

Data journey map: a process for co-creating data requirements for health care artificial intelligence

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Suggested citation. Charles C; Tulloch C; McNaughton M; Hosein P; Hambleton IR. Data journey map: a process for co-creating data requirements for health care artificial intelligence. *Rev Panam Salud Publica.* 2024;48:e107. <https://doi.org/10.26633/RPSP.2024.107>

ABSTRACT

The Caribbean small island developing states have limited resources for comprehensive health care provision and are facing an increasing burden of noncommunicable diseases which is driven by an aging regional population. Artificial intelligence (AI) and other digital technologies offer promise for contributing to health care efficiencies, but themselves are dependent on the availability and accessibility of accurate health care data. A regional shortfall in data professionals continues to hamper legislative recognition and promotion of increased data production in Caribbean countries. Tackling the data shortfall will take time and will require a sustainably wider pool of data producers. The data journey map is one approach that can contribute to overcoming such challenges. A data journey map is a process for organizing the collection of health data that focuses on interactions between patient and health care provider. It introduces the idea that data collection is an integral part of the patient journey and that interactions between patient and provider can be enhanced by building data collection into daily health care. A carefully developed and enacted data journey map highlights key points in the care pathway for data collection. These so-called data hotspots can be used to plan – then eventually implement – appropriate AI health care solutions. In this article we introduce the idea of journey mapping, offer an example using cervical cancer prevention and treatment, and discuss the benefits and challenges to implementing such an approach.

Keywords: Artificial intelligence; noncommunicable diseases; delivery of health care; data collection; Caribbean Region.

The United Nations (UN) identifies 58 small island developing states (SIDS), including 29 in the Caribbean (1). Most Caribbean islands are classified by the World Bank as middle- or high-income countries, and generally score high on the UN Human Development Index: 2022 values between 0.55 in Haiti and 0.84 in Saint Kitts and Nevis, and an average score of 0.75 across 15 territories (2). Despite these indicators, Caribbean SIDS face shared environmental, economic, and social vulnerabilities due to their small size and geographical isolation (3). These factors limit their capacity to effectively respond to environmental and health emergencies. Recognizing these resource

limitations, regional organizations and international partnerships provide important frameworks for collective action and advocacy (4, 5).

Among SIDS, limited health care resources and infrastructure regularly include a scarcity of medical facilities, equipment, and health care professionals. Geographical isolation exacerbates these challenges, hindering access to specialized care and complicating the transport of patients for treatment. External factors, such as natural disasters, can acutely disrupt health care services, and economic constraints, including dependence on external aid and the high cost of health care, chronically strain

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health care systems. This situation is compounded by complex chronic disease multimorbidity across SIDS, which is centered on lifestyle diseases linked to nutrition and physical inactivity, but is increasingly linked to emerging acute public health emergencies, such as coronavirus disease 2019 (COVID-19), dengue, and chikungunya (6, 7). There is a pressing need for sustainable health care solutions – likely through international collaborations – to enhance the resilience and capacity of health care systems in these vulnerable regions.

PROMISE OF AI FOR INCREASING HEALTH CARE RESILIENCE

There are opportunities for artificial intelligence (AI) systems to contribute to the above-mentioned health care solutions. In the short term, already available AI-driven telemedicine and remote diagnostics can provide reliable access to medical expertise despite geographical remoteness. In the longer term, the potential of predictive analytics could aid early detection and management of chronic diseases prevalent in the Caribbean. In the event of natural disasters, AI-assisted rapid response mechanisms for resource allocation can assist with continuity of care during crises. Health care efficiency is key for small islands, but health system reorganizations are difficult to achieve with limited resources. AI tools offer opportunities to optimize limited resources, streamlining health system operations. Using AI for training and decision support could mitigate the effect of workforce shortages.

CHALLENGES FOR AI ADOPTION IN HEALTH CARE

Global challenges

The use of AI in health care has generic challenges. AI systems will process extensive patient datasets, raising concerns about confidentiality and wider ethical concerns such as how to achieve informed consent for AI systems, the risk of algorithmic bias, and the potential exacerbation of health inequalities (8, 9). Integrating AI into existing health care infrastructures requires substantial process change, staff retraining and acceptance, and regulatory compliance.

