



PaJR as the Foundation for Next Generation Telemedicine

Mansi Agrawal¹, Braahmani Bobba², Yousra Iftequar³, Macharla Lekhana⁴,
Aditya Samitinjay Gade⁵, Vivek Podder⁶, Rahul Kulkarni⁷,
*Rakesh Biswas⁸

¹ Mahatma Gandhi Memorial Medical College, Indore 452001, Madhya Pradesh, India
mansi.agrawal605427@gmail.com

² Kamineni Institute of Medical Sciences, Narketpally 508254, Telangana
braahmani15@gmail.com

³ Dr. VRK Women's Medical College, 500008 Telangana, India
dr.yousraiftequar@gmail.com

⁴ The Oxford Medical College Hospital and Research Centre, Bengaluru - 562107, Karnataka,
India
lekhana.macharla@gmail.com

⁵ Department of Endocrinology & Diabetes, Sycamore House, Watford General Hospital,
WD180HB, UK
aditya.samitinjay@nhs.net

⁶ Division of Gynecologic Oncology, Mount Sinai Medical Center, Miami, FL 33140, USA
drvivekpodder@gmail.com

⁷ DoNew, Pune 411057, India
rahul@godonew.com

⁸ Corresponding Author, Department of Medicine, Kamineni Institute of Medical Sciences,
Narketpally 508254, Telangana, India
rakesh7biswas@gmail.com

Abstract. This chapter is the succeeding section to Chapter 2 based on Participatory Medicine Models and Learning. The roots of telemedicine grew decades ago and is revolutionizing healthcare. But why do we need telemedicine and what exactly is telemedicine? The following chapter answers these questions with in depth explanation of one of our pioneering telemedicine models, Patient Journey Records (PaJR). The concept behind PaJR, utilization of its data and its workflow along with real-world scenarios are discussed here. We are growing forward with this journey with new reformations every day. PaJR is not only a tool making data collection and follow-up process easier, it's also an effective learning tool for all the learners involved in the patient's journey. In a brief sentence, PaJR is akin to the patient's personal journal with interactive and professional feedback from the health personnel on a regular basis making telemedicine available via basic digital tools equitable.

Keywords: Telemedicine, Patient Journey Record, User driven healthcare, patient centered outcomes.

1. Introduction

1.1 Telemedicine: What, How and Why?

Human beings are complex and sensory beings, processing the world not just through measurable symptoms or digital signals but through layers of consciousness, perception, and deeply personal experiences. Yet, healthcare systems across the world often flatten this complexity into generalized protocols and one-size-fits-all solutions. Protocols become rigid, appointments become rushed, and the subtle textures of a person's life fade into the background. The result is a growing disconnect between the clinical model and the lived experience of health and illness.

Telemedicine, born out of necessity and matured by innovation, is a step toward bridging this disconnect. It uses telecommunications technology to deliver care across distance, time, and socioeconomic barriers. Whether it's a mother managing her child's asthma in a rural village or an elderly man consulting his cardiologist from his living room, telemedicine allows healthcare to meet people where they are, on their phones, in their language, and in the flow of their everyday lives.

But more than just technological progress, telemedicine represents a shift in the philosophy of healthcare: from hospital-centered to patient-centered and from episodic treatment to continuous engagement. It reminds us that healing doesn't always happen in white coats and hospital beds. Sometimes, it begins with a video call, a reassuring voice, and the feeling that someone is truly listening even from miles away.

1.2 From Concept to Action: The Need for Implementation

Making telemedicine truly meaningful goes far beyond installing servers or downloading an app. Are we just uploading the old system into a digital format, or are we genuinely inviting patients to step into the center of their care journeys?

The real challenge is translating the promise of digital health into accessible, equitable practice. In communities where even getting to a clinic is a financial and physical burden, telemedicine holds immense potential, but only if it's designed with empathy, not just efficiency.

