





University of Applied Sciences and Arts Western Switzerland

# Digital Health Interventions to Increase Health Knowledge Related To Sickle Cell Disease

# David-Zacharie ISSOM, MSc, MBA, PhD

Scientific Collaborator – Division of Medical Information Sciences (HUG)

Expert-Patient / Head – Patient-led Research Hub (ESCF)

Assistant Professor – Institute of Information Systems (HES-SO)



# Digital Transformation of Healthcare to Achieve..







# JUNE 16-18 2022 Paris, Novotel Tour Eiffel





# THE HUMAN POPULATION IS HEALTHIER THAN EVER BEFORE



Mean global life expectancy at birth (years)









# BUT TO ACHIEVE THIS WE'VE EXPLOITED THE PLANET AT AN UNPRECEDENTED RATE



1850 1900 1950 2000





# ANTHROPOCENE or CAPITALOCENE?

Nature, History, and the Crisis of Capitalism

CHRISTIAN PARENTI | EILEEN CRIST | JUSTIN MCBRIEN Donna J. Haraway | Elmar Altvater and Daniel Hartley

> EDITED BY JASON W. MOORE



# **REDUCED INEQUALITIES:** WHY IT MATTERS

### What's the goal here?

To reduce inequalities within and among countries.

### Why?

Inequalities based on income, sex, age, disability, sexual orientation, race, class, ethnicity, religion and opportunity continue to persist across the world. Inequality threatens longterm social and economic development, harms poverty reduction and destroys people's sense of fulfilment and self-worth. This, in turn, can breed crime, disease and environmental degradation.

In-person

and on-line

Congress

and make the plane! and make the plane! better for all if people are excluded from the chance for a better life. And despite some positive signs, inequality is growing for more than 70 per cent of the global population, exacerbating the risks of divisions and hampering economic and social development. Furthermore, COVID-19 is hitting the most vulnerable people the hardest, and those same groups are often experiencing increased discrimination. Almost **2 in 10** people reported having personally experienced discrimination on at least one of the grounds established by international human rights law

REDUCED

Department of Economic & Social Affairs

CDP Background Paper No. 42 ST/ESA/2018/CDP/42

May 2018

# Priority to the furthest behind

Marc Fleurbaey Princeton University

### ABSTRACT

The UN Resolution heralding the Sustainable Development Goals pledges to leave no one behind, and moreover "to reach the furthest behind first". This priority echoes the priority to the worst-off that is being discussed in philosophy, economics and related disciplines, but also the pleas of many actors who represent or fight for the most disadvantaged populations. This paper argues that serious theories do support such a priority and that the best policies implementing this priority do not necessarily involve the most intuitive anti-poverty targeted measures.

JEL Classification: D63, I38

4<sup>th</sup> Global Congress Sickle Cell Disease

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Topical Review

# Reducing Health Care Disparities in Sickle Cell Disease: A Review

LaTasha Lee, PhD, MPH<sup>1</sup><sup>®</sup>; Kim Smith-Whitley, MD<sup>2,3</sup>; Sonja Banks, MPA, MBA<sup>4</sup>; and Gary Puckrein, PhD<sup>5</sup>

### PUBLIC HEALTH REPORTS

Public Health Reports 2019, Vol. 134(6) 599-607 © 2019, Association of Schools and Programs of Public Health All rights reserved. Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/0033354919881438 journals.sagepub.com/home/phr

**SAGE** 

### Abstract

Sickle cell disease (SCD) is an inherited blood disorder most common among African American and Hispanic American persons. The disease can cause substantial, long-term, and costly health problems, including infections, stroke, and kidney failure, many of which can reduce life expectancy. Disparities in receiving health care among African Americans and other racial/ethnic minority groups in the United States are well known and directly related to poor outcomes associated with SCD. As an orphan disease—one that affects <200 000 persons nationwide—SCD does not receive the research funding and pharmaceutical investment directed to other orphan diseases. For example, cystic fibrosis affects fewer than half the number of persons but receives 3.5 times the funding from the National Institutes of Health and 440 times the funding from national foundations. In this review, we discuss the health inequities affecting persons with SCD, describe programs intended to improve their care, and identify actions that could be taken to further reduce these inequities, improve care, control treatment costs, and ease the burden of disease.

### **Keywords**

sickle cell disease, health care disparities, access to care, Medicaid, community health centers

Strategies to **rapidly** reduce health inequalities and empower neglected populations



# -LEAN ICT-TOWARDS DIGITAL SOBRIETY

REPORT OF THE WORKING GROUP DIRECTED BY HUGUES FERREBOEUF FOR THE THINK TANK THE SHIFT PROJECT – MARCH 2019





This study was carried out wit the support of the Agence française de développement and the Caisse des Dépôts



"The most complex societal challenge is to overcome mistrust & racism in order to empower & engage a community that has historically been denied their right to health."

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Paris, Novotel Tour Eiffel

- 3x more common than cystic fibrosis
- 3.5 times less public funds (NIH)

In-person

and on-line

Sickle Cell

Disease

- 75 to 971 times less private funds
- 2.3x less likely to receive funds to conduct clinical studies
- 1.8x fewer scientific publications / knowledge

#### Abstract Key Points Question Are differences in disease IMPORTANCE Sickle cell disease (SCD) and cystic fibrosis (CF) are severe autosomal recessive specific funding between sickle cell disorders associated with intermittent disease exacerbations that require hospitalizations disease and cystic fibrosis associated progressive chronic organiziumy, and substantial premature mortality. Research funding is a limited with variations in drug development an resource and may contribute to health care disparities, especially for rare diseases that research publications? disproportionally affect economically disadvantaged groups Findings. This cross-sectional study of OBJECTIVE To compare disease-specific funding between SCD and CF and the association between research funding and outputs for cysti funding and research productivity. ibrosis and sickle-cell disease found that both federal funding and DESIGN, SETTING, AND PARTICIPANTS This cross-sectional study examined federal and pundation expenditures were grea foundation funding, publications indexed in PubMed, clinical trials registered in ClinicalTrials, gov, and for cystic fibrosis compared with sickle new drug approvals from January 1, 2008, to December 31, 2018, in an estimated US population of cell disease. Significantly more researc approximately 90 000 individuals with SCD and approximately 30 000 individuals with CF articles and drug approvals were found for cystic fibrosis compared with sickle MAIN OUTCOMES AND MEASURES Federal and foundation funding, publications indexed in cell disease, but the total numbers of PubMed, clinical trial registrations, and new drug approvals. clinical trials were similar Meaning The findings show that RESULTS From 2008 through 2018, federal funding was greater per person with CF compared with disparities in funding exist between SCD (mean [SD], \$2807 [\$175] vs \$812 [\$147]; P < .001). Foundation expenditures were greater for sickle cell disease and cystic fibrosis and CF than for SCD (mean [SD], \$7690 [\$3974] vs \$102 [\$13.7]; P < .001). Significantly more research that these disparities may be associated articles (mean [SD], 1594 [225] vs 926 [157]; P < .001) and US Food and Drug Administration drug with decreased research productivity approvals (4 vs T) were found for CF compared with SCD, but the total number of clinical trials war and novel drug development for sidde similar (mean [SD], 27.3 [6.9] vs 23.8 [6.3]; P = .22). cell disease CONCLUSIONS AND RELEVANCE The findings show that disparities in funding between SCD and Supplemental conten CF may be associated with decreased research productivity and novel drug development for SCD. Increased federal and foundation funding is needed for SCD and other diseases that Author affiliations and article information a isted at the end of this article disproportionately affect economically disadvantaged groups to address health care disparitie Sources: https://doi.org/10.1182/blood-2018-99-115609 MMA Network Ones. 2020-3031-6201737. doi:

Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity

Faheem Farooo, MD: Peter J. Mogawael, MD. PhD: Sophie Lanzkron, MD: Carlton Havwood, PhD: John J. Strouse, MD. PhD

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# Empowerment

"The efforts an individual or a group can make to control and change their destiny (...)"