Caribbean-specific challenges

In the Caribbean, these global challenges are also relevant while additional, region-specific obstacles exist. The cost of developing, implementing, and maintaining AI systems is a barrier for small economies, and a limited computing infrastructure will impede regional AI development. The Caribbean has notable emigration of health care and technology talent, leading to a shortage of regional AI expertise. Frequent natural disasters, notably hurricanes, disrupt health care services and technology infrastructure, creating challenges to the sustainability of AI.

Issues with data availability and quality, including the collection, standardization, and volume of health care data, seriously affect AI effectiveness in the region. For the remainder of this article, we will explore the issue of health care data availability in the Caribbean. Unless these regional challenges can be tackled, Caribbean nations will likely have to rely on AI

solutions developed elsewhere. These solutions may not align with the specific needs and contexts of Caribbean countries, and are likely to be developed using culturally inappropriate datasets.

Telehealth and other examples of AI-driven health care innovation are not isolated from the wider health care governance and administrative environment. An AI-driven health care intervention will rarely provide a sustainable solution to systemic and institutional challenges in health care and, at worse, may exacerbate or temporarily mask structural challenges, for example related to expertise or funding shortfalls. It is within this challenging context that we now describe a process for AI implementation that attempts to link technological innovation with current health care practice.

JOURNEY MAP

A journey map is a planning tool used widely in business to document user experience. It visually depicts the process a user or customer goes through to achieve a goal with a product or service. The narrative mapping follows a user through a system from initial interaction to a final outcome or ongoing relationship. The technique places the user at the center of the journey and doing this allows the product or service provider to identify areas for improvement. The journey map, although developed initially in marketing and customer relations, has wide potential application in health care (10, 11). We propose using a journey map for data to identify key points in the health care system where support might be provided to reliably collect data and where AI tools could be used.

DATA JOURNEY MAP

We propose the idea of a so-called data journey map for health care, with a goal of helping the data producer – in this case the health care provider – map the journey of a typical patient through the health care system. The mapping procedure helps the health care provider think about data collection in the context of their own health care provision. This approach could help the provider see data capture as an integral part of patient-centered care. Journey maps are traditionally used to understand user experience. While this remains possible in our context, the main goal of this data journey map process is to co-create with health care providers an understanding of a patient's health care interactions. Each interaction can then generate associated data, which ultimately can facilitate AI development. Journey maps have been used previously to understand patient experience, but to our knowledge have not been adapted to better understand data gaps (12–14).

PROPOSED PROCESS FOR DEVELOPING A DATA-JOURNEY MAP

Applying the concept of a journey map to health care data collection requires mapping the health care delivery process as a series of interactions between user and provider. The resulting map highlights key points in the patient care pathway where data collection is required to enable AI implementation. These data collection points have variously been called digital or

data hotspots, and in the context of disease surveillance would include all data collected to achieve recognized performance indicators.

Each hotspot becomes a data collection node, providing data that feeds into what has collectively become known as a data lake – essentially a large collection of database tables. Data quality is managed at the hotspot before entry to this lake.

Our proposed data journey map should broadly follow four steps, outlined in the following paragraphs. We first describe these steps for a generic health care pathway and then offer a specific example using cervical cancer prevention and treatment. Ultimately, different areas of health care will require a tailored data journey map, and we envisage nested maps, with an overarching map, for example for cancer care, sitting above more detailed maps for each cancer type.

Step 1. Document the health care landscape. A crucial first step is to define the environment within which the particular health care journey exists. This will likely require new data collection and could include information from areas such as national demographics and epidemiological profiles, clinical guidelines, availability of services and resources for the health care journey in question, cost of care, and available health information systems. This contextual information will vary, often considerably, between settings, and will be used to improve the cultural relevance (model specificity) of eventual AI solutions in new health care environments.