Illness is not merely a clinical event; it is an experience. A disruption. A quiet shift in the rhythm of daily life. While disease may be defined in biomedical terms by lab values, scans, and diagnoses, illness lives in the space between the science and the self. It's the fatigue that makes breakfast feel like a burden, the shortness of breath that whispers fear during a walk, or the silence that follows when words feel too heavy. If telemedicine is to mean anything beyond convenience, it must transform how people feel about their care: more seen, more heard, and more capable of healing in ways that matter to them.

2. What is the Patient Journey Record (PaJR)?

2.1 Origin and Principles

At its most honest, medicine has always been a conversation. A quiet exchange of fears, hopes, and knowledge between someone seeking help and someone offering it. But in today's world of quick consults, clinical codes, and digital dashboards, that conversation is often lost.

Patient Journey Record (PaJR), which originally started as Patient Health Record (PHR), began with a simple idea: what if patients could document their own experience of illness, not just the clinical symptoms, but the thoughts, routines, habits, and life events that shaped their health? PaJR has evolved into a tool for both prospective insight and retrospective analysis, helping patients and healthcare providers alike see not just where things went wrong, but why.

While medicine has made enormous strides in decoding the “micro” i.e., genetics, epigenetics, and molecular pathways, there has been far less attention to the “macro” i.e., the everyday behaviours, environments, and lived experiences that interact with those microscopic mechanisms. Our diets, our stress, the quality of our sleep, the air we breathe, and the pace at which we live. These are not side notes; they are central characters in the story of illness and recovery. PaJR brings these macro-level influences into view. By encouraging patients to track their journey over time, reveals patterns that might otherwise be missed. Moments where lifestyle and environment intersect with biology to tip the scales toward health or disease.

PaJR is a living narrative, a continuous, evolving account of a patient's life as they experience health and illness. It is not confined to clinic walls or hospital visits; rather, it begins when the patient begins to notice a change, and it extends beyond the prescription pad or discharge note. It tracks meals, moods, sleep, conversations, symptoms, doubts, recoveries, and relapses. It creates a space where care is not episodic, but continuous; not impersonal, but deeply individualized.

At its core, PaJR is built on the principle of **user-driven health care (UDHC)**. It assumes that patients are not passive recipients of care but active participants with valuable insights, capable of contributing meaningfully to their health journey. PaJR was born from the need to reconnect the clinical with the personal, to ground healthcare once again in the patient's lived reality. It seeks to reverse the historical asymmetry of knowledge between doctor and patient by encouraging transparency, mutual learning, and co-creation of health goals. No two individuals experience illness in the same way. Even with the same diagnosis, the lived realities diverge based on personality, context, culture, and memory. What may seem like a minor complaint to one may feel like an existential threat to another. And so, to care for illness requires more than treating the disease; it demands attention to the narrative that surrounds it.

Crucially, PaJR does not function in isolation. It thrives in a connected ecosystem of clinicians, caregivers, peers, students, and technologists who interact, observe, learn, and support. It's a communal record, maintained with consent, and designed to

encourage continuous learning across generations and geographies. In the age of Web 2.0 and Web 3.0, where communication is rapid, decentralized, and personal, PaJR aligns itself with the spirit of these networks.

