

Indigenous Scientist: Digital & Health Science Transformation

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Abstract. As an indigenous scientist, I have dedicated all my professional life to protecting people using informatics for public policy to the privacy of users, patients, clients, and citizens as a human right and obligation as part of the United Nations international development goals. I am reflecting on my earliest knowledge of the impact of data and information privacy on my journey as scientist. I was just a number out of many other numbers as an indigenous child. The aim of this paper is to share my own personal experience together with one of my students. Now working with data as a scientific task within the data modeling to measure poverty. As a datum with human value, I was a 1) Female child with young parents, 2) Low socioeconomic status & 3) Identified as an indigenous person within a minor language group. These three data descriptions described me as a person who needed protection of my human dignity and identity as a child, based on all the protocols of social services for providing help. In conclusion, as scientists, we need to remember when using client data in vulnerable contexts and protection of their privacy, due to the potential risk of active discrimination. Thanks to my extensive education in Australia, I became an outlying datum that deviated from the data modeling applied to me. Today, I work for Privacy digital standards to impact real life with respect to human dignity and obtain accurate scientific interpretations of human beings' realities.

Keywords. data, science, digital interpretation, life & impact

1. Introduction

I'm a grown woman dedicated to researching the power of data for healthcare improvement within the justice system in Australia and around the world. Nowadays, I am writing these lines while sitting peacefully in my beautiful regional home in Geelong. While I reflect on my current reality and all the blessings I am living with my current professional life as a leader in legal services using data governance principles for protecting human dignity, I cannot believe all the growth I reached by educating myself at every chance I had in Chile, Latin America and Australia.

Some key data from my education journey include i) during my infancy I traveled through several public schools while moving homes several times with my family, with poor academic performance, ii) during my teenage years, I was bullied for being different and dressed poorly with the expectation of the educational uniforms, iii) I performed the

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entry national exam for entering to the local university at my eighteen years, obtaining an extremely low mark, from the 850 I got below the average mark, only reaching 381 marks.

In contrast, the data from my educational journey at the international level is very different, especially considering how I arrived in this world: a girl with indigenous blood. My origin is very extraordinary and particular; I was born as a human being with three very marked social characteristics: i) born a girl, ii) poor and iii) indigenous far south of the world, in an underdeveloped country called Chile [1],[2].

Data for my adult life was very amazing when I arrived in Australia in 1991, a migrant who could not speak English and had poor management skills for embracing new paradigms for an indigenous woman without an identifiable local community. Just remembering my own parents who were teenagers who formed a family without any social or community support: gives me the strength to try my best in this new educational adventure in a land far away called folklore Down Under.

Let's share my own journey of witnessing real-life impact using my own data for my own human awareness and development. This area of interest is well researched for decades within health informatics as a discipline for the implications of using data, information, knowledge, decision, and actions in real life. Firstly, the implication of being a girl in Science is explored in the section on the science of living. Secondly, daydreaming as a way to understand the world is shared with possible wishes as a teenager. Thirdly, the science of pain in life explores the challenges where my life was hard without proper healthcare services within a vulnerable community as indigenous woman. Finally, I reflect on the transformation based on Digital and Healthcare Informatics and share thoughts for future generations.

2. The science of living

There is not a book to teach us how to protect our lives in this digital world, however, despite all the hard experiences in life during my time as a future scientist: education is the power that has transformed my own destiny in health informatics. With each concept, research project, new investigation, and several digital innovations for human dignity I embrace them in my own life for the last 30 years. My learning process started with the wisdom of extreme challenges in the family I was born in. For my first two decades of life, I was hugely a datum for society in general, then when I arrived in Australia as a migrant in 1991, I discovered the possibility to enter university as a new mother and wife. As a mature aged student, I embraced my first bachelor of Nursing with an emphasis in psychiatry, to then being selected to do an Honours degree to conduct research in Quality and Safety for healthcare management. I always worked in clinical services at public hospitals in Melbourne and regional services, since I lived on a farm with my young family. Once I completed my first research project in the local innovation centre for a new hospital, I started to enjoy the science of caring for healthcare delivery using the electronic health record at the time. I was invited to join three research teams to do my Ph.D. with a full scholarship. I truly embrace research and teaching at University part-time since I was committed to providing patient care by doing night shifts. Reflecting back, I did shift work for twenty years in order to gain a good education, while completing my doctorate program and then my post-doctoral for patient safety using artificial intelligence.