Step 2. Map the patient care journey. The typical patient care journey is a series of interactions between an individual and health care providers. For primary prevention, this journey might include, for example, vaccination or screening programs for eligible population groups, with follow-up after abnormal screening results. For tertiary care, this journey might include stages such as patient check-in, initial assessment, diagnosis, treatment planning, treatment delivery, follow-up, and discharge.

Step 3. Develop the data collection detail. From step 2, the data to be collected at each patient-provider interaction would be described as a data dictionary; each data hotspot should have an associated dictionary. The data dictionary should include structured metadata, ideally using a recognized standard (15). The data collection will likely include personal and sensitive data variables, so compliance with national data regulations must be ensured.

Step 4. Link journey to opportunities for AI integration. With a completed journey map, areas for potential AI assistance can be highlighted, based on instances of high data production. Steps 3 and 4 can be an interactive process between data producers and AI experts to ensure appropriate data for a proposed AI implementation. An integral part of this iterative process will be the development and operationalization of analysis algorithms on aggregated data at each data collection node, or on a wider range of data within the data lake, providing co-created AI health care solutions.

Many health data producers will see strong similarities with current best practice, with step 2 analogous to the creation of data collection flowcharts, step 3 analogous to metadata creation, and step 4 analogous to a statistical analysis plan. Nevertheless, these technical processes are regularly separated from health care practitioners. The benefit of repackaging the process as a journey map rests in helping providers link data

collection more closely to the personal journeys they take with their patients.

CASE STUDY: CERVICAL CANCER PREVENTION AND TREATMENT IN ANTIGUA AND BARBUDA

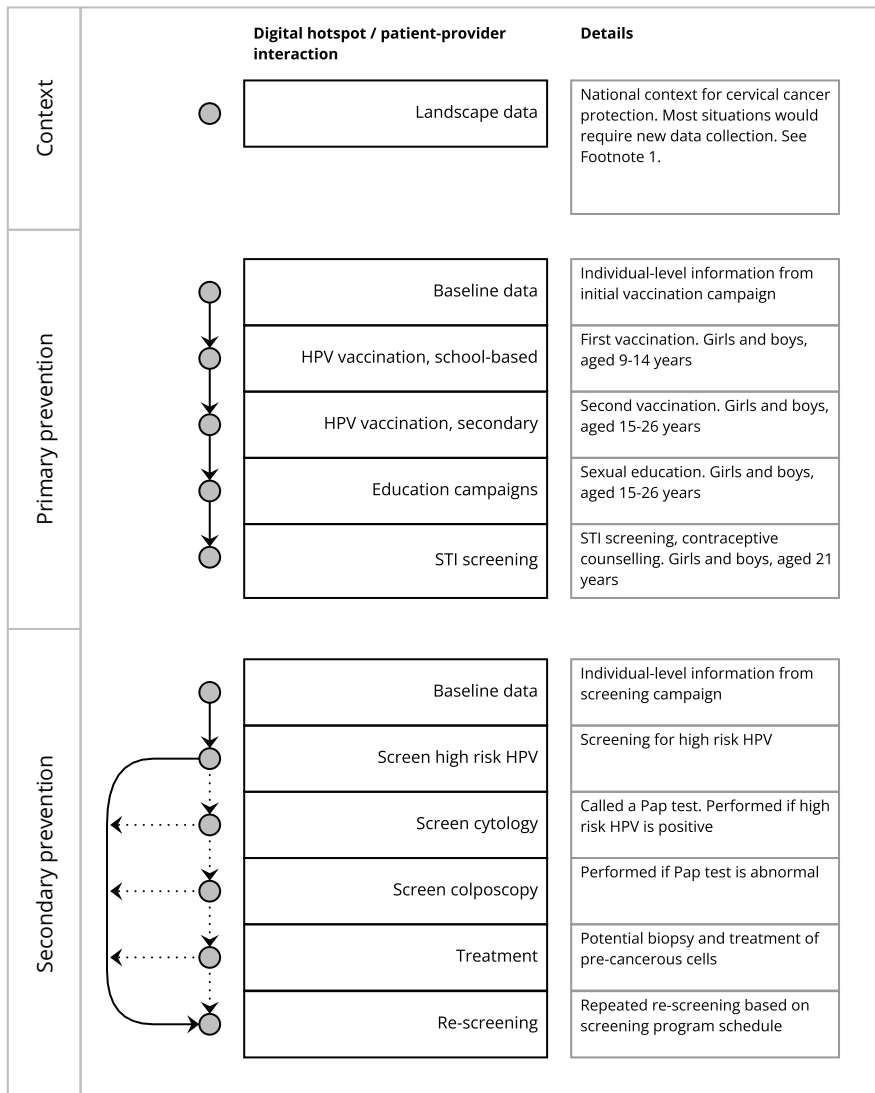
Cervical cancer care encompasses primary prevention (human papillomavirus vaccination (HPV)), secondary prevention (cervical cancer screening and precancerous lesion treatment), and tertiary prevention and care (invasive cervical cancer treatment and management). Our example covers vaccination, screening and treatment, but we note that the vaccination and screening data journey aims to prevent the need for tertiary treatment. Thus, the vaccination and screening data journey could sensibly be considered a separate journey to that of cancer treatment.