2.2 Workflow of PaJR: Create your own PaJR

Now that we have established an understanding of the concept of PaJR and the story behind it, let's understand the workflow of PaJR. This workflow can be charted a map for future telemedicine revolutions in underprivileged areas where PaJR can be utilized to improve healthcare facilities. At the heart of PaJR lies the patient's real-time data collection. There are several key stakeholders involved with their unique roles in PaJR along with student volunteers making it a great success as explained in Chapter 1. The primary end-user in PaJR is the patient. The entire process starts with the patient's interest in enrolling on PaJR, and then the journey of "Create your own PaJR" commences. The patient either remotely or in a hospital setting approaches the doctors utilizing PaJR and who gets their informed consent signed. Once the ethical doubts and concerns of patients are addressed during the consent taking procedure, a volunteer, usually a medical student, takes a detailed history from the patient telephonically or in person as convenient at both the ends. All the information is de-identified ranging from clinical history proformas to any investigation documents before uploading on the database. A WhatsApp group via www.pajr.in is created including patient, patient's advocate or attender, doctors, involved medical students, researchers and navigation staff who updates patient's data regularly. Patients are then required to follow-up as advised by the treating physician with regular WhatsApp updates. This deidentified data via WhatsApp is uploaded on the online medicine blogspot publicly accessible for education or case report follow-ups. The conversational advise and journey of the WhatsApp PaJR is also regularly uploaded without any identifier of medical team or the patient. WhatsApp serves as platform for patients to store their files, making themselves conscious about their habits and health, acting as medical journal handy anytime with better communication and feedback from healthcare professionals. This also aids the medical team to identify patient-centered outcomes and priorities. PaJR not only brings together doctors and patients closer in decision making but also involves researchers and exploration of different endpoints via medical student's active discussions. It also bridges the gap between traditional case report publication methods and reporting since wide set of data is available on medical blogspot which can be accessed by different physician treating a similar case presentation with a 360 degree view approach involving not only the medical interventions but also necessary lifestyle changes, diets and psychological support which often gets missed in traditional case report publications.

A brief step-by-step guide on PaJR workflow is given in Figure 1

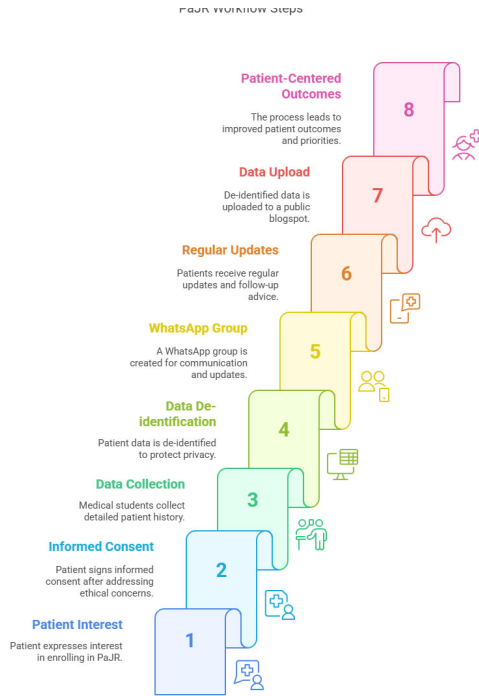


Figure 1: The ladder of successful delivery of patient centered outcomes-step-by-step guide of PaJR workflow

2.3 The Outreach of PaJR: Where it is being utilised and Innovations

At present, PaJR is globally available at no cost to every patient and healthcare provider willing to embark on telemedicine journey. The blogspot data is widely accessible publically for educational purposes. Most of the data is from Narketpally, Telangana, India but data from Singapore and Australia has also been recorded via PaJR. The key question remains, how can this data be utilised for medical education and research?

Referring to the most common disease presentations prevalent in the world like diabetes, its pathology, clinical presentations and complications have a huge spectrum. Students actively involved in reading the medical blogspot can utilise this PaJR data to learn about monitoring of sugar levels protocols, timeline of variations in clinical symptoms, discovery of new symptomatology and visual learning via in from the investigations and other documents available on the blogspot. In a similar fashion, a technique of long-term follow up protocol and importance is passed on to the

prospective doctors training them to treat patients with a long-term view rather than short term decision making. Essentially, this form of participatory medicine involving medical students also hones their clinical skills of history taking and inculcates an empathetic ear towards the patients. Therefore, participatory medicine is also paving a way for participatory learning. This forces students to co-relate the cases available in their mobile phone with the textbooks or notes they're following. New and rare presentations often missed out in curriculum oriented books can also be learnt via PaJR giving students the courage to face atypical presentations and prompting new approaches via first hand involvement in the patient's journey or via previous recorded blogspots.