- 1. change their life by building new capacities (e.g., skills, knowledge)
- 2. transform their living conditions by interacting with other people
- 3. effectuate their power over society

Sources: Zimmerman MA. Empowerment Theory 2000. Consolidated Guideline on Self-Care Interventions for Health, WHO 2003







Home / Activities / Improving health literacy



"Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their

capacity to use it effectively, health literacy is critical to empowerment." Health Promotion Glossary, 1998.

Global Conaress In-person Sickle Cell nd on-lin Disease

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"Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions.

By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment."



# Digital health literacy



Internet Interventions Volume 27, March 2022, 100500



Digital health literacy as a super determinant of health: More than simply the sum of its parts

Robin van Kessel <sup>a, b, c</sup>  $\stackrel{\circ}{\sim}$   $\stackrel{\boxtimes}{\sim}$ , Brian Li Han Wong <sup>c, d, e</sup>, Timo Clemens <sup>a</sup>, Helmut Brand <sup>a, f</sup> Show more  $\checkmark$ 

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https://doi.org/10.1016/j.invent.2022.100500 Under a Creative Commons license Get rights and content • Open access

# Highlights

- Civic literacy refers to the ability to engage meaningfully with one's community.
- Digital, health, and civic literacy are key predictors for digital health literacy.
- The extent to which these three affect digital health literacy remains unclear.
- Building digital health literacy is vital to limit inequalities from expanding.



# Better understand the determinants of inequalities



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2.5

Health Information Technology Standards Series Editor: Tim Benson

Tim Benson Grahame Grieve

# Principles of Health Interoperability

FHIR, HL7 and SNOMED CT

Fourth Edition

# Springer

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# Leveraging health information

- Information is an ethereal commodity
  - "the **data** and **knowledge** that intelligent systems use to support their decisions."
- Health information
  - Any personal information about a person's health or disability
- Health informatics
  - 1. Information and Communication Technologies (ICTs) to help with **decisions** and **actions** required to **improve patient outcomes** by making **better use** of health-related **information**
  - 2. Knowledge management  $\rightarrow$  making the best use of knowledge
  - 3. Knowledge representation and reasoning  $\rightarrow$  in the field of AI, it means modelling information about the world in a form that a computer system can use to solve complex tasks



# Digital Health Interventions (DHIs) [health services delivered electronically through formal or informal care] can lead to positive health outcomes

- Improve health literacy
- Encourage better lifestyle choices
- Raise self-awareness
  - e.g., patient-generated health data (PGHD)
- Help manage lifelong conditions
- Facilitate navigating in information flows





# From information overload to educated and empowered decision-making



15 years, the publication number has increased by an average of 51 publications each year, rising from approximately 400 to nearly 1200 per year.

Kato GJ. New insights into sickle cell disease: mechanisms and investigational therapies. Curr Opin Hematol. 2016;23(3):224-232. doi:10.1097/MOH.000000000000247



# JUNE 16-18 2022

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# Non-digital educational interventions

Received 7 Petroary 2012 Revised 28 March 2012 Accepted 21 April 2012

DOR TO LLUB AND DOUBLE

ORIGINAL ARTICLE

Clinical Nursing WILEY

### A rapid evidence assessment of sickle cell disease educational interventions

Anthonia Etoniogbo Oti MSc. MPH, BSc (Hons), Theatre Practitioner<sup>1,2</sup> Kim Heves PhD, MPhil, PGLTHE, BA (Hons), Senior Lecturer<sup>2</sup> Fave Bruce PhD, MSc, BSc, Senior Lecturer<sup>23</sup> Lecturer<sup>2</sup>

(SCD) pain management in the UK.

Aims and objectives: To assess the impact of educational interventions on the knowl-

edge and attitude of healthcare professionals (HCPs) regarding sickle cell disease

Background: Variations and inadequate pain management due to HCPs' lack of knowl-

edge and negative attitude is still an ongoing global concern for SCD patients despite

availability of effective treatment and evidence-based guidelines. Several interna-

tional studies have implemented interventions aimed at improving knowledge, atti-

tude, and pain management. No review on the effectiveness of these interventions

was found. Also, no previous intervention done in the UK was found from the thor-

ough search of research databases. However, there are estimated 340,000 genetic

Methodic Anapid evidence assessment was conducted between March 2021-January

2022 following the PRISMA 2020 guidelines. Included papers must have an educa-

tional intervention about SCD or related symptom management where the learners.

were HCPs. Excluded papers were these not published in English or before 2000.

The following databases were searched: CINAHL, MEDLINE, PubMed America and

Europe, Scopus, PsycINFO and Web of Science. Data quality was assessed using the

Mixed Methods Assessment Tool (MMAT) and analysed using a narrative approach.

Results: Ten studies were included in the final review. Overall, they reported improved

outcomes in six rusin thereex knowledge, attitude, perception, adoption, satisfaction

and efficiency. Fire studies reported statistically significant improvement in at least

ane outcome, four studies reported positive improvement, and two studies reported

no significant improvement in knowledge and attitude. These heterogeneous studies

were implemented once, and all designs were prone to blac; this makes it difficult to

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carriers with about 12,500-15,000 estimated people living with SCD in the UK.

Design: Rapid Evidence Assessment of existing evidence.

state how effective interventions are for SCD.

Abstract

Station NHS Foundation Trust, Farmworth, Ballon, UK Reading of Psychology, Health and Social Care, Manchester Matropolitan University, Manufacture UK Star School and Million Marith Nationals Manchesber, UK

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### ARTICLE

Educational Intervention to Improve the Health Outcomes of Children With Sickle Cell Disease

Randa Shahine, RN, Lina Kurdahi Badr, PhD, RN, CPNP, FAAN, Dima Karam, BS, & Miguel Abboud, MD

#### ADSTRACT

Introduction: Allworth sickle cell disease (SCD) is the most common single gene disorder worldwide, caregivers of children do not have adoptate knowledge about the filmers and to management. The purpose of this study was to assess the efficace of education along with tailored written materials in changing the behaviors of caregisers to help them provide where care for children with WID. Methods: A preintervention and postintervention quasi-

experimental design was used. A convenience sample of 43caregivers of 57 children were asked to complete a questionas the related to the interval of the selection of the latter of the sectors and a first enderse tional sessions. The scherational sessions (the intercention) were provided to categivers at the Children's Career Center in labaron by one registered name, one certilled pediatric many mathema and one pediate benatidents. Transmis-

Famila Shahine, Boghtoned Narse, Children's Carear Cantas, Faint Laborer

Line Kardabi Rade Perdanase Annas Pacific University Annas CA Data Kasara, Research Assistant, Children's Cansor Denter, Fight 1. Lobarow

Mount Aktion at Chair of Pediatron, American University of Berryl Medical Cantan, Beirst, Lebaron, Carillets of interest. None in report. Correspondence Lina Russiah Bask PHD, FM, CPRP, FMM, Asusa

Pacific University, Acusa, GA 91782; a mail: Exerciting-u.acla 0001-1211/0200.00 Capyright to 2015 by the National Association of Pediatric

toriers. Published by Elsevier Inc. All rights second.

