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Personalized Health Care in a Data-Driven Era: A Post–COVID-19 Retrospective

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Personalized Health Care in a Data-Driven Era: A Post—COVID-19 Retrospective

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In this retrospective commentary, we present the "worldview"[1,2] of 43 health care stakeholders (across the roles of patients, health care practitioners, health policy researchers, payors, policymakers, health care providers, and technology vendors) with diverse experiences and expertise. This was obtained in the course of our ongoing field investigations on the personalized health care as a service (PHCaaS) design. As a research methodology, we adopted a branch of system thinking known as Soft System Methodology 3, a consistent variant of design science research.[3,4] Because Soft System Methodology 3 requires a comprehensive understanding of the given "problematic situation" in need of a solution, a systematic literature review to obtain a contextual understanding of contemporary PHCaaS served as a starting point.[5] Specifically, an extensive background review of emerging information technologies[6] and an extensive review of system design principles and rules for PHCaaS[7] were examined to design a feasible ecosystem. Refinement of design specification and validation of the design were achieved through design refinement interviews and a design validation workshop, respectively.[8,9] Here, participating health care stakeholders (known as informants in the parlance of grounded theory research) shared their viewpoints, experience, and informed insights about PHCaaS. An open call for participation was emailed to the members of Health Informatics New Zealand (www.hinz.org.nz) and the Health Informatics Forum (www.healthinformaticsforum.com), strictly adhering to the principle of informed participation. Because the field study was conducted during the pandemic, interactions were mainly through online interviews and focus group workshops, which were purposed to distill and incorporate participants' viewpoints with diversified digital health care experience and expertise. The Table lists participating health care stakeholders or informants included in this commentary (Supplemental Table, available online at https://www.mcpdigitalhealth.org/). A thematic semantic analysis[10] of their concerns and expectations using NVivo[11] as an information-mining tool suggests that patient-centric, personalized health care (PHC) incorporating interoperability standards, dynamic consent management, and state-of-the-art data privacy and security measures can potentially offer transparent, portable, and scalable health care services, addressing the gap in current practices. Figure 1 is a word-cloud of systematic semantic analysis, generated by NVivo using text from transcriptions of design refinement interviews. It is clear that interoperability, sustainability, accountability, individualization, and implementation are "top of mind" concerns that informants have in their worldviews of PHCaaS,

Health Care Providers

Building on electronic health records (EHRs) or electronic medical records, health care providers now demand robust application programming interfaces that provide utilities for data interoperability and availability in a context-sensitive manner. They also demand data privacy by design and privacy by default in system development and operations. Over time, health care providers have learned the importance of routine system security updates and their potential to reduce malpractices such as identity theft, data breaches, and cyberattacks.[12] They have also learned how patient-controlled EHRs can encourage patient engagement, opt-in, active participation, and transparency in health care service delivery. Active bench-learning from other industries, such as banking,[13] retail,[14] and insurance,[15]

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have enabled health care providers to benefit from best practices and lessons learned on applying emerging technologies to achieve secure and effective data sharing. Providers have also adopted digitally enabled and internationally recognized performance evaluation standards to assess treatment efficacy and improve service quality over the usage cycle. On user-centricity, the providers now prefer simple, intuitive augmented reality (AR) interfaces[6,16,17] to fulfill patients' emotional, clinical, and practical needs. One key takeaway from the COVID-19 pandemic for health care providers is the potential of remote monitoring with biosensor devices in delivering PHC.

Health Policy Researchers

During the same period, health policy researchers observed a significant escalation in digital health service usage.[18−20] This digital health engagement trend emerged as the key enabler for revamping existing health information ecosystems and needs to be prolonged to enable optimal data usage in health care delivery. Scholars and policymakers also understand that digitally enabled, user-centric health care service design is a key success factor in the emerging era of data-driven PHC. Patients expect user-centric (empathic), simple, intuitive, and customizable digital health service design with ubiquitous, assignable access privileges. They appreciate the current practice of multifactor authentication mechanisms for user verification, data privacy, and security, because these design considerations are central to a trustworthy digital health ecosystem. Research on the effect of emerging technologies such as artificial intelligence (AI), internet of things (IoT), big data, blockchain, and the metaverse on PHCaaS has attracted increasing attention from these stakeholders.