In 2020, the World Health Organization (WHO) launched a global strategy to accelerate the elimination of cervical cancer through three key pillars: vaccination, screening, and treatment. (16). To date, cervical cancer control efforts in Antigua and Barbuda have been ongoing for 6 years beginning with the formation of the Cervical Cancer Task Force in 2018. Antigua and Barbuda was one of the first countries in the Caribbean to introduce HPV vaccinations and testing in a national program, with assistance from the Pan-American Health Organization (PAHO) revolving fund – a procurement mechanism facilitating equitable access to life-saving health products across the Americas (17). Since then, considerable gains have been made towards reaching the WHO cervical cancer targets for 2030 (90% of girls fully vaccinated with the HPV vaccine by the age of 15 years; 70% of women screened with a high-performance test by 35 years of age and again by 45 years of age). However, the COVID-19 pandemic has had a negative effect on the progress of prevention roll-out.

Cervical cancer primary prevention in Antigua and Barbuda involves vaccinations for all adolescent girls (between ages 9 and 14 years) and repeated screening for adult women beginning at age 25 years in the general population and age 21 years for women living with human immunodeficiency virus (18, 19). Each health care interaction has an associated data dictionary. For adult screening (ideally every 3 to 5 years and more frequently if abnormal results are found), the associated data dictionaries define data elements collected repeatedly over time. A data dictionary can be maintained on a simple spreadsheet and should be easily accessible by all data producers. Many data dictionary examples are available online, such as the large-scale data dictionary maintained by the National Health Service of the United Kingdom of Great Britain and Northern Ireland (20). A journey map flowchart for primary and secondary prevention is shown in Figure 1, and a listing of data collection points on the patient care pathway for prevention and treatment with suggested AI support mechanisms is summarized in Table 1.

The cervical cancer data journey map serves as a strategic overview for identifying data hotspots and understanding the potential for AI analytics across the continuum of cervical cancer prevention and treatment. Perhaps most importantly, the map introduces the idea that data collection is an integral part of the patient journey, and that interactions between patient and health care provider can be enhanced by building data collection into daily health care.

FIGURE 1. Journey map flowchart for primary and secondary prevention of cervical cancer



○ Each circle represents a digital hotspot / patient-provider interaction, with associated data.

Footnote 1. A landscape survey is a concept from the World Health Organization cervical cancer screening toolkit, to better understand the context within which a cervical cancer prevention program resides. New data collection would likely be needed for this information, which could include data collection in eight domains: national demographics and epidemiological profile, clinical guidelines, service availability, human resources for health, available equipment and supplies, laboratory supply, costings, and an overview of functional health information systems.

HPV, human papillomavirus; STI, sexually transmitted infection.
 Source: Prepared by authors.