Published online August 10, 2016.

http://dx.doi.org/10.1016/j.podbc.2014.06.807

84 Volume 28 a Number 1

#### locariment (HD) visits and honorializations were command 2 months before and 2 months after the intervention. Benaltic A statistically significant increase was found in the involving of caregoon about the cause, symptoms, and management of the disease. A statistically significant decrease occurred in the number of hospitalizations before and after the intercention but not in the number of sixin to to 113. Multiple reservation analysis found that none of the background satiables were tolated to knowledge, ID sists, or hespitalizations

#### KEY WORDS

Sickle cell-disease, education, readmission, Lebanon

Sickle cell disease (SCD) is the most common single sense disorder workbyde, with an autosomal mode of inheritance and different clinical manifestations in rations othnic unsums and populations. It affects 1 in Still Blacks in the United States and records as Manifley, people worldwide with predominance in populations of the sub-Sahara, India, and the Middle East (Inati et al., 2007; McGann, Nero, & Ware, 2013; Okpula 2005). Different types of SCD cuist, including sidde cell artenta, stekle-hemoglobin C disease, stekle betaplus flulassemia, and sielde beta-zero flulassemia, with prevalence of certain types in particular ethnic groups. Although it is inherited genetically, the symptons of the disease are affected by environmental factors and are due to the replacement of more than 50% of the hemoslobir-bets sense with the hemoslobin S

Journal of Parliable Health Com-

#### Received: 23 October 2018 Revised: 20 February 2019 Accepted: 5 March 2019

RESEARCH ARTICLE

DOI:10.1002/Mix.27722

Medicine St. Louis, Missouri

Mount

Nashalle, Tewassee

Correspondence

<sup>2</sup>Siteman/Cancer Center, St. Louis, Missouri

University School of Medicine, St. Louis,

\*Program in Occupational Thorapy, Washington

"Brown University Presidence, Rhode Island

Teleforers Medical College Scheeled Medicine

Coordinal, California Division of Memoryatican

Oncology Department of Pediatrics, Washing

University School of Medicine, 6425, Exclud.

Carmon Res 6716, St Louis, MC(47110)

Email callouncilwast.odu

Pediatric - Horses Blood & Con aspho WILEY Cancer

### Implementation of an educational intervention to optimize self-management and transition readiness in young adults with sickle cell disease

Cecelia L. Calhoun<sup>1,2</sup> 💿 Regina A. Abel<sup>3</sup> Hai Ahn Pham<sup>4</sup> Shomari Thomoson<sup>5</sup> Allison A. King<sup>1,2,3</sup>

#### 7Division of Hernatology Decology, Department Abstract of Pediatrics, Washington/University School of

Background: The transition from the peclistric setting to adult care is a well-described period of morbidity and mortality for persons with sickle call disease ISCDI. We sought to measure the feasibility and effectiveness of providing skill-based educational handouts on improving selfmanagement and transition readiness in addressents with SCD.

Methodic This was a single-center study in which participants completed a self-assessment, the Adolescent Autonomy Checklist (AAC), to assess transition readiness and self-management skills. at baseline. After results were reviewed by the study coordinator, participants were provided with skill-based handouts on noted areas of deficit. The AAC was subsequently completed at a followup visit. All data were stored electronically and transferred into SAS for statistical analyses.

Results: Sixty-one patients completed the AAC at baseline and postintervention. At baseline patients reported needing the most help with skills in money management, living arrangements, vocational skills, and emergency and healthcare skills. Postintemention, statistically significant improvements (P < 0.05) accurred in skills related to laundry, housekeeping, healthcare, and seeual development. A regression model exploring the time to follow-up showed that most improvements could not be attributed to maturation alone.

Conclusion: This study showed that educational handouts are a readily implementable and wellaccepted intervention among adulescents with SCD who identify challenges with skills necessary to successfully transition to adult care. Distinguishing which transition needs are best improved with this type of intervention will help to strengthen the multidisciplinary approach necessary to support adolescents and young adults with SCD as they matriculate to adult care.

KEYWORDS education, sickle cell disease, transition, young adult





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Clinical implications: Education and written materials written in a simple language that is understand by 5th geaders were decreasing the number of hospitalizations of children with

SCD. J Pollair Health Care, (2015) 29, 51-40.

# WHO's Classification of DHIs





# Types of Educational Digital health interventions

- Transmit targeted health information based on health status or demographics
  - Health education, behavior change communication
  - Health promotion communication, client-centered messaging
  - Health communication based on a known client's health status or clinical history
- Alerts for preventive services and wellness
  - Notifications & reminders for appointments, medication adherence, follow-up services
  - Communication for retention in care, continuity of care



# Types of Educational Digital health interventions

- Offer training content and reference material
  - mLearning, eLearning, virtual learning, micro-learning
    - Educational videos, multimedia learning and access to clinical guidance
    - Training reinforcement and refreshers
- Assess capacity of clients
  - Quizzes, interactive exercises, challenges to assess disease-specific knowledge and competences





# Examples of educational DHIs for patients

#### JMIR PEDIATRICS AND PARENTING

Saulsberry et al

Original Paper

### Web-Based Technology to Improve Disease Knowledge Among Adolescents With Sickle Cell Disease: Pilot Study

Anjelica C Saulsberry<sup>1</sup>, BA; Jason R Hodges<sup>1</sup>, MA, PhD; Audrey Cole<sup>1</sup>, MSN; Jerlym S Porter<sup>2</sup>, MPH, PhD; Jane Hankins<sup>1</sup>, MD, MS

<sup>1</sup>Department of Hematology, St Jude Children's Research Hospital, Memphis, TN, United States
<sup>2</sup>Department of Psychology, St Jude Children's Research Hospital, Memphis, TN, United States

#### Corresponding Author:

Jane Hankins, MD, MS Department of Hematology St Jade Children's Research Hospital 262 Danny Thomas PI Memphis, TN, United States Phone: 1 9015954153 Ehani: jane-barkins@istjude.org

### Abstract

Background: Advancements in treatment have contributed to increased survivorship among children with sickle cell disease (SCD). Increased transition readmess, encompassing disease knowledge and self-management akils before transfer to adult care, is necessary to ensure optimal health outcomes. The Sickle Cell Transition E-Learning Program (STEP) is a public, Web-based, 6-module tool designed to increase transition readmess for youth with SCD.

Objective: The objective of our study was to investigate the participation rate of youth with SCD in STEP and its association with transition readiness.

Methods: This was a single-center, Institution Review Board-approved, retrospective cohort review. A total of 183 youths with SCD, agod between 12 and 153 years, were offered STDP as an adjunct to inclinic disease disease. The Participation rate (number of patients who used at least offered and the STDP model by those approached) was calculated. The association among the number of STDP modules completed, disease knowledge, and self-management was explored.

Results: Overall, 53 of the 183 approached adolescents completed at least one STEP module, yielding a participation rate in STEP of 20.0%. Of the 53 participants, 37 and 39 adolescents had alsoes knowledge and self-management confidence rating available, respectively. A pointive correlation (-0.47) was found between the number of STEP modules completed and disease knowledge scores. We complete a strength we have a strength of the strength

Conclusions: Improvement in disease knowledge in addressence is critical to ensure the youth's ability to self-care during the period of transition to adult care. Despite low participation, the cumulative exposure to the STEP program suggested greater promotion of disease knowledge among addressens with SCD before transfer to adult care.