Apart from focusing on automating the data collection process and participatory medicine, there several other domains where PaJR team is involved:

1. Spectroscopic food analysis: AI food plate analysis is currently unreliable. Spectroscopic analysis offers an accurate alternative for macronutrient identification. Our goal is to integrate this reliable method into our WhatsApp operations.
2. Non-Invasive Glucose Monitoring: Blood glucose monitoring has been a huge roadblock particularly because it is invasive and quite a number of patients are needle-phobic. While continuous glucose monitors (CGMs) exist, their high cost and limited 10-14 day lifespan are significant drawbacks. A non-invasive glucose monitor has the potential to revolutionize current practices.
3. Smartwatch based vascular metrics: Automation thrives on minimal human intervention. While frequent blood pressure (BP) tracking is the current standard for cardiovascular health, it's cumbersome, and smartwatches require manual BP machine calibration. Vascular health, accessible throughout the body, holds the key to radically improving disease outcomes, particularly by understanding the microvasculature. Emerging metrics like Photoplethysmography (PPG), heart rate variability (HRV), pulse wave velocity (PWV), and flow-mediated dilatation (FMD) offer promising avenues for vascular health assessment.
4. The Sensor: The ultimate sensor would complete the input-process-output cycle, but history suggests innovation is endless. In a growth-seeking environment, the 'pie only grows larger' and humans are (within current constraints of available knowledge) known to have 5 basic senses – touch, vision, taste, hearing and smell with a few additional senses – sense of space and time and position and vibration. If these inputs become measurable with a sensor and the outcomes too are measured, then the 'process' knowledge gap can be filled.

3. Revolutionary Real world Patient journeys from PaJR_

PaJRs have proved their worth among healthcare professionals associated with it, and have greatly benefited patients that played an active role in taking control of their

health. Here, we would like to share some examples of the different ways PaJRs have worked in helping patients get better:

PaJRs most commonly help manage cases that require long-term careful monitoring of drug-intake: for instance, insulin in type 1 DM or hypoglycemic drugs in type 2 DM, thyroid medication in hypo or hyperthyroidism, hypertension medication, to name a few. Alongside these, patients are encouraged to modify their lifestyle too, to see how far it can benefit them.

3.1 PaJRs and the Metabolic Syndrome

Metabolic Syndrome[1], characterised by truncal obesity, insulin resistance, dyslipidemia and hypertension among others, is now a common clinical entity and more of a lifestyle disease than a pathological entity, with increased caloric intake [2] being the major environmental contributor to this disease. While drug control is initiated when symptoms of disease manifest, lifestyle modifications have truly proven to halt, or even reverse, the progression to a disease-free state [3]. Here, we share some of our metabolic syndrome patients who have begun to improve with monitoring.

A 63 year old male with metabolic syndrome and dyspnea[4], carefully documented his daily activity and food intake, and such active documentation helped both the doctors and the patient to make a careful analysis and plan his meals according to the Harvard Healthy Eating Plate [5] , which led to improved quality of life.

Another 65 year old female patient [6], who was a known case of hypertension and CABG, had initially presented with left hemiparesis, a known complication of metabolic syndrome. She was admitted and then treated for it. Upon follow-up at the OP, she presented in a wheelchair, having given history that she was not quite capable of walking without a walker, and a BP of 76/62 mmHg. Suspecting steroid use due to a Cushingoid habitus by a physician in her PaJR, inquiry was made into her medication intake, wherein she was found to be taking Prednisolone for the last 20 years, which led to adrenal insufficiency and possible avascular necrosis of both femur heads. Monitored withdrawal was then planned.

While in the first case better quality of life was achieved and increased satisfaction was reported, in the second scenario the hidden cause to symptomatology and pathology was identified via PaJR follow-up groups. These details can be missed by traditional methods of follow-ups and history taking where patients often feel obliged to participate rather than feeling supportive for their health.