For instance, blockchain characteristics such as decentralization, tamper-resistance, traceability, and immutability are potential to the following: (1) provide secure and accountable health data sharing, (2) improve the data privacy and integrity for PHC, and (3) reduce the overall health care administrative costs.[21−23] Metaverse as a simulation and AR platform could potentially improve virtual training, medical education, and collaboration among health care stakeholders by providing effective health data visualization to assist in AI-based decision making,[24-26] leading to more accurate, precise, PHC. Digital health researchers anticipate significant benefits of real-time, remote-sensing, and notification capabilities with IoT, machine learning models, and big data. Occurrences of cyber incidents, such as unauthorized intrusions and data theft in health care systems, have led to a reexamination of existing health data policy regarding patients' control over data sharing. Policymakers also demand regulatory concern in reviewing the existing notification distribution mechanism in digital health scenarios because current practices allow information asymmetry in favor of state-appointed policy advocates and regulators. Policy research has long advocated a common interoperability standard for effective health data interoperability, which is also a key to system scalability.

Health Care Practitioners

Our field research informs us that health care practitioners believe that the interoperability and portability of EHRs are to be the key enablers of uninterrupted data exchange in the data-driven health care ecosystem. They support the practice of patient-controlled data usage because it promotes patient empowerment and user-centricity and assures transparency in system operations, data security, privacy mechanisms, and consequently, trustworthy health care. Ironically, a misconception about "replacing doctors with AI" exists among contemporary health care practitioners, despite familiarity with its scope, application, capability, and limitation for years. The trend of disruptive integration of emerging information technologies into contemporary health care settings worldwide has led to fears of dehumanization[27,28] or depersonalization.[29,30] We have evidenced doctors using search engines to look up facts[31,32] and now acknowledging the use of AI chatbots,[33,34] such as Chat Generative Pretrained Transformer (ChatGPT).[35] An example use-case of ChatGPT as medical advisory service may be found in the Supplemental Table. In the current digital transformation of health care, it is challenging to persuade health care practitioners that such change is inevitable and would be beneficial. PHCaaS could provide data support to health care practitioners and provide efficacy in health care services and

TABLE. List of Participating Health Care Stakeholders

Informant No.	Stakeholder type	Affiliation	Position	Years of experience in digital health	Country	Specialization
1	Policymaker	Cloudspotter Consultancy	Consultant	10+	United Kingdom	Strategic planning, project ideation, stakeholder consultation, policy advocacy
2	Policymaker	Mercy Public Hospitals Inc	Chief health information services manager	10+	Australia	Strategic planning, stakeholder consultation
3	Policymaker	The Press	Senior health reporter	10+	United Kingdom	Project ideation, health policy advocacy
4	Policymaker	Directorate General of Health Services	Director general	10+	Bangladesh	Strategic planning, project ideation, stakeholder advisory, policy advocacy
5	Health policy researcher	Institute of Environmental Science and Research, New Zealand	Scientist	7	New Zealand	Bioinformatics, patient-centric health care design
6	Health policy researcher	School of Public Health, University of Sydney	Postdoctoral researcher	10+	Australia	Public health, digital mental health, health services research
7	Health policy researcher	Centre for Public Health Data and Policy, Australian National University	Research fellow	10+	Australia	Public health, patient-centric health care design, health system research, implementation science
8	Health policy researcher	Centre for Primary Health Care and Equity, University of New South Wales	PhD researcher	10+	Australia	Public health, population health, digital health
9	Health policy researcher	Auckland District Health Board (ADHB)	Analyst	10+	New Zealand	Health informatics, social media in health care, EHR/EMR, digital health
10	Health policy researcher	MYOB	ERP support analyst	2	China	New Zealand health care, blockchain, precision health care, health informatics
11	Health care practitioner	Doc Cure Health Tech Limited	General physician	8	Bangladesh	Telehealth, e-health
12	Health care practitioner	Doc Cure Health Tech Limited	General physician	4	Bangladesh	Telehealth, e-health