(JMIR Pedlatr Parent 2020;3(1):e15093) doi: 10.2196/15093

Received: 1 December 2017 Revised: 25 February 2018 Accepted: 6 March 2018

DOI: 90.1002/ptx.27081

### RESEARCH ARTICLE



### Mobile health intervention for youth with sickle cell disease: Impact on adherence, disease knowledge, and quality of life

Lindsay M. Anderson<sup>1</sup> (10) | Sarah Leonard<sup>2,3</sup> | Jude Jonassaint<sup>4</sup> | Joseph Lunyera<sup>2</sup> | Melanie Bonner<sup>1</sup> | Nirmish Shah<sup>2</sup>

"Decortment of Postholacy and Neuroscience Abstract Dake University, Durham, North Carolina <sup>2</sup>Department of Pediatrics, Duke University Medical Center, Darham, North Carolina \*Department of Pediatrics, Eastern Carolina University Commille, North Carolina, \*School of Medicine, University of Pittsburgh, Pittshurgh, Penerolivania Correspondence Linches M. Andrewen, Demartment of Psychology and Neuroscience. Duke University, DUMC Box. 3527.Derham.NC 27710 Email: Landerson-Lilgmail.com **Funding information** Grant approace Dale Institute for Health Issues

Backgeward: Atherence to illness self-narragement among yourly with sickle cell disease (SCD) positively impacts health relationes and documes ownid healthere cells. Despite this, childron with SCD too several hariners ta adherence, avita that areain mackensis to low. The current feasibility study examined the Intensive Training Program (ITP), a mobile bealth (heff kull) intervention for youth with SCD designed to promote disease knowledge, adherence, and public-provide communication.

Precedure: Yosti with 5CD orscic/bel hydrowras lictower agos 7-38 completed backine diease knowledge and psychosocial assessments and thin were provided with the ITP ago. Youth participated in the 70-bit PTE charge which they completed three obtacies modules, tracked asherence through daily self-recorded videos on the ago, and received video mesages from providers. Participants completed poststady knowledge, psychosocial, and lossibility questionmates. Medicalizing session and MPR was obtained in durmasy-well rates.

Results: Thirty-two youths (mean age = 12.0 yourd) participated, with an average adversees tracking rate of 0.6 standard deviation = 0.34, Ad any indicated deviational means of MPR 05.57-07.47 P < 0.000, d = 0.73 and disease investeding 159-458.67, P < 0.0001. There was variable engagement in the TIP; completers demonstrated significantly better SCD related functioning (P < 0.02), higher parent-reported transment incidencing P < 0.051, and lower pain ingrate than noncompleters of the TIP (P < 0.05).

Canadialons: Results support the HTP can testibly be implemented to promote adherence aroung youth with SCD. All participants demonstrated hormand adherence and disease bioweledge. However, there was activitide engigeneet and only intervention completes showed improvements in problemacil outcomes. Further research in mediato biomedic to enablate lengteers actiones and ways to promote engigeneet in mislikah interventions more play youth.

KEYWORDS adherence, mobile health, quality of life, sickle cell disease

### JMIR MHEALTH AND UHEALTH

Tam et al

#### Original Paper

An Electronic Teaching Module for Improving Knowledge of Self-Management of Vaso-Occlusive Pain Crises in Patients With Sickle Cell Disease: Pilot Questionnaire Study

Tammie Tam<sup>1</sup>, BSc; Maria R Baer<sup>2</sup>, MD; Lewis L Hsu<sup>3</sup>, MD, PhD; Jennie Y Law<sup>2</sup>, MD

University of Maryland School of Medicine, University of Maryland, Baltimore, MD, United States

<sup>3</sup>Markene and Stewart Grazzschuara Comprehensive Cancer Center, University of Maryland School of Medicine, University of Maryland, Baltimore, MD, United States

<sup>1</sup>Comprehensive Sixkle Cell Center, Division of Padatria Hernatology/Oncology, Department of Padiatrics, University of Elisais at Chicago, Chicago, IL, United States

#### **Corresponding Author:**

Jennie Y Lane, MD Marlenz and Sixward Gracensbuarn Comprehensive Cancer Center University of Maryland School of Medicine University of Maryland 22 S Greene Street SOD15C Balainnov, MJ, 21201 United States Phone: 1410.328 6396 Taci: 1410.328 6396 Taci: 1410.328 6396

#### Abstract

Background: For patients with siddle cell-disease (SCD), effective management of suso-occlusive crises (VOCs) is integral to provision of care, as nearly all affected indexiduals will suffice from VOCs in their lifetime. A recent systematic review of technological interventions to improve aedf-management in the care of SCD concluded that electronic health has the potential to improve the care of individuals with SCD.

Objective: The aim of this study was to assess the value of an electronia teaching module (ETM) provided by Emmi Solutions for educating adult SCD patients on VOC self-management and treatment options for SCD.

Methods: A pretest assessed adults with SCD for baseline knowledge with regard to self-management of VOCs. Participants then watched the 35-min ETM and completed a posttest and survey on the ETM.

Results: A total of 30 adults enrolled. Their knowledge scores improved (pretest median 66.5% and postnet median 85%; 29-001). In total, 18 participants (1873), 99% agreed that they "kanned a lot" or "kanned something" from the ETM. The most common topic about which they reported learning was hydroxymm. A total of 12 participants (1270), 99%) agreed with the summers that they "weakl recommend the medials to a friend or family neurober with siddle cell disease."

Conclusions: The ETM is associated with an increase in knowledge in patients with SCD. Limitations of the study include small sample size, so associated of knowledge before premolule quotionnaire completion, and no longitudinal follow-up. Identifying patients with SCD who domonstrate affectly for self-education via an ETM may further enhance utility of this tool to obtain and empower patients.



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# eHealth: a potential game changer?

- Chronic disease management is correlated with poor adherence to complex daily treatment regimens (e.g., self-care), which limits overall effectiveness of treatments
- mHealth has the potential to increase patient adherence, facilitate patientprovider communication, and improve disease-specific knowledge, which can increase health outcomes

bal Congress

Sickle Cell

Disease

In-person

and on-line

Congress

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#### JMIR MHEALTH AND UHEALTH

Viewpoint

# The Potential of mHealth as a Game Changer for the Management of Sickle Cell Disease in India

#### Ravindra Kumar, PhD; Aparup Das, PhD

ICMR-National Institute of Research in Tribal Health, Jabalpur, India

### Corresponding Author:

Aparup Das, PhD ICMR-National Institute of Research in Tribal Health ICMR-NIRTH Campus Nagpur Road, PO Garha Jabalpur, 482003 India Phone: 91 7612370800 Email: aparupdas@nirth.res.in

### Abstract

Sickle cell disease (SCD) is a chronic genetic disease that requires lifelong therapy and monitoring. Low drug adherence and poor monitoring may lead to an increase in morbidities and low quality of life. In the era of digital technology, various mobile health (mHealth) apps are being tested for their potential in increasing drug adherence in patients with SCD. We herewith discuss the applicability and feasibility of these mHealth apps for the management of SCD in India.

(JMIR Mhealth Uhealth 2021;9(4):e25496) doi: 10.2196/25496

### KEYWORDS

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sickle cell disease; drug adherence; mHealth; India

### Background

In recent years, a revolution in information technologies has greatly influenced health care practices under the broad definition of digital health. Digital health practices are becoming highly adaptable in both developed and developing countries [1]. Moreover, with the increasing use of smartphones, smart watches, and artificial intelligence-based devices, mobile health (mHealth) is expected to define the standard of health care delivery across the globe. Specifically, mHealth apps can be used to increase disease awareness, increase drug adherence, provide cognitive behavioral therapies, and track health care delivery [2-5]. There are more than 325,000 mHealth apps available for Android and Apple smartphones [6]. Various mHealth apps have been clinically tested for their effect on compliance for many chronic diseases worldwide [7-11] and there are mounting indications that support the feasibility and applicability of mHealth interventions for better compliance in managing chronic diseases in pediatric patients as well. During the ongoing COVID-19 pandemic, mHealth has emerged as a silver bullet, not only for teleconsultations and telemonitoring of patients with chronic diseases, but also for increasing health care delivery in remote areas [12-14].