DISCUSSION

Promise of AI in health care

Despite important regional health gains, the Caribbean has an unsustainable level of chronic disease exacerbated by an aging population and environmental and climate challenges. In addition, the region is unlikely to meet its Sustainable Development Goal targets (21). In other parts of the world, AI is contributing to cancer detection, with much research concentrated in the areas of cancer, nervous system diseases, and cardiovascular diseases (22–24). AI solutions could contribute to overcoming the ongoing Caribbean challenges, from facilitating personalized

strategies for disease prevention to monitoring patient progress and creating bespoke treatment pathways (25).

In the Caribbean, the use of AI in health care, either identified in peer-reviewed literature or available as commercial products, is uncommon and the adoption of AI for regional health care can realistically be classified as occasional and exploratory. Multiple reasons exist for this slow adoption but data scarcity is a main factor. Specifically for health, the widespread use of hard-copy record-keeping and the slow transition to electronic medical records are a key barrier. For AI to be successfully implemented in Caribbean health care there must be a paradigm shift in the strategic collection of data resources, with subsequent best-practice data handling and improved opportunities for data re-use.

TABLE 1. Cervical cancer data journey data hotspots mapped by AI of opportunities to improve prevention and treatment

Cervical cancer patient pathway: data hotspots	Potential AI algorithm	Potential outcome to inform cervical cancer prevention and treatment
Vaccination		
School-based HPV vaccination for girls aged 9–14 years	Cluster analysis	<ul style="list-style-type: none"> Improved segmentation of the population Enhanced personalization of health messages Increased effectiveness of health campaigns Optimization of resource allocation
Secondary group for vaccination of girls and women aged 15–26 years	Predictive modelling	<ul style="list-style-type: none"> Enhanced: forecasting accuracy; identification of barriers to vaccination; optimization of resource allocation; and tailored public health strategies Prioritization of resources based on known behaviors and medical history for high-risk groups
Screening		
Women aged 25–65 years invited for screening	Time series; multivariate algorithms	<ul style="list-style-type: none"> Improved patient engagement and education through targeted counselling Accurate risk assessment of development of cervical cancer Classification/prediction of patient risk Prioritization for closer follow-up
Women living with HIV invited for screening at age 21 years		
Screen-positive women referred for colposcopy	Support vector machine; random forest classifier; decision tree classifier; logistic regression	<ul style="list-style-type: none"> Improved efficiency of the referral process by potentially reducing the number of unnecessary colposcopies Focusing of health care resources based on needs, thus optimizing patient care pathways
Treatment		
Colposcopy and biopsy	A gradient boosting machine. Neural network	<ul style="list-style-type: none"> Personalized treatment plans based on predicted risk of progression Identification of patients who might benefit from more aggressive treatment or closer follow-up Resource optimization by focusing attention on patients with a higher likelihood of progressing to invasive cervical cancer Enhanced patient counselling about cervical cancer risk based on individual assessment
High grade pre-cancer lesion management and treatment	Convolutional neural network	<ul style="list-style-type: none"> Improved accuracy in differentiating between lesions that require immediate treatment and those that may be monitored Predictive insights into the likelihood of a lesion progressing to invasive cancer Personalized treatment regimens based on individual risk profiles
Patients with symptoms or suspicious clinical findings of cervical cancer referred to the gynecological oncology service	Support vector machine	<ul style="list-style-type: none"> Stratification of patients based on the severity of their symptoms, clinical findings and the likelihood of cancer Improved triage processes, ensuring that patients with the most severe symptoms and clinical findings are given priority for diagnostic procedures
Confirmed cancer cases treated	Deep neural network	<ul style="list-style-type: none"> Predictions about the potential outcomes of different treatment options, helping clinicians to personalize treatment plans Prediction of treatment most likely to be effective for personalized therapy Estimation of the likelihood of cancer recurrence after treatment Assessment of patient prognosis based on treatment response
Post-treatment follow-up	Recurrent neural network, particularly long short-term memory networks	<ul style="list-style-type: none"> Early detection of cancer recurrence by identifying patterns that indicate a high risk of return Personalized scheduling of follow-up visits based on predicted risk levels Ongoing monitoring of patient health to adjust treatments proactively

AI, artificial intelligence; HPV, human papillomavirus; HIV, human immunodeficiency virus.
Source: Prepared by authors.