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TABLE. Continued

Informant No.	Stakeholder type	Affiliation	Position	Years of experience in digital health	Country	Specialization
13	Health care practitioner	Department of Internal Medicine, William Osler Health Centre, Brampton Civic Hospital	Specialized physician	10+	Canada	Internal medicine, rheumatology, e-health
14	Health care practitioner	Canterbury District Health Board (CDHB)	Community nurse	9	New Zealand	Mental health, community health, telehealth, m-health
15	Health care practitioner	CDHB	Registered nurse	10+	New Zealand	Mental health, community health, telehealth, m-health
16	Health care practitioner	CDHB	Health care assistant	5	New Zealand	Primary care, mental health, e-mental health, digital health
17	Health care practitioner	CDHB	Mental Health assistant	5	New Zealand	Primary care, mental health, e-mental health, digital health
18	Health care practitioner	CDHB	Health care assistant	2	New Zealand	Dentistry, mental health, e-health, EHR/EMR
19	Health care practitioner	CDHB	Enrolled nurse	10+	New Zealand	Mental health, e-mental health, community health digital health
20	Health care practitioner	CDHB	Enrolled nurse	10+	New Zealand	Mental health, e-mental health, forensic health, digital health
21	Health care practitioner	CDHB	Registered nurse	10+	New Zealand	Mental health, e-mental health, community health digital health
22	Technology vendor	LifePlus Bangladesh (Powered by Labaid)	Product designer	4	Bangladesh	UI UX designer, digital health
23	Technology vendor	LifePlus Bangladesh (Powered by Labaid)	Software engineer	3	Bangladesh	Backend developer, e-health
24	Technology vendor	LifePlus Bangladesh (Powered by Labaid)	Software quality assurance engineer	2	Bangladesh	Software quality assurance, digital health
25	Technology vendor	Westwing www.westwing.de	Software frontend engineer II	5	Germany	Full-stack development, digital health
26	Technology vendor	Plexure	Senior software engineer	2	New Zealand	Health navigation systems, health information system developer
27	Technology vendor	Brain Station 23	Head—strategic business unit	3	Bangladesh	Biomedical engineering, health informatics, blockchain

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TABLE. Continued

Informant No.	Stakeholder type	Affiliation	Position	Years of experience in digital health	Country	Specialization
28	Technology vendor	ZTE Corporation	Core network (cloud) engineer	4	New Zealand	Health informatics, EHR/EMR, digital health
29	Health care provider	LifePlus Bangladesh (Powered by Labaid)	Assistant general manager (marketing and business development)	8	Bangladesh	Health care marketing and business development, digital health
30	Health care provider	Labaid Cancer Hospital & Super Speciality Center	Deputy manager	6	Bangladesh	Health care resource management, e-health
31	Health care provider	LifePlus Bangladesh (Powered by Labaid)	Product development analyst	8	Bangladesh	Health care business analytics, e-health
32	Health care provider	MySoft Limited	Assistant manager (business development)	4	Bangladesh	Health care marketing and business development, digital health
33	Health care provider	ADHB	Medical administrator	5	New Zealand	Health informatics, EHR/EMR, digital healt.
34	Health care provider	ADHB	Data administrator	10+	New Zealand	Health informatics, EHR/EMR, digital health
35	Patient	Department of Philosophy, University of Canterbury	PhD researcher	10+	New Zealand	Experienced e-health user
36	Patient	—	Homemaker	7	New Zealand	Experienced e-health user
37	Patient	University of Canterbury	IS tutor and researcher	5	New Zealand	M-health, telehealth, health applications
38	Patient	—	Self-employed business owner	4	New Zealand	M-health, telehealth, health applications
39	Patient	Ministry for Primary Industries	Principle financial analyst	6**	New Zealand	M-health, telehealth, health applications
40	Patient	Radio Ektara	Audio engineer	8	New Zealand	M-health, telehealth, health applications
41	Payor	ADHB	ACC administrator	8	New Zealand	Health claims analysis, EHR/EMR, digital health
42	Payor	ADHB	ACC coordinator	10+	New Zealand	Health claims analysis, EHR/EMR, digital health
43	Payor	ADHB	ACC administrator	4	New Zealand	Health claims analysis, EHR/EMR, digital health

EHR, electronic health record; EMR, electronic medical record.