# Sickle Cell Disease: A Life-threatening and Highly Morbid Disorder

Sickle cell disease (SCD) is a genetic and chronic ailment, highly prevalent in Sub-Saharan Africa, the Middle East, the Mediterranean region, India, and parts of Central and South America. Globally, more than 300,000 children are born each year with SCD and three countries (Nigeria, India, and the Democratic Republic of Congo) bear about half of the global burden [15]. Patients with SCD often present with acute complications (eg. bone pain crisis, acute abdominal pain, acute chest syndrome, visceral sequestration crisis, aplastic crisis, acute anemia, cerebrocardiovascular complications, priapism). Chronic morbidities in SCD (eg, chronic pain syndrome, disease, hepatobiliary complications, renal complications, leg ulcer, musculoskeletal complications, and psychosocial or psychiatric issues) are often encountered [16].

The under-five mortality of SCD varies significantly depending on the availability of health care facilities and infrastructure. For example, in low-income countries with poor access to health care services, mortality can reach up to 90% [15]. There is now growing evidence that continuous interventions through disease-modifying drugs such as hydroxyurea and prophylactic

Kumar & Das

# mHealth: Poor long-term adoption: < 1 week!

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- Lack of evidence on efficacy and usefulness
- Too little attention to patients' views / priorities
- Top-down patient-"centered" approaches
  - Data security, privacy, design, ease of use, features



Disease

Codul Editor Energing Interactions Low retention, unrepresentative samples prevalent among large app-based digital health studies

recently published analysis of eight digital studies found a median dropoff of 5.5 days, as well as a redominantly young and white pool of participants.



Health research studies conducted using health research apps are capable of recruiting a larg number of participants, but these efforts often see early dropouts and do not errolls samples representative of the larger population, according to a study published this week in NPJ Digita Medicine.

# nature medicine

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nature > nature medicine > focus

### Focus 07 October 2020

# Achieving patient-led research

Researchers are often keen to learn from the people who their work could help, but knowledge gaps and power dynamics on both sides can make it seem like an insurmountable task.

In this collection, we look at ways patients, communities and researchers have found innovative ways to work together and break down barriers. People with lived experience of disease offer advice to improve co-production of knowledge with patient partners, we explore the growing influence of patient representatives and patient groups on research policy and learn how an international group of scientists are learning how to make their research equitable from local communities around the world.



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From patient-centered design / research to patient-led design / research

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# **Patient-centric approaches**

Patient involvement generally happens during the final stages

Designers / HCPs see a problem and a solution

- Main disadvantages:
  - Slow to implement
  - Mismatch with patient-important needs
    - Tend to overlook efficacy & usefulness

et al. Acad Emera Med. 20

# **Patient-led design approaches**

# Patients determine the focus of an intervention

Patients live the problem, see **what** should be the focus on & **how** it should be solved

• Advantages:

our Eiffel

- Facilitate faster innovation WITH COMMUNITY
  - Novel features matching patient-important needs
- Provide input to less-well-funded health issues
- More patient engagement & more co-operation
  - Patients share good ideas rapidly (word of mouth)
  - Any healthcare system stakeholder can be involved

# Accelerating good health for all by automating reuse of heterogenous digital health information

**BUILDING EMPOWERING DIGITAL TWINS** 

# How a digital twin is created

and on-line

Sickle Cell

Disease

Instead of relying on traditional data collections that are too old, narrow and static, the health ecosystem can create a holistic data picture of a patient to help enable personalized, real-time and predictive human-centered care.



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# The other 80% of data that determines patient health is outside the medical record

Enhanced ability to access and integrate real-world data from digital devices:

- Digital health app data
- Fitness trackers
- Wearable data

## Trusted research environments and other licensing deals to access health system data:

- Clinical data
- EHR information
- Pathology, histology, radiology and other procedural notes
- Case history notes
- Medical claims data
- Medication orders, co-prescriptions and refills



Closer access to and relationships with patients, where regulatory systems allow:

- Patient-reported outcomes
- Adverse event reporting
- Quality-of-life measures
- Diet and lifestyle diaries
- Family history

# Greater integration of diagnostic data:

- Biomarker panels
- Genomics and other omics data
- Consumer genetics and other consumer diagnostics

## Better social listening:

0

Online patient communities data







# JUNE 16-18 2022 Paris, Novotel Tour Eiffel





[JsonPropertyName(DigitalTwinsJsonPropertyNames.DigitalTwinETag)]
public string ETag { get; set; }

[JsonPropertyName(DigitalTwinsJsonPropertyNames.DigitalTwinMetadata)]
public MyCustomDigitalTwinMetadata Metadata { get; set; } = new MyCustomDigitalTwinMetadata();

```
[JsonPropertyName("temperature")]
public double Temperature { get; set; }
```

[JsonPropertyName("humidity")]
public double Humidity{ get; set; }

### internal class MyCustomDigitalTwinMetadata

```
[JsonPropertyName(DigitalTwinsJsonPropertyNames.MetadataModel)]
public string ModelId { get; set; }
```

[JsonPropertyName("temperature")]
public DigitalTwinPropertyMetadata Temperature { get; set; }

[JsonPropertyName("humidity")]
public DigitalTwinPropertyMetadata Humidity { get: set: }

# Leveraging Digital Traces to Understand and **Change Behaviours**



th

# Leveraging Digital Traces to Understand and Change Behaviours

- Web scraping
  - Websites extraction, Google
- APIs
  - Twitter, Reddit, StackExchange
- Sensor analysis / transcription
  - Youtube, safety cams, TVs
- Sentiment analysis
  - Facebook, Instagram

# Digital Traces: New Data, Resources, and Tools for Psychological-Science Research

# ASSOCIATION FOR PSYCHOLOGICAL SCIENCE

Current Directions in Psychological Science 2019, Vol. 28(6) 560–566 © The Author(s) 2019 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/0963721419861410 www.psychologicalscience.org/CDPS ©SACE

## Anat Rafaeli, Shelly Ashtar, and Daniel Altman

The William Davidson Faculty of Industrial Engineering & Management, Technion - Israel Institute of Technology

## Abstract

New technologies create and archive *digital traces*—records of people's behavior—that can supplement and enrich psychological research. Digital traces offer psychological-science researchers novel, large-scale data (which reflect people's actual behaviors), rapidly collected and analyzed by new tools. We promote the integration of digital-traces data into psychological science, suggesting that it can enrich and overcome limitations of current research. In this article, we review helpful data sources, tools, and resources and discuss challenges associated with using digital traces in psychological research. Our review positions digital-traces research as complementary to traditional psychological-research methods and as offering the potential to enrich insights on human psychology.