3.2 PaJRs and Type 1 Diabetes

Type 1 Diabetes Mellitus[7] is a disease of autoimmune pancreatic destruction, and thus, exogenous insulin supplementation becomes necessary in order to maintain proper glucose regulation in the body. This is a cumbersome process for the patient,

especially a newly diagnosed one, who might not know what to look for. Thus, close monitoring by a physician can be of immense help.

A 4 year old child's[8] food intake and insulin supplementation is meticulously monitored by her attender and shared on an everyday basis, with modifications made for every meal that the child has, ranging from difference in quality of food, or quantity.

A 30 year old female[9], diagnosed with Diabetes type 1 in 2015, has meticulously documented her journey through her PaJR. Monitoring her over a period of time, her PaJR physicians have noticed that her insulin reserve is improving, possibly suggesting some amount of pancreatic recovery.

Both the cases present new insights to PaJR. The attender of 4 year old being in constant contact with the medical team not only felt confident in administering insulin but also received immediate advice on regular activities. Motherhood itself comes with varieties of challenges especially in the school-going age groups. While facing day-to-day new life milestones, type 1 diabetes is an additional burden on the mother requiring continuous monitoring and lifestyle changes. This journey didn't only require medical expertise and advice from her team but also emotional and psychological support until it became adaptive. Adults diagnosed with diabetes Type 1 need not only regular monitoring but also health education in case of emergencies and logistic requirements made easy via PaJR group.

3.3 PaJRs and Thyroid disease

Thyroid disease, based on etiopathogenesis, presents with a spectrum of symptoms for the patient, ranging from hypermetabolic [10] responses to hypometabolic[11] responses, and all cause significant morbidity to the patient, unless proper lifelong medication[12] is taken. PaJRs can help a patient with a thyroid disease in this respect too, to closely monitor their symptoms and quality of life.

Chronicled here is a careful history and lifestyle of a 56 year old female [13] with hypothyroidism along with some other symptoms, such as insomnia, tinnitus, vertigo and migraine, with her thyroid symptoms monitored carefully, along with inquiry into her other conditions, such as identifying triggers for her migraine, and so on. In such cases, it's often difficult for patients to give an elaborate one-time history in a correct sequence to identify associated aggravating and relieving factors. PaJR follow-up helped the patient avoid the triggers for her migraine and identify the relieving factors helping her the most.

Another 24 year old male patient[14] with subclinical hypothyroidism, new onset irritable bowel syndrome, and hair loss, all of which are being suspected as being autoimmune, are being investigated, and lifestyle modifications have been suggested to the patient, especially for his IBS symptoms. This patient was also followed up with stool images for Bristol Stool Scale and exploring any other causes of bowel

symptomology via PaJR group which often can be missed to capture in the traditional pattern of healthcare system.

3.4 PaJRs and lifestyle modification/seeking to improve overall health

Lifestyle modification, no matter what disease the patient may be having, can greatly impact a patient's overall health. Better quality of food based on the Harvard Healthy Eating Plate, and increased physical activity are proven [15] to enhance a patient's quality of life significantly. Some of our well documented lifestyle modifications are presented here:

A 44 year old female [16] has carefully documented her blood sugars, blood pressure and meal intake for the last few months, and has already reported an improvement in her quality of life - improved energy levels, decreased weight, and so on.

A 33 year old female [17] with post traumatic headache regularly chronicles her energy input and output and mentions any symptoms as soon as they appear, such that they are addressed at the earliest.

3.5 PaJRs for monitoring chronic illness states, and intervening as necessary

An 18 year old [18] and her attender together have carefully shared her history from when her mother was pregnant with her, to her current states of constant fevers and latest atopic dermatitis. Considering all her significant past history from a CVA at eight days of birth to asthma attacks, and epileptic attacks, having a PaJR helps both her and her physicians to have all her data in one place. She also regularly shares her energy inputs and outputs, and any sudden bout of illness that might plague her, and her PaJR team intervenes as necessary.