FIGURE 1. Word-cloud of stakeholders' worldviews.

delivery. It would not be socially desirable to replace health care practitioners with cloud technology. PHC requires implementing and feasibly adopting EHR data models, clinical gold standards, genomic profiles, and AR simulations to develop patient treatment plans and ensure PHC delivery. Large data sets support this from health and fitness monitors (IoT-enabled, AI-supported, biosensor-based smart medical wearables) in real-time to develop precise, patient-centric models for treatment plans. Undoubtedly, technology, in general, and AI, in particular, will transform the nature of work in the health care sector. As a result, health care practitioners are concerned that enabling all of the above could potentially introduce a fully digitalized health intervention practice that reduces their roles in human oversight.

Payors

In the PHCaaS ecosystem, payors understand the value of personalized digital health services and their potential to improve health care efficacy, quality, experience, and associated costs. The COVID-19 pandemic witnessed unprecedented health care demand and related challenges, exposing payors and regulators to the risk of unfair treatment of marginalized communities.[36-38] They have understood the importance of good-quality EHRs and the resulting technological advancements in health care services. It has led to a broad positive sentiment for future technology-feasible and economically-viable personalized digital health services for sustainability in health care.

Patients

Prospective patients of PHCaaS demand a positive user experience with access to their health records. They expect seamless data-centric PHC services. Like other health care stakeholders, patients are also concerned about health data privacy and security. They acknowledge adopting complex, multilayered data privacy and security mechanisms (ie, encryption schemes) in system operations and health care service delivery. They support the practice of "prior notification and consent" regarding security and system updates to establish transparency. Furthermore, they understand the need to maintain stringent data quality standards to function effectively with data interoperability among the stakeholders. For example, regular adherence testing to verify whether unauthorized access, modification, or deletion of EHRs had taken place would assure regulators and patients themselves that their data are secure and hence the PHCaaS is trustworthy. Blockchain and smart contracts could serve this purpose.