### Keywords

digital traces, big data, automated data collection, computer-aided text analysis, sentiment analysis



Remaining challenges of digital health

- Data capture & harmonization
- Data protection & quality assurance
- Data sharing & communication

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- Data standardization & interoperability
- Data reuse & analytics

al Congress

Sickle Cell

Disease

In-person

and on-line

Congress

- Data interpretation  $\rightarrow$  new knowledge
  - Convert several \*omics data streams into useful, *actionable* output

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## npj Digital Medicine

# PERSPECTIVE OPEN Why digital medicine depends on interoperability

Moritz Lehne <sup>[0]</sup>, Julian Sass <sup>[5]</sup>, Andrea Essenwanger <sup>[0]</sup>, Josef Schepers <sup>[0]</sup> and Sylvia Thun<sup>1,2,3</sup>

Digital data are anticipated to transform medicine. However, most of today's medical data lack interoperability: hidden in isolated databases, incompatible systems and proprietary software, the data are difficult to exchange, analyze, and interpret. This slows down medical progress, as technologies that rely on these data – artificial intelligence, big data or mobile applications – cannot be used to their full potential. In this article, we argue that interoperability is a perequisite for the digital innovations envisioned for future medicine. We focus on four areas where interoperabellity is a perequisite for the digital important: (1) artificial intelligence and big data; (2) medical communication; (3) research; and (4) international cooperation. We discuss how interoperability can facilitate digital transformation in these areas to improve the health and well-being of patients worldwide.

npj Digital Medicine (2019)2:79; https://doi.org/10.1038/s41746-019-0158-1

#### INTRODUCTION

The digitalization of medicine promises great advances for global health. Electronic medical records, mobile health appc, medical imaging, low-cost gene sequencing as well as new sensors and wearable devices provide an ever-increasing flow of digital health data. Combined with artificial intelligence, cloud computing and big data analytics, this wealth of data holds huge potential for healthcare and can improve the lives of millions of patients worldwide – with better diagnostics, personalized treatments, and early disease prevention.<sup>16</sup>

But medical data are only useful if they can be turned into meaningful information. This requires high-quality datasets, seamless communication across IT systems and standard data formats that can be processed by humans and machines. Judged by these criteria, however, large parts of today's medical data are virtually useless: Hidden in isolated data silos and incompatible systems, the data are difficult to exchange, process and interpret. In fact, the current medical landscape seems less characterized by "big data" but rather by a large number of disconnected small data. These are suboptimal conditions for the data-driven technologies anticipated to drive medical innovation. Uncovering the full potential of digital medicine requires an interconnected data infrastructure with fast, reliable and secure interfaces, international standards for data exchange as well as medical terminologies that define unambiguous vocabularies for the communication of medical information. In short: Digital health depends on interoperability.

The aim of this article is to show why interoperability is so important for achieving the full potential of digitalization in healthcare and medicine. Although the importance of interoperable health IT systems is increasingly acknowledged.<sup>7-8</sup> awareness of this topic is still relatively low among healthcare professionals especially compared with topics such as artificial intelligence, big data or mobile technologies, which are generally seen as the main drivers of digital health innovation.<sup>710-71</sup> Accordingly, progress in health interoperability is slow.<sup>16</sup> Here, we argue that interoperability is indispensable for advances in digital health and that it is, in fact, a prerequisite for most of the innovations envisioned for future medicine.

Our article starts with an overview of interoperability and its different levels: technical, syntactic, semantic, and organizational It then shows how interoperability can improve medicine, focusing on four areas that especially benefit from (and sometimes crucially depend on) interoperable health IT systems: (1) artificial intelligence and big data; (2) medical communication; (3) research; and (4) international cooperation (Fig. 1). We chose these four areas because they illustrate particularly well how interoperability can facilitate digital transformation and improve medicine and healthcare (however, the areas are not mutually exclusive, and advancing, for example, medical communication can also improve international cooperation). Note that our views are shaped by our German/European perspective. However, we discuss points general enough to be relevant for international readers. Also note that, though giving some examples of specific health IT standards and medical terminologies that can improve interoperability, this article does not aim to provide detailed technical discussions of specific standards or terminologies (this information can be found elsewhere<sup>15,16</sup>).

#### INTEROPERABILITY

Interoperability can be broadly defined as "the ability of two or more systems or components to exchange information and to use the information that has been exchanged".<sup>17</sup> Most definitions further distinguish between different components, layers or levels of interoperability.<sup>15,16</sup> Although these components can slightly differ across definitions, they generally follow a distinction between lower-level technical components and higher-level organizational components. In line with this conceptualization, this section gives a brief overview of technical, syntactic, semantic and organizational aspects of interoperability.

<sup>1</sup>Berlin Institute of Health (BIH), Berlin, Germany, <sup>2</sup>Charité – Universitätsmedizin Berlin, Berlin, Germany and <sup>3</sup>Hochschule Niederrhein – University of Applied Sciences, Krefeld, Germany

Correspondence: Moritz Lehne (moritz.lehne@bihealth.de)

Paris, Novotel Tour Eiffe Published online: 20 August 2019

Scripps Research Translational Institute

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# Knowledge Graphs as Enhancers of Intelligent Digital Twins

#### Nada Sahlab<sup>\*</sup>, Simon Kamm<sup>\*</sup>, Timo Müller<sup>\*</sup>, Nasser Jazdi (IEEE senior member), Michael Weyrich Institute of Industrial Automation and Software Engineering University of Stuttgart Stuttgart, Germany \*These authors contributed equally to this publication (surmame.name/(dias.uni-stuttgart.de

Abstract ---Cyber-Physical Systems, characterized by networking capabilities and digital representations, offer many promising potentials for industrial automation. In an attempt to further enrich the system's digital representation by incorporating interdisciplinary models and considering a continuous and synchronized representation of it within the cyber layer, the concept of the Digital Twin emerged, enabling system monitoring, virtual commissioning, failure diagnosis and simulations by managing the Cyber-Physical Systems data along its lifecycle. To add further intelligence into the Digital Twin, the architecture of the intelligent Digital Twin was proposed. Nevertheless, managing and relating the complex and dynamic digital models as well as the heterogeneous data of the intelligent Digital Twin present open challenges. Due to their inherent extensibility and adaptability as well as their semantic expressiveness, Knowledge Graphs are a suitable concept to overcome these challenges and enable reasoning to gain new insights. Prominent applications of Knowledge Graphs are recommendation systems and exploratory search within the semantic web. However, there seems to be a lacking yet potential applicability for Knowledge Graphs in the industrial domain. Therefore, this contribution proposes a Knowledge Graph enhanced architecture of the intelligent Digital Twin, offering capabilities, which are internal linking and referencing, knowledge completion, error detection, collective reasoning and semantic querying. Based on the proposed concept, potential application fields for Knowledge Graph enhanced intelligent Digital Twin are addressed.

in the form of digital models along with additional computational components are applied in the cyber layer to realize desired use cases. One research objective aims at taking advantage of these digitally available data of systems by considering every possible artifact digitally available throughout the lifecycle. Combining multidisciplinary static design models with dynamic operational data in one unified construct continuously representing physical systems enables various use cases, such as virtual commissioning, simulations prior to reconfigurations as well as predictive maintenance. This combination of models and dynamic data is the research objective addressed by the concept of Digital Twins.

In parallel, another research objective focuses on the applicability of artificial intelligence and machine learning algorithms to the industrial domain e.g. for optimizing production processes. What characterizes this application field is the prerequisite of having large datasets and narrow as well as specific problem areas. Choosing a proper learning algorithm based on the categories and the many subcategories of supervised or unsupervised learning as well as adjusting parameters to model the problem, using this model would result in predictions or detections specific to the problem. Examples include anomaly detection for quality assurance in produced parts [3].

