

Perspective

How Crowdsourced Constructive Intelligence Can Inform Chronic Condition Self-Management Strategies

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ABSTRACT

The world has moved from an “*Age of Information*” into an “*Era of Knowledge Creation*”. Social networks permit people to interact, share, validate, replicate, and modify their experiences in real-time to the benefit (and risk) of themselves and the network itself. We can now facilitate asking and tasking patient communities to help solve shared problems and needs. The purpose of this position paper is to *describe a digitally enabled social network defined within a chronic condition patient population, and facilitated around condition self-management can generate new knowledge and improved outcomes for the population*. The source of this new knowledge would emanate from network member data and their individual experiences of self-management and general healthcare. We review the concepts of crowdsourcing, collective, connective, collaborative, and constructive intelligence that can gather individual experiences and evaluate them for optimal effectiveness, aggregate them, and then feed findings back to the network. This creates a constructive social network that can foster optimized coordination of learning and innovation within the network. In addition to the constructs referenced above, this paper will also center around the concept of “expert patient”, integrated with the provider or other facilitators/caregivers. We will lay out a framework for applying these concepts for better understand chronic health conditions and self-management. Even though crowdsourcing was found to hold some potential in this context more future studies are however needed to validate the method.

Keywords

Crowdsource; Collective intelligence; N-of-1; Chronic condition self-management; Expert patient; Social Support.

INTRODUCTION

The world has moved from an “*Age of Information*” into an “*Era of Knowledge Creation*”. Highly developed social networks permit large numbers of people to interact, share, validate, replicate, and modify their experiences in real-time to the benefit (and risk) of themselves and the network itself. Where the right concepts meet the right technology, providers, provider novices (i.e., trainees), subject matter experts, and patient populations we can now facilitate asking and tasking patient communities as collaborators with providers of all disciplines in solving shared problems and needs.^{1,2} This technology-enabled network is ideal for what best-selling science and technology author Johnson³ has referred to as liquid networks. A liquid network is to be contrasted with a gaseous or solid network. In a gaseous network, ideas flow freely but do not stay in proximity with sufficient time and consistency to create new forms, ideas, or solutions and therefore rarely combine to define new innovative answers. A solid network by contrast and the effect of its rigidity, does not allow for sufficient exposure of

ideas to one another with sufficient frequency and therefore never has the opportunity to connect. The digitally enabled network now allows for the creation of liquid contexts that foster new ideas that combine into innovative forms.

The purpose of this position paper is to *introduce the concept of a digitally enabled context by which social networks defined within a chronic condition patient population, and facilitated around condition self-management can generate new knowledge and improved outcomes for the population in aggregate stemming first from “small data”*. The source of this new knowledge would emanate from network member data and their individually generated experiences of self-management and general healthcare. We review the concepts of crowdsourcing, collective, connective, collaborative and constructive intelligence that can gather individual experiences and evaluate them for optimal effectiveness, aggregate them and then feed findings back to the collective. This then creates a constructive social network that works to fosters optimized coordination of learnings and innovation within the network. In addition to the constructs referenced above, this

paper will also center around the concept of “expert patient”, integrated with the provider or other facilitators/caregivers. We will lay out both a justification and framework for applying these concepts and crowdsourced methodologies for better understanding of chronic health conditions and the self-management knowledge that develops through the collective and facilitated expert patient experience of patients within a network.

SMALL DATA AND INDUCTIVE REASONING

The healthcare industry has embraced the Big Data era in both word and deed. Given the rise and innovation curve associated with precision and personalized medicine, now is the time to also consider “small data”. The term small data has been used differentially in a variety of contexts. However, within this context, small data refers to the evaluation of selective measures of the individual and interpreted at the level of the individual. This includes all the standard medical or psycho-behavioral metrics (e.g, blood pressure, blood glucose, weight, mood, steps, etc.). The clinical objective here is to develop a clinically appropriate “digital twin” that allows for more refined measurement-based care^{4,8} that deeply integrates into concepts of ecological momentary assessment and intervention.⁹⁻¹¹

Small data and N-of-1 evaluation create the opportunity to evaluate everyone uniquely and are truer to life than current clinical practice.¹²⁻¹⁴ This approach provides individualized feedback (including to relevant providers) about the quality and strength of the patient’s unique treatment response. Like more traditional approaches, N-of-1 can incorporate biological (genomic), behavioral, psychological, and digital health data such that user-patients can begin to evaluate the relationships of their own treatment response patterns and the contingencies that impact them in their own lives. For the clinician, this form of scientific and behavioral interaction can help them validate or reject the impact a given treatment has for a given patient with increased efficiency and accuracy.

This framework does not challenge group science (randomized controlled trials (RCTs)) or Big Data but rather that by using N-of-1 methodology, time-ordered data gets optimized and thereby provides a new metric, from the growing deluge of time-ordered data now coming from new measurement technologies (wearable devices, nano-technology, ingestables, implantable, pervasive wireless connectivity, internet of things (IoT)). The ecologically momentary technology now commercially available permits us to collectively engage in such discoveries and N-of-1 outcomes aggregated upward to serve as the new learnings as they reach a threshold of member replication. The question then becomes: “What stakeholders are best positioned to enable and activate such