In my personal memories, during my early days as a future scientist, I do not clearly remember having close friends from my birthplace, where I lived with my parents. I also don't remember very well the physical place where I was born, since we moved many times with my family throughout the metropolitan region of my country of origin, Chile seeking a safe and healthy life. However, now I can see data describing the place where I came to this world with interactive maps online, and this region is still a place highly stigmatized by most of my compatriots and strangers to this part of the world [3].

This town is called “La Legua”. Its name comes from the old measurement of distance similar to what can be covered in a day, either on foot or on horseback. However, “La Legua”, my place of origin, is a poor neighborhood, with very challenging social issues, located almost exactly 5 kilometers from the center of Santiago, within the area of San Miguel. This is a very symbolic geographical place from a political perspective since vulnerable communities were established with a collective commitment to reach housing for their families. It emerged in the 1930s, with the arrival of dozens of working families of saltpeter miners in northern Chile and peasants from the south. My grandparents came from the north, and they came with their indigenous heritage to the capital, to this poor neighborhood, with our Aymara blood.

It is fair to remember Chilean history, during the 1970s, the capital of the metropolitan region used to have one million inhabitants, with a life expectancy at birth of 62 years, and a national poverty headcount ratio was over 70% (4). Nowadays, 50 years later, the population stands at nearly 10 million with some of the best income and life expectancy indicators in Latin America. In contrast, during my infancy, my family reality had all key social determinants shaping the impact of our growth as children: including being the middle daughter of teenage parents who unexpectedly became a family of 5. I can't even imagine how difficult it must have been to take care of us, in an underdeveloped country of the last century.

2.1. Girl in Science

The precision of living as a girl in science is very challenging within the developing environment in South America. Access to mathematical exercises, science and technology is rare for children within that given social context. Only 16% of my generation have university studies, indigenous women in Chile are historically underrepresented in the academic context without access to science or technology studies [5], to be honest, no one in my family ever talked about university. The urgency of our needs and narrow circumstances did not allow us the privilege of reflecting. My own dad reached third grade and my mum completed a certificate for sewing. Consequently, I knew when I had my two girls that they deserve to have access to the right education, and all the research I have done while I was pregnant with my first child, made me recognize the importance of data and quality information for human development [2]. More than twenty years ago, while doing my Ph.D. in health informatics at the number one university in Melbourne, Australia, my first daughter as a baby provided me with the commitment and passion to work toward mobile computing for patient safety [6]. Respecting the accessibility to healthcare was a real necessity for me since at the time, the father of my gorgeous baby was a patient that had the fortune of having a kidney transplant and provided us the opportunity to have our own family. Then I was awarded a scholarship to do my doctorate at the faculty of medicine and nursing as part of the collaboration between clinical placement at one of the largest public hospitals in the state of Victoria. Having access to science and knowledge allowed me not to take 180 years

to get out of the material poverty in which I was born [7]. Today more efforts and opportunities must be generated so that every indigenous or non-indigenous girl and woman has the option of taking the path of science and technology with equity, non-discrimination, and self-determination.

3. The science of daydreaming

The next chapter of my life includes the power of daydreaming as a teenager and not much data available for the opportunities for my adult life within my original territory. Opportunities to engage with science or technology at school were totally absent at the time of entering my youth [8]. I used to be very proactive in my community. I learned to measure the kilometers to exercise. Despite all the hard work for my physical training at the local gym, I dedicated myself to being a missionary of the local church. At home, I always dreamed of having a celebration on my own terms with my friends from school: but that never happened. When I started to mature, I thought that just being alive was an existential blessing for every human being thanks to my instinct to help others. I have always considered myself a contemplative, of deep reflections, but I also, always as a woman felt in the wrong place at the wrong time. I couldn't share these ideas with others at that time, because of my surroundings. I did not know that these ideas were part of my passion and vision of life as an indigenous scientist.

There is only an opportunity to recognise the good times with my family. When I turned 14, my mum told me that I had the wonderful opportunity to finally have my own birthday celebration, with all my family and my friends: a dream comes true finally.

The occasion was made on the entrance patio of my humble home. This was built with recycled wood collected by my own parents. At that moment in my own history, I felt important and valued, maybe for the first time, it was when we sang the happy birthday song, but this time was dedicated to me. I couldn't help but feel the joy in my sore stomach, I was, for the first time, the center of attention for my loved ones. I was wearing a dress made just for me; its colors were soft and highlighted my brown skin (just like my grandfather: truly Aymara). I also remember how well dressed everyone was that day. My family even invited some of our friends, neighbors, and clients. I felt alive and loved by my family. I felt beautiful, like a rough diamond looking for an opportunity. I was a diamond in the rough waiting for the chance to show how beautiful I was. I can say this now, understanding that every girl or boy is a blessing, like what happened that day. I can't help but evoke my feelings at that time even now, as a mother. That amazing day was very special and full of hope for my life. Until now, I keep photos of that birthday that I currently share with my daughters and students seeking projects of digital innovation to help vulnerable communities.