AI implementations are already a health care asset in some low-resourced settings (26, 27). In the context of our cervical cancer case study, AI has been used to improve cervical cancer screening and predict cervical cancer progression (28). For the Caribbean to take advantage of such advances, governance must support the creation of AI data inputs and build the human capital required to develop and manage AI systems.

Usefulness of the data journey map

The data journey map offers an easy-to-use process for identifying suitable areas for AI implementation. The focus on patient–provider interactions allows data producers to co-create data systems with health care providers, helping to combine data collection with the provision of care. As well as highlighting digital data hotspots, the process of creating a journey map will highlight pathways that need additional data.

The proposed use of the data journey is timely, coinciding with the end of the PAHO plan of action for strengthening information systems for health, 2019–2023 (29). The plan recognized that the Americas region must prepare for a range of technological developments that will affect health systems, including AI. The aim of the action plan was to: (i) utilize interconnected and interoperable information systems to upgrade health services; (ii) assist with the introduction of information and communication technologies to improve information exchange; and (iii) improve the management of structured and unstructured data for the benefit of public health. These aims will increase in importance as potential digital solutions multiply, and the journey map can offer one process to bring the technical and often administrative process of data collection closer to the daily experiences of health care professionals.

Using our case study of cervical cancer, the first strategic step of the PAHO action plan for the prevention and control

of cervical cancer is to “improve cervical cancer program organization and governance, information systems, and cancer registries”, highlighting the need for improved data availability as a foundation step for AI implementation (30). Any resulting increase in available and accessible data will supplement a data pool dominated by information from populations of European-descent, potentially biasing AI models when adapting for ethnically diverse regions. Data sovereignty is a crucial endeavor and is still in its infancy.

The need for increased use of data-driven evidence to bring about better outcomes at the patient-provider interface is an argument widely accepted among health care practitioners and technology developers (31). Nonetheless, the concept of data (more usefully data converted to actionable evidence) as the key to better health care decision-making is generally not operationalized, with this practical bottleneck particularly prevalent in resource-limited settings (32).

Potential challenges

The availability and accessibility of large amounts of data of varied types and provided quickly – that is, the concept of so-called big data – brings benefits for dependent AI technologies. The global progress towards increased data availability and widespread AI adoption is widely documented. We have mentioned a number of challenges to generating and using such data, which are exacerbated in resource-limited environments. The push in the Caribbean for universal health coverage is hampered by many process bottlenecks, limiting the current ability for data-driven health care solutions (27, 33).

Access to digital information remains key, and interoperability is essential for integration between data sources. In resource-limited settings, the continued use of older hardware or software systems is commonplace and these often do not

have the ability to export data or interact using application programming interfaces.

Security, ethical, and regulatory challenges exist at the regional and national levels in the Caribbean, detracting from potential economies of scale. Locally, AI should be used to supplement not supplant human decision-making, and patients must consent to and be aware of the use of their data in local AI implementations (34).

Lastly, the need for an appropriately skilled workforce with expertise in specific health care domains, data science and AI engineering are vital for any health care initiative. Multidisciplinary collaborations can encourage the strengthening of AI capacity (35).

Author contributions. All authors conceived the original study, and wrote and revised the manuscript. All authors reviewed and approved the final version.

Acknowledgements. We thank colleagues who contributed to many insightful discussions on the role of AI in health care.

Conflicts of interest. None declared.

Funding. The authors received no funding specifically for this manuscript. IRH is funded by the Inter-American Development Bank to develop a regional data-sharing project, CaribData: Caribbean data-driven resilience (<https://www.iadb.org/en/whats-our-impact/RG-T4186>).

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Manuscript received on 12 August 2024. Revised version accepted for publication on 12 August 2024.