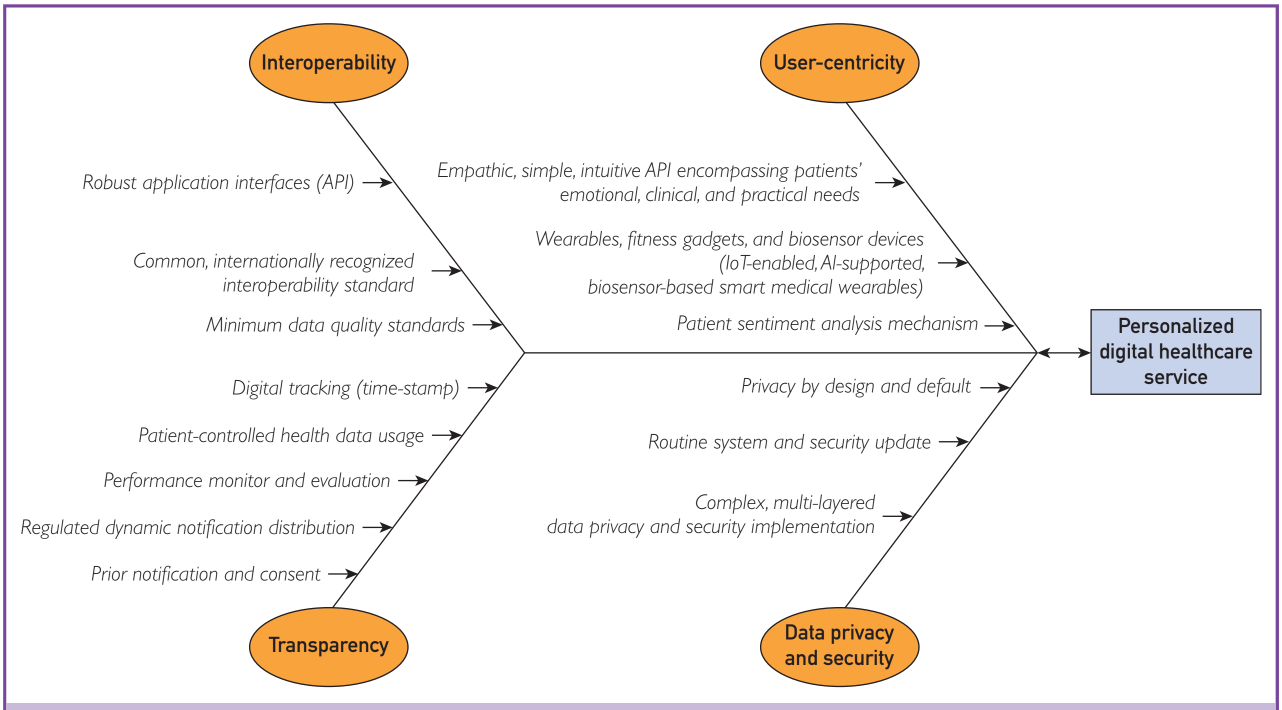

FIGURE 2. The diagram of PHCaaS by Ishikawa.[39]

Technology Vendors

Consistent with the perspective of health care providers, technology vendors also acknowledge the need to monitor and evaluate health care practitioners' performance while treating patients and demand the integration of viable technological solutions in health care delivery systems. Regarding health data privacy and security, they support the inclusion of additional security mechanisms, such as trustless platforms, in addition to conventional data management techniques. They agree that health data interoperability in less-developed economies is a great challenge owing to the lack of standards per se, even within the same jurisdiction. Many countries have laws that prohibit storing and sharing identifiable health care data offshore. Therefore, as with the case of health care researchers and practitioners, technology vendors recommend

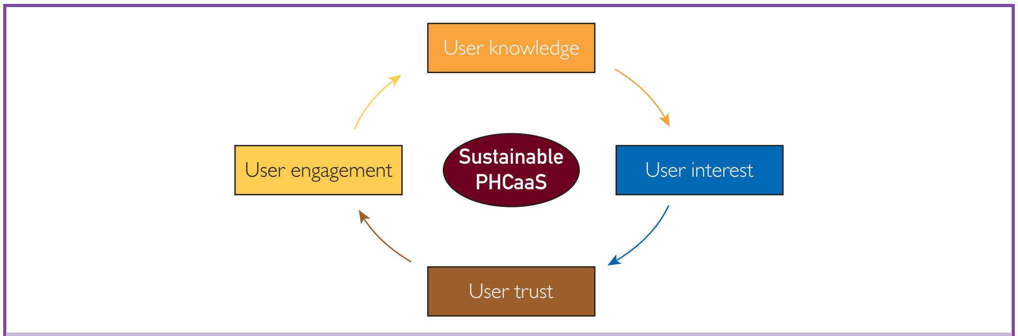

FIGURE 3. A conceptual framework for sustainable PHCaaS.

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adopting a commonly used interoperability standard for seamless data exchange among health care stakeholders.

Policymakers

Digital health policymakers acknowledge the importance of privacy and security in every aspect of health care data cycle (ie, collection, storage, analysis, and sharing) to prevent patient harm. They recommend obtaining and using patients' health care data with prior consent to establish transparency in digital health practices. Regarding wearables or fitness gadgets, policymakers recommend expanding these IoT-enabled, AI-supported biosensor devices, and their usage should be rolled out in context-specific approaches. Such patient-centric information protocols may potentially impact patient engagement in PHC services. Furthermore, policymakers believe that securing higher opt-in rates may be beneficial to offering health data aggregation at an extensive scale, which is significant for health care training, improvement, and development.

In summary, our field investigation[7] revealed a set of design parameters that health care stakeholders deem necessary for PHCaaS. Figure 2 illustrates this set of needs articulated by health care stakeholders and the actions to be considered while developing PHC services in a contemporary data-driven context. On the basis of these insights from the field, we may conjecture that user-centric PHC incorporating recognized, commonly used interoperability standards, dynamic consent management, and state-of-the-art data privacy and security measures can potentially offer a transparent, interoperable, and scalable health care service. However, implementing such desired health care services should progress in collaboration with health care stakeholders with alternative perspectives to encompass their real-world experience and expertise in health care service delivery.