By combining these two research objectives, the Digital Twin is enriched with additional modules containing further







# **Review Article**

OMICS A Journal of Integrative Biology Volume 24, Number 10, 2020 Mary Ann Liebert, Inc. DOI: 10.1089/omi.2020.0153

# The Sickle Cell Disease Ontology: Enabling Collaborative Research and Co-Designing of New Planetary Health Applications

Victoria Nembaware,<sup>1</sup> Gaston K. Mazandu,<sup>1</sup> Jade Hotchkiss,<sup>1</sup> Jean-Michel Safari Serufuri,<sup>1</sup> Jill Kent,<sup>2</sup> Andre Pascal Kengne,<sup>3</sup> Kofi Anie,<sup>4,5</sup> Nchangwi Syntia Munung,<sup>1</sup> Daima Bukini,<sup>2</sup> Valentina Josiane Ngo Bitoungui,<sup>6</sup> Deogratias Munube,<sup>7</sup> Uzima Chirwa,<sup>8</sup> Catherine Chunda-Liyoka,<sup>8</sup> Agnes Jonathan,<sup>2</sup> Miriam V. Flor-Park,<sup>9</sup> Kevin Kum Esoh,<sup>10</sup> Mario Jonas,<sup>1</sup> Khuthala Mnika,<sup>1</sup> Chandré Oosterwyk,<sup>1</sup> Upendo Masamu,<sup>2</sup> Jack Morrice,<sup>1</sup> Annette Uwineza,<sup>11</sup> Arthemon Nguweneza,<sup>1</sup> Kambe Banda,<sup>1</sup> Isaac Nyanor,<sup>12</sup> David Nana Adjei,<sup>5</sup> Nathan Edward Siebu,<sup>5</sup> Malula Nkanyemka,<sup>2</sup> Patience Kuona,<sup>13</sup> Bamidele O. Tayo,<sup>14</sup> Andrew Campbell,<sup>15</sup> Assaf P. Oron,<sup>16,\*</sup> Obiageli E. Nnodu,<sup>17</sup> Vivian Painstil,<sup>18</sup> Julie Makani,<sup>2</sup> Nicola Mulder,<sup>19</sup> and Ambroise Wonkam<sup>1</sup>; on behalf of the Sickle Cell Disease Ontology Working Group

### Abstract



Sickle cell disease (SCD) is one of the most common blood disorders impacting planetary health. Over 300,000 newborns are diagnosed with SCD each year globally, with an increasing trend. The sickle cell disease ontology (SCDO) is the most comprehensive multidisciplinary SCD knowledge portal. The SCDO was collaboratively developed by the SCDO working group, which includes experts in SCD and data standards from across the globe. This expert review presents highlights and lessons learned from the fourth SCDO workshop that marked the beginning of applications toward planetary health impact, and with an eye to empower and cultivate multisite SCD collaborative research. The workshop was organized by the Sickle Africa Data Coordinating Center (SADaCC) and attended by 44 participants from 14 countries, with 2 participants connecting remotely. Notably, from the standpoint of democratizing and innovating scientific meeting design, an SCD patient advocate also presented at the workshop, giving a broader real-life perspective on patients' aspirations, needs,



# Staying grounded to patients' real-world

#	Feature	% (N = 33)
1	Help to detect the early signs of crisis	75,76%
2	Offer general information about your disease	75,76%
3	Advices and feedback about how to self-care in your daily life	60,61%
4	Help to avoid the triggering of crisis	57,58%
5	Information about your current health status	51,52%
6	Ease the access to medical assistance in case of emergency	42,42%
7	Help to have a healthy lifestyle	42,42%
8	Offer a permanent contact with healthcare providers	33,33%
9	Assist when performing physical activities	30,30%
10	Provide information about your disease in case of emergency	30,30%
11	Access your medical record and allow to keep it up to date	27,27%
12	Arrange and manage your medical appointments / check-ups / follow-up	24,24%
13	Help to contact support groups in case of crisis	18,18%
15	Provide information that educates your friends / family / people you meet	15,15%
16	Offer an emotional / psychological support outside crisis	12,12%
17	Ease the access to medical assistance in everyday life	9,09%
18	Help to contact support groups outside crisis	9,09%
19	Offer an emotional / psychological support in case of crisis	9,09%

Table 3. Overview of potential influencers of adoption through the capability, opportunity, motivation, and behavior

Requirement	Quotes	COM-B system
Prevent crises by avoiding symptoms	12	Automatic motivation
Family and social community support (shareability)	15	Automatic motivation
Gain more control on disease through daily self-care supp	ort 28	Physical capability
Limit management	9	Physical capability
Importance of information trustworthiness	17	Physical opportunity
Invisibility or inconspicuousness	9	Physical opportunity
Similarity with messaging apps	8	Physical opportunity
Automatic reminders and automatability	5	Physical opportunity
Simplicity	3	Physical opportunity
Learn trigger factors	14	Psychological capability
Predict health outcomes	11	Psychological capability
Receive threshold alerts	10	Psychological capability
Feedback on self-care practices	17	Psychological capability
Customizable	8	Reflective motivation
Privacy Sources: Issom et al. 2	01042021 20	Reflective motivation
Learn what other patients do	14	Social opportunity

# Issom et al. 2018



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Major factors influencing health outcomes / QoL in SCD

Hypoxemia, fever, dehydration, fatigue, corticosteroids, Sleep & rest, pollution, Pain, ADHD, physical exertion, cold & wind,

intake of stimulants, **Stress**, alcohol, **slowed blood circulation**, acidosis, tobacco, **hormonal disturbances, hemolysis**, **infections**, etc.



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# Wearable devices for continuous monitoring of biosignals: Challenges and opportunities 😨 🐵

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Tucker Stuart,<sup>1</sup> (b) Jessica Hanna,<sup>1</sup> (b) and Philipp Gutruf<sup>1,2,3,4,a)</sup> (b)

### **AFFILIATIONS**

<sup>1</sup>Department of Biomedical Engineering, University of Arizona, Tucson, Arizona 85721, USA <sup>2</sup>Department of Electrical and Computer Engineering, University of Arizona, Tucson, Arizona 85721, USA <sup>3</sup>Bio5 Institute, University of Arizona, Tucson, Arizona 85721, USA <sup>4</sup>Neuroscience GIDP, University of Arizona, Tucson, Arizona 85721, USA

Note: This paper is part of the special issue on Emerging Technologies in Wearable Sensors. <sup>a)</sup>Author to whom correspondence should be addressed: pgutruf@email.arizona.edu

### ABSTRACT

The ability for wearable devices to collect high-fidelity biosignals continuously over weeks and months at a time has become an increasingly sought-after characteristic to provide advanced diagnostic and therapeutic capabilities. Wearable devices for this purpose face a multitude of challenges such as formfactors with long-term user acceptance and power supplies that enable continuous operation without requiring extensive user interaction. This review summarizes design considerations associated with these attributes and summarizes recent advances toward continuous operation with high-fidelity biosignal recording abilities. The review also provides insight into systematic barriers for these device archetypes and outlines most promising technological approaches to expand capabilities. We conclude with a summary of current developments of hardware and approaches for embedded artificial intelligence in this wearable device class, which is pivotal for next generation autonomous diagnostic, therapeutic, and assistive health tools.

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Nilufar Baghaei Julita Vassileva Raian Ali Kiemute Oyibo (Eds.)