Mapa de trayectorias de datos: un proceso para el establecimiento conjunto de los requisitos de datos para el uso de la inteligencia artificial en la atención de salud

RESUMEN

Los pequeños Estados insulares en desarrollo del Caribe disponen de recursos limitados para la prestación de servicios de salud integrales, y se enfrentan a una incidencia cada vez mayor de enfermedades no transmisibles como consecuencia del envejecimiento de la población regional. La inteligencia artificial (IA) y otras tecnologías digitales son prometedoras para impulsar la eficiencia en la atención de salud, pero dependen de la disponibilidad y accesibilidad de datos precisos. La escasez de profesionales de la gestión de datos en la región sigue constituyendo un obstáculo para el reconocimiento legislativo y la promoción de una mayor generación de datos en los países del Caribe. Solucionar este problema llevará tiempo y requerirá contar con un mayor número de personas expertas en la generación de datos. El mapa de trayectorias de datos es un método que puede contribuir a superar estos desafíos. Consiste en un proceso para organizar la recopilación de datos de salud que se centra en las interacciones entre pacientes y prestadores de atención de salud. Introduce el concepto de que la recopilación de datos es una parte integral de la trayectoria de los pacientes y de que las interacciones entre pacientes y prestadores de atención pueden mejorarse mediante la integración de la recopilación de datos en la atención de salud cotidiana. Un mapa de trayectorias de datos elaborado y aplicado de forma cuidadosa permite destacar los puntos clave para la recopilación de datos en el itinerario de la atención de salud. Estos denominados “puntos críticos” pueden utilizarse para planificar, y luego aplicar, soluciones de IA adecuadas para la atención de salud. En este artículo, presentamos el concepto de la elaboración de un mapa de trayectorias de datos, mostramos un ejemplo de su uso para la prevención y el tratamiento del cáncer cervicouterino y analizamos los beneficios y los desafíos de aplicar este método.

Palabras clave: Inteligencia artificial; enfermedades no transmisibles; atención a la salud; recolección de datos; Región del Caribe.

Mapa de jornada de dados: um processo de cocriação de requisitos de dados para inteligência artificial na atenção à saúde

RESUMO

Os pequenos Estados insulares em desenvolvimento do Caribe têm recursos limitados para prestar serviços de saúde integrais e enfrentam uma carga cada vez maior de doenças não transmissíveis, agravada pelo envelhecimento da população regional. A inteligência artificial e outras tecnologias digitais prometem contribuir para a eficiência da atenção à saúde, mas dependem da disponibilidade e da facilidade de acesso a dados precisos relacionados à atenção à saúde. O déficit regional de profissionais de processamento de dados continua dificultando o reconhecimento legislativo e a promoção do aumento da produção de dados nos países do Caribe. Resolver o déficit de dados levará tempo e exigirá um conjunto mais amplo e sustentável de profissionais de processamento de dados. O mapa de jornada de dados é uma abordagem que pode contribuir para superar esses desafios. O mapa de jornada de dados é um processo para organizar a coleta de dados de saúde que se concentra nas interações entre pacientes e profissionais de saúde. Esse mapa apresenta a ideia de que a coleta de dados é parte integrante da jornada dos pacientes e que as interações entre pacientes e profissionais de saúde podem ser aprimoradas pela incorporação da coleta de dados no cotidiano da atenção à saúde. Um mapa de jornada de dados cuidadosamente desenvolvido e implementado destaca os principais pontos do percurso assistencial para a coleta de dados. Estes *hotspots* de dados podem ser usados para planejar — e em seguida implementar — soluções adequadas de inteligência artificial na atenção à saúde. Neste artigo, apresentamos a ideia de mapeamento de jornada, oferecemos um exemplo usando a prevenção e o tratamento do câncer do colo do útero e discutimos os benefícios e os desafios da implementação dessa abordagem.

Palavras-chave: Inteligência artificial; doenças não transmissíveis; atenção à saúde; coleta de dados; Região do Caribe.