The festive feeling from my family was lived with the most delicious cake I've ever tasted, and even one of my best friends was dressed up as Michael Jackson, to brighten up the evening. He was clean-shaven and ready to show off his best dance steps. It was a lot of fun and made me feel part of that community as I feel right now with my colleagues from the large academy of Health informaticians around the world. That day I felt for the first time that I was already a full-fledged woman. That local community also expected me to marry soon and have children as a social norm. I realized then, at that party, that my destiny was not there for me. That proposal looked like a shortsighted horizon for me for what, intimately, I believed could become my own possibility: felt a different instinct at the time.

This transformative birthday was an invitation to be me and to see my own values clearly. I started reading actively for the first time in my daily life. The only book I had within my reach was the Bible, thanks to a local church activity. It was a social worker and nun who played with the children in town and invited me to help others. We used to run around the soccer field that was near my house.

I recall this stage of my life as Courage. All social data about me and all the adverse events, and complex family challenges make me stronger. It is difficult to understand social circumstances that are not lived. My parents were beautiful teenagers who were good parents as they could, in a complex and dangerous place, I learned to be resilient and to understand love as the force that It allows us to believe and not let ourselves be destroyed by the environment. Especially now, I work with this type of young families in Australia, especially the priority groups for protecting their dignity using data governance principles, including indigenous data, family violence victims, child protection data, and criminal reinsertion into the community.

4. The science of pain

Several initiatives around the world show key data elements for the first thousand days of child development with the intention to predict the kind of human being that person becomes [9]. Reflection on my own infancy: poverty was part of this stage of life with several pain in the process. Firstly, I hate to wash dishes right now and I believe this is the trigger for the type of living conditions I had [10]. Doing the dishes is a constant trauma for me, peeling potatoes is another one, and having a bathroom inside my home.

Multiple influences of social data are based on the difficulties of our family living in areas without electricity and water. When I was a child, I was assigned to do the dishes at the local restaurant that my parents owned, and I was in charge of making sure the business kitchen was available for the clients [11]. You may be wondering why.

I grew up with a strong entrepreneurial family. My parents, who were teenagers, found themselves without a proper home and we as a family needed to survive anywhere with a roof over our heads. Washing the dishes was always a challenge for everyone and for some reason I always finished doing them in order to help.

Since I was a baby, I lived and was raised in a home without a toilet. I was 14 years old, the family was able to access a social housing place, where my parents decided to open a neighborhood bar. Therefore, I did not live with the expectation that my parents would go to work and eat dinner as is expected of a family.

The task that I had to perform every day as a teenager was to wash the dishes not only for my family but also for everything that was busy in the bar. Sometimes, I found myself washing dishes for hours on end. Many times I felt like a slave, so I was constantly looking for reasons to leave the house. I used to like to sell food on the street to have the opportunity to experience my own freedom. Until now, having my hands with liquid soap makes me cringe from the lack of control of my life: until now that scares me a lot.

To any girl or boy who goes through similar situations, who understands that he was born out of love. That it will not be easy, that you will have good and bad experiences, but that you can learn from each one of them. You will have scars, but those scars will also be a push to find your being and find what you are called to be, your destiny, your life [10] [12].

5. The transformation based on Digital & Healthcare informatics

The journey I am living as an indigenous scientist, allows me to work with millions of patients, users, and clients' data within vulnerable contexts. The process of making informed decisions allow me to delivery projects of big data for complex public services for vulnerable populations.

When I turned 35 years old, I was invited to be part of the United Nations team at the knowledge network at the World Bank. I truly never thought of working at a financial institution with over 188 members states, since all my professional life I have practiced health informatics principles within the health sector and academic environments. I was a clinical teacher while doing research at health smart initiatives in Victoria, Australia. Once, I collaborated to open the only center of clinical informatics in Australia at the time, I was approached to be an eHealth adviser for the implementation of an electronic health record for the whole state.

Entering the public arena opened many opportunities to achieve digital transformation with clinical data for quality services. Together with my local team, we embrace new informatics structures for the diversity of software for more than 150 healthcare centers.

Reflecting on this professional journey as a national leader and then global indigenous scientist into digital health for quality and safety using member state investment portfolios, allows me to humbly suggest the following:

- In any type of digital transformation, we must as scientists respect the human dignity and see any type of data with a human face [13].
- Digital transformation is about helping people within health informatics parameters for respecting human dignity, especially minorities groups such as indigenous communities [14].
- Healthcare informatics involved not only the person who requires the service, in addition to the rights as a human being within an ecosystem for human development in their own family and community [15].