LNCS 13213

# Persuasive Technology

17th International Conference, PERSUASIVE 2022 Virtual Event, March 29–31, 2022 Proceedings



# Persuasive technologies

"Persuasive technology is an interdisciplinary field of research focused on the design, development, and evaluation of interactive technologies aimed at changing people's attitudes or behaviors through persuasion, but not coercion or deception"

JUNE 16-18 2022



### Designing gamification and persuasive systems: a systematic literature review

Jeanine Kratha and Harald F. O. von Korflescha

<sup>a</sup> University of Kohlenz-Landau, Universitaetsstrasse 1, Kohlenz, 56070, Germany

#### Abstract

Gamification design has been an important issue for practitioners and researchers since the beginning of research on gamification. With the increasing divergence of gamification in diverse areas, various design principles have been proposed. Yet, existing reviews focus on the synthesis of scientific knowledge about the design process and specific design elements, neglecting the importance of guidelines and principles to make appropriate design choices in order to achieve the desired outcomes. Therefore, this systematic review identifies, analyzes, and categorizes 30 articles that propose design guidelines for gamification and persuasive systems from various application contexts to provide scholars and practitioners with an overview in designing gamified interventions. More than 60 different principles have been identified, which can be divided into user-oriented principles to achieve the intended behavior. system-oriented principles to ensure a hedonic user experience, and context principles. Since the results are primarily conceptual, further research is invited to investigate the effectiveness of different principles based on the context of application to further refine the recommendations for specific use cases of gamification.

#### Keywords 1

Gamification, Design, Persuasive Systems, Literature Review, Gamification Design

### 1. Introduction

Over the last decade, gamification has evolved as an effective tool for creating positive experiences such as engagement and enjoyment [1]. Gamification is based on psychological effects of games, such as autonomy, competence and flow [2], and promotes intrinsic motivation for human behavior in nongame contexts [3].

The design of gamification has gained scientific attention in several disciplines, particularly education [4, 5]. But academic research remains still largely focused on listing and cataloging design patterns [6] or motivational affordances [1, 2]. These are elements such as badges and leaderboards [7] and represent the lowest level of abstraction in

5th International GamiFIN Conference 2021 (GamiFIN 2021). April 7-10, 2021 Finland EMAIL: jkrath@uni-koblenz.de (A. 1); harald.vonkorflesch@uni-

koblenz.de (A. 2) ORCID: 0000-0003-4996-1147 (A, 1): 0000-0003-2087-471X (A



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gamification design [7]. However, their use needs to be guided by design principles [7], which specify the overall game model developed by the use of particular game design methods [7].

Recent systematic reviews have analyzed design methods [8, 9, 10] and conceptual models [9] of game design. However, a comprehensive overview is still missing concerning design principles, where existing syntheses remain narrowed to the contexts of education [4, 5, 11] and energy games [12]. Design principles represent an important bridge between the two other levels of abstraction design methods and models on the one hand and design patterns and motivational affordances on the other. They help practitioners, such as teachers, physicians or managers, to choose

User-oriented principles for behavioral outcomes

#### Individual behavior principles

Provide immediate positive feedback Introduce behavioral incentives Offer informational content Frame the intervention with storytelling Divide content in tasks and steps Guide users with persuasive messages Provide data for (self-)monitoring Visualize progress Provide clear and meaningful (self-set) goals Allow for the evaluation of one'sown knowledge Show how behavior relates to the goals

### Social behavior principles

Gamified system

inter

the

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Context

Allow social comparisons Encourage social collaboration Connect users for social interaction Allow showing status and gainingsocial recognition Allow social competition Enable social learning Provide community support

#### Exemplary patterns / motivational affordances

Points, badges, levels, performance stats, progress Achievements, rewards (in-game and real world) Quizzes, assistance, reminders, virtual helpers Narrative, avatar, role play Challenges, missions Reminders, cues, suggestions Tracking, performance stats Levels, status bars, achievements, badges Tasks, goal setting, clear goals Quizzes, questions Impact visualizations, performance stats

#### Exemplary patterns / motivational affordances

Leaderboards, rankings Multiplayer, teams, collective voting Social networking features, teams Peer-rating, profile, medals, trophies Challenges, leaderboards Knowledge sharing (forums) Knowledge sharing (forums), peer-rating, praise

System-oriented principles for hedonic experiences and affective reactions

#### Hedonic experience principles

Personalize the system contents and mechanics Increase and adjust difficulty over time Enable freedom of choice Ensure continuous excitement with new or hidden content Provide multiple paths to achieve a goal 

#### Exemplary patterns / motivational affordances

Avatar, character, virtual identity, customization Levels, skill trees, increasing difficulty, timer Missions, challenges, anarchic gameplay Unlockable content, easter eggs, narrative Challenges, missions, nonlinear gameplay

### Context principles

Consider the context and location of the intervention Include target group in co-design Prioritize aesthetic design Consider the ethics of design, privacy protection and trustworthiness



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# Examples of "Serious games"



*Fig. 1.* Stimuli environment: (a) image of real laboratory (b) virtual laboratory (camera view for the stimuli videos) (c) contaminated







# Towards automated patient-decision aids and health recommender systems for SCD to predict VOCs







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# Hi, I'm TREVOR, the AI-powered Sickle Cell Coach who simplifies your life!



# A discreet chatbot to capture, model & automatically analyze real-world patient-generated health data





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# An easy-to-use and engaging tool to support patient empowerment & therapeutic education





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# **Fvidence-based micro**learnings to accompany step-by-step capacity building

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Drépadémie Accueil Tableau de bord Mes cours

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- Etre coaché pour être actif régulièrement, mais modérément co
  - · Apprendre à pratiquer une activité physique adaptée en tout sécurité
  - Eviter de déclencher une crise en suivant les précautions adéquates
  - Gagner en capacité physique, musculature, en forme physique tout en réduisant la fréquence des symptômes et en augmentant ta résilijence

#### #1 La drépanocytose et moi

Syllabus



### · Qu'est ce que la drépanocytose ?

- Comment peut-on être atteint de la drépanocytose ?
- Quels sont les symptômes de cette maladie ?

Au cours de cette mini formation, tu seras à même de répondre à ces questions. Composé de deux quiz et d'un cours, tu pourras grâce à ce format suivre ton évolution.

#### #2 Vie saine et drépanocytose



- Comment vivre au mieux au quotidien avec la drépanocytose ?
- Quelles sont les habitudes de vie à avoir pour réduire les symptômes de la maladie?
- Quels sont les risques à éviter lorsque l'on est atteint de drépanocytose ?

Ce cours te permettra de répondre à ces interrogations mettant en lumière l'importance d'une vie saine.

### #3 Douleurs, infections et drépanocytose



- Syllabus
- Les symptômes de la drépanocytose peuvent-ils être évités ?
- Pourquoi ces douleurs ?
- Des infections sont-elles à surveiller ?

Durant ce cours, tu pourras en apprendre davantage sur les causes des douleurs et infections et sur comment les soulager ou éviter.

#### #4 Complications principales de la drépanocytose



- accident vasculaire cérébral
- nécrose avasculaire
- syndrome thoracique aigu
- rétinopathie
- priapisme
- ostéomyélite
- ulcères de jambe
- calculs biliaires
- · complications rénales





# Micro-learnings to motivate step-by-step learning



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# #3 Douleurs, infections et drépanocytose

# Take home message

- Digital patient twins can leverage data beyond the traditional approaches
  - Precision SoDH, patient-generated health data, digital biomarkers, digital footprints
- Educational DHIs may provide healthcare providers, patients and pharmaceutical companies with targeted learnings
- Automated data analysis shows actionable insights and trends to improve patient-important health outcomes  $\rightarrow$  better schedule medical visits
- Patient-led approaches facilitate design and delivery of personalized, equitable, sustainable and efficient care
- Persuasive chatbots are easy-to-use, robust and can be used in LIMICs



« The highest activity a human being can attain is learning for understanding, because to understand is to be free»

- Baruch Spinoza

david.issom@escfederation.eu



# **VPH CONFERENCE** 2022 Digital twins for personalized treatment development and clinical trials