Implications for Digital Health Policy

Digital health stakeholders have long experienced numerous sociotechnical challenges, such as fear or resistance by patients and providers to novel technologies such as wearable devices, machine learning models, and simulation using digital twins. Some of these are recurring themes in design interviews—interoperability, sustainability, accountability, individualization, and implementation. Stakeholders are reasonably aware of emerging personalized digital health care services that potentially improve the current efficacy of digital health. However, due to differing priorities and worldviews, most stakeholders appear unfamiliar with technological innovations and applications in a broader health care context. Therefore, disruptive technical integration into contemporary health care settings could create a fear of dehumanization[27,28] or depersonalization,[29,30] despite knowing the strengths and limits of such technologies.

Therefore, use-cases that support inclusive and sustainable PHCaaS are a key policy imperative for achieving sustainability development goals for universal health care that is affordable and accessible across the globe. In order for digital health to expand to such a role, the informed support of policymakers is required for buy-in of other stakeholders through demonstrations, workshops, conferences, discussions, forums, and training. The value of experimenting with digital health use-cases among stakeholders would invariably bring about a more cooperative rather than a competitive ecosystem and its antecedent reduction in duplicating data and systems. Moreover, stakeholders' heightened awareness of digital health innovations may raise user knowledge, interest, and trust in emerging digital health services and result in higher user opt-in (active engagement). Such practices in digital health systems may be influential in supporting sustainable health care.

A key promise of PHCaaS is that the value of big data accrues to patients in form of preventative medicine, in which significant connections may be made between genetic profiles and wellness outcomes, typically mediated by medical interventions and lifestyle changes. Although the power of such insights (or might we say, data-driven hindsight) are truly transformational, they also open a pandora's box of ethical dilemmas such as rationing scarce resources, stigmatizing people with predispositions, and penalizing such risks with punitive measures such as higher premiums or special treatment. Nothing in this commentary downplays the importance of medical ethics in delivering PHCaaS, a discussion best served by informed decisions and agreed to by policymakers, researchers, health care providers, and the public.

Figure 3 illustrates the conceptual framework for sustainable PHCaaS. In such a user-centric ecosystem, patients and health care providers could be co-opted into collaborating for value. Specifically, patients consent to sharing nonpersonally identifiable information to build predictive and prescriptive models for treatment and using these machine learning and simulation models, doctors provide training and oversight to test, validate, and improve the same. In short, in such an ecosystem, the quality and integrity of patient data are critical.

The United Nations envisions sustainability in health care by 2030.[40] Sustainability Development Goal 3 may seem ambitious but not impossible in the context of current trajectories. Specifically, data-driven digital health platforms are key to accessing global best practices and gold standards of care. Such technological integration has already been realized in various health care settings around the globe. However, the sustainability of these existing implementations requires the integration of other emerging information technologies for the connectivity, security, storage, modeling, and analytics of such PHCaaS. Consistent with Lin's[41] worldviews as a health care practitioner, we may conjecture that primary health care clinicians will lead this transformation to integrate the silos of automation, such as EHRs or electronic medical records, augmented technologies such as AI, IoT, blockchains, and digital twins, and secure cloud platforms with contemporary health care stakeholders, upscale patient engagement, and offer context-aware, data-driven health care for the well-being of humanity. By the same token, technology providers and researchers will lead to the adoption of use-cases that demonstrate to stakeholders the efficacy of PHCaaS.

POTENTIAL COMPETING INTERESTS

The authors have no conflict of interest to disclose.

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SUPPLEMENTAL ONLINE MATERIAL

Supplemental material can be found online at https://www.mcpdigitalhealth.org/. Supplemental material attached to journal articles has not been edited, and the authors take responsibility for the accuracy of all data.

Abbreviations and Acronyms: **AI,** artificial intelligence; **API,** application programmer interface; **AR,** augmented reality; **EHR,** electronic health record; **IoT,** internet of things; **PHC,** personalized health care; **PHCaaS,** personalized health care as a service

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