed.). Association for Computing Machinery, United States, 2–8. https://doi.org/10.1145/3347444.3356237

[30] Timothy Neate, Aikaterini Bourazeri, Abi Roper, Simone Stumpf, and Stephanie Wilson. 2019. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland Uk) *(CHI '19)*. Association for Computing Machinery, New York, NY, USA, 1–12. https://doi.org/10.1145/3290605.3300880

[31] Francisco Nunes, Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik Grönvall, and Cristiano Storni. 2015. Self-Care Technologies in HCI: Trends, Tensions, and Opportunities. *ACM Transactions on Computer-Human Interaction* 22, 6 (Dec. 2015), 33:1–33:45. https://doi.org/10.1145/2803173

[32] Chi Young Oh, Yuhan Luo, Beth St. Jean, and Eun Kyoung Choe. 2022. Patients Waiting for Cues: Information Asymmetries and Challenges in Sharing Patient-Generated Data in the Clinic. *Proceedings of the ACM on Human-Computer Interaction* 6, CSCW1 (April 2022), 107:1–107:23. https://doi.org/10.1145/3512954

[33] Tom Ongwere, Andrew B.L. Berry, Clara Caldeira, Rosa I. Arriaga, Amid Ayobi, Eleanor R. Burgess, Kay Connelly, Patricia Franklin, Andrew D Miller, Aehong Min, and Nervo Verdezoto. 2022. Challenges, Tensions, and Opportunities in Designing Ecosystems to Support the Management of Complex Health Needs. In *Extended Abstracts of the 2022 CHI Conference on Human Factors in Computing Systems* (New Orleans, LA, USA) *(CHI EA '22)*. Association for Computing Machinery, New York, NY, USA, Article 71, 7 pages. https://doi.org/10.1145/3491101.3503714

[34] Tariq Osman Andersen, Francisco Nunes, Lauren Wilcox, Elizabeth Kaziunas, Stina Matthiesen, and Farah Magrabi. 2021. Realizing AI in Healthcare: Challenges Appearing in the Wild. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems (CHI EA '21)*. Association for Computing Machinery, New York, NY, USA, 1–5. https://doi.org/10.1145/3411763.3441347

[35] M. Rijken, M. Jones, M. Heijmans, and A. Dixon. 2008. Supporting Self-Management. In *Caring for People with Chronic Conditions: A Health System Perspective*, E. Nolte and M. McKee (Eds.). McGraw-Hill Open University Press, Maidenhead, Berkshire, United Kingdom, 116–142.

[36] Neelima Sailaja, Joseph Lindley, Lachlan Urquhart, Derek McAuley, and Ian Forrester. 2021. Human-Data Interaction Through Design: An Explorative Step from Theory to Practice Using Design as a Vehicle. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems* (Yokohama, Japan) *(CHI EA '21)*. Association for Computing Machinery, New York, NY, USA, Article 113, 5 pages. https://doi.org/10.1145/3411763.3441344

[37] M.C. Schraefel, Josh Andrés, Aaron Tabor, Scott Bateman, Abby Wanyu Liu, Mike Jones, Kai Kunze, Elizabeth Murnane, and Steeven Villa. 2021. Body As Starting Point 4: Inbodied Interaction Design for Health Ownership.. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems* (Yokohama, Japan) *(CHI EA '21)*. Association for Computing Machinery, New York, NY, USA, Article 85, 5 pages. https://doi.org/10.1145/3411763.3441335

[38] Yiyang Sheng, Julie Doyle, Raymond Bond, Rajesh Jaiswal, Shane Gavin, and John Dinsmore. 2022. Home-Based Digital Health Technologies for Older Adults to Self-Manage Multiple Chronic Conditions: A Data-Informed Analysis of User Engagement from a Longitudinal Trial. *DIGITAL HEALTH* 8 (Jan. 2022), 20552076221125957. https://doi.org/10.1177/20552076221125957

[39] E. H. Simpson. 1951. The Interpretation of Interaction in Contingency Tables. *Journal of the Royal Statistical Society: Series B (Methodological)* 13, 2 (1951), 238–241. https://doi.org/10.1111/j.2517-6161.1951.tb00088.x

[40] Helena Tendedez, Maria Angela Ferrario, and Roisin McNaney. 2019. 'The Issue with That Sort of Data?': Clinicians' Accountability Concerns Around COPD Self-Monitoring Tools. In *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing (CSCW '19)*. Association for Computing Machinery, New York, NY, USA, 382–386. https://doi.org/10.1145/3311957.3359464

[41] Nan Tu, Xiao Dong, Pei-Luen Rau, and Tao Zhang. 2010. Using cluster analysis in Persona development. In *Conference on Supply Chain Management and Information*. IEEE, Hong Kong, China, 1–5.

[42] Nervo Verdezoto, Francisco Nunes, Erik Grönvall, Geraldine Fitzpatrick, Cristiano Storni, and Morten Kyng. 2014. Designing Self-Care for Everyday Life. In *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational (NordiCHI '14)*. Association for Computing Machinery, New York, NY, USA, 821–824. https://doi.org/10.1145/2639189.2654837

[43] Daricia Wilkinson, Moses Namara, Karla Badillo-Urquiola, Pamela J. Wisniewski, Bart P. Knijnenburg, Xinru Page, Eran Toch, and Jen Romano-Bergstrom. 2018. Moving Beyond a "One-Size Fits All": Exploring Individual Differences in Privacy. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems (CHI EA '18)*. Association for Computing Machinery, New York, NY, USA, 1–8. https://doi.org/10.1145/3170427.3170617

[44] Bernhard Wöckl, Ulcay Yildizoglu, Isabella Buber, Belinda Aparicio Diaz, Ernst Kruijff, and Manfred Tscheligi. 2012. Basic Senior Personas: A Representative Design Tool Covering the Spectrum of European Older Adults. In *Proceedings of the 14th International ACM SIGACCESS Conference on Computers and Accessibility* (Boulder, Colorado, USA) *(ASSETS '12)*. Association for Computing Machinery, New York, NY, USA, 25–32. https://doi.org/10.1145/2384916.2384922