6. Impact for new generations

The following lines are from one of my research students, as evidence of the current role I dedicated myself for the last two decades. Mario Donoso Fredes said:

I write these lines as a co-author, student and young researcher. I have had the opportunity and the privilege of making learning and knowledge my path, a path that for various reasons has been digital. These contexts have given me the opportunity to connect with an infinite and diverse set of sources; people, communities, literature, data, but also expose me to risks of being inconsistent, superficial, fragmented and liquid.

I remember the interview I had with Carol for my first research internship at CIDLA, it was honestly not what I expected for an academic interaction based on my own prejudices and Chilean culture. This meeting allowed us to know each other not only as student and teacher, but also as persons; our histories, families, interests, motivations, and hobbies were central themes of an extensive talk.

Our first interactions planted two crucial milestones in my learning and research journey. First, **the reflection of being**. Before I joined the research team, I received two uncomfortable questions during my interview. They asked me, Who are you? Why do

you want to be a researcher? Those questions made me blush because I did not expect a question of this nature in a highly technical context. With the courage that only ingenuity can give us, I asked why is it important for you to philosophize in digital innovation, software development and applied research? The answer was, of course, much more sophisticated than my question: “We live in an ocean of data and information, an infinity of sources, qualities, quantities, therefore, we will always have the risk of getting lost. How lost we are will depend on our ability to reflect, be faithful to our being and our compromise for the truth at the service of others”. As you can expect, my first assignment was not a literature review or data analysis. I spent at least three weeks studying and reflecting with the team about teaching and learning, leadership, and the role of being in research, a human integration of knowing, doing and being.

Second, **the community of practice**. My first days at CIDLA were marked by a great diversity of people, disciplines and areas of knowledge. For the first time I experienced that learning and knowledge rests in a diversity of opinions and that the ability to see connections between fields, ideas, and concepts is a core skill in research. Those of us who dedicate ourselves to research understand that this is not about a particular task or a job, it is a lifestyle in which, moved by curiosity and self-awareness, we offer intangible and personal resources to contribute to the generation and interpretation of knowledge. Fortunately, we share this beautiful and frustrating lifestyle with many people, diverse disciplines, our main opportunity. Collaboration! is the mantra and principle that I hear every day at CIDLA. It refers to the ability to engage and connect effectively, while preserving autonomy and control over the resources provided in a common project. Collaboration is about will, passion and self-determination not regulated by a contract, is related to the principle of good faith. This new way of learning, connectivism, gave me a new perspective as student and researcher, an invitation to practice with pluralism and based on trust”

7. Final thoughts

The impact of using data, information, and knowledge is powerful for helping others and for our own self-evaluation for inner awareness of our own actions. I learned 8 years ago of the impact of justice in our lives by completing a Master of Law, with an emphasis on constitutional rights. I remember after visiting around sixty countries as part of my work as a consultant for the World Bank, the necessity of health informatics in the **legal and ethical** framework for digital education & health. I called this my magic triangle for human rights within digital transformation: health, education & justice.

Therefore, I decided to study law, conducting applied research at the faculty of law number one in Latin America. It was difficult to study for a couple of years with lawyers and several experts in constitutional law in Spanish. My emphasis is to invite all the future generations innovating in digital transformation to seek the ethical and legal implications of their creation in hardware, and software and most importantly educate the new digital skills, knowledge, and attitudes toward cybersecurity.

Right now, I am a happy indigenous scientist that works for the Australian government as a data governance manager for vulnerable communities seeking access to justice. In addition, I am the co-founder of CIDLA.ORG with an amazing scientific team from all over the world, including a 1) registered research center, 2) ONG for digital innovation with social impact and 3) my own company that works with indigenous communities to create prototypes using artificial intelligence by using mobile

technologies. My commitment to vulnerability is real everyday by using the principles of health informatics science in indigenous communities, and poor contexts for protecting the privacy of vulnerable people and communities in order to prevent intentional discrimination.

After all, I had become an outlying datum that deviated from the data modeling applied to me since I was a poor child and migrant to Australia 32 years ago. Today, I dedicated all my research to Privacy digital standards, as a manner to impact real life with respect to human dignity and obtain accurate scientific interpretations of human beings' realities. We, as research community, must ensure human dignity for all when doing our investigation with digital data and that requires us to protect our user, patients, help seeker or client's data within their social, economic and political environments.

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