PaJRs also become important in monitoring patients on long term medication like epileptic medication, as chronicled in this case of a 6 year old girl [19] who has been on antiepileptic medication since she was 4, and her attenders are currently querying into stopping the antiepileptic medication as they have noticed some side-effects in their child due to it. Another quick outpatient consultation for a 55 year-old woman with anxiety primarily because of her daughter was suffering from panic attacks with alkalotic tetany and her daughter were suffering this because she was emotionally attached to another 14 year old girl in her neighbourhood living next door who was suffering from an inoperable brain tumor and doctors had just given up on her. The doctors showed them this connection based on their own data and reassured them that things will get better with time. They were asked to derive everyday support via PaJR groups.

Mentioned above are some of the most common cases we come across in practice, and how a PaJR can help manage them. Owing to their common nature, only this set of diseases have been considered for this subsection. However, this is not a generalisation of PaJRs, for any patient with any kind of problem can have a PaJR and begin to work towards improving themselves.

To create a revolutionary change in one's health and life, one does not need to make revolutionary changes; just small, disciplined steps toward a better future. This is one of the main aims of PaJR: by involving a patient actively in their health journey leading to an improvement in their overall health status, is the common theme in all of these case reports.

4. Limitations and Future Directions

The CBBLE/PaJR process is a functional low-resource settings prototype of a pragmatic trial - understanding patients with a 360 view, conducting treatment with that 360 context, collaborative treatment and learning process, and consented documentation as PaJR case report EHRs available open access and logged daily in online learning portfolios archived[20]. Very few health systems follow this construct.

Future of an albeit Orwellian, transparent, accountable, syndromic approach to medical education and research and its ethical ramifications:

Medical professionals must prioritize aforementioned case-based reasoning CBR, healthcare information systems that regularly provide a transparent individual patient clinical audit in real time with rigorous evidence appraisal to avoid therapeutic missteps.

Transparency in Research would not just remain confined to highlighting the importance of publishing all trial data, including negative results, but would insist on all making available contextual data surrounding each and every trial patient participant to inform clinical decisions. Some lessons for medical education:

Curriculum Shift: An individual patient-centred syndromic approach will enable moving beyond foundational knowledge (Bloom's levels 1–2) to cultivate critical appraisal skills and teach students to dissect study designs, recognize bias, and assess real-world applicability.

Case-Based Learning: Using regular, connected, and contextual "real patient" data over simulations can better demonstrate the consequences of uncritical acceptance of biased data.

Advocacy Training: Can empower future clinicians and their patients to challenge misinformation and advocate for ethical research practices. [21]

Chapter Summary: Key Messages to Remember

- Telemedicine serves to bridge the disconnect between traditional clinical models and the complex, personal lived experience of health and illness.

- The Patient Journey Record (PaJR) is a pioneering telemedicine model that functions like a patient's personal journal, enriched with interactive and professional feedback from health personnel.
- PaJR is conceptualised as a living narrative, providing a continuous, evolving account of a patient's life and their experience with health and illness, extending beyond clinic visits to track daily aspects like meals, moods, and symptoms, fostering deeply individualized care.
- At its core, PaJR is built on the principle of user-driven healthcare (UDHC), recognising patients as active participants with valuable insights capable of contributing meaningfully to their health journey.
- The workflow of PaJR involves the patient initiating the process by giving informed consent, followed by a detailed history taken by volunteers (often medical students). De-identified information is shared and updated regularly within a WhatsApp group involving the patient, caregivers, doctors, students, researchers, and staff. This de-identified data is then uploaded to a publicly accessible online medical blogspot for educational purposes.
- Real-world applications demonstrate that PaJR is valuable for long-term monitoring and management of chronic conditions such as metabolic syndrome, Type 1 diabetes, and thyroid disease.
- Although, PaJR serves as a prototype for a patient-centered, case-based approach to medical education and research, providing students and professionals with access to real, contextual patient data; there are some limitations and future directions impending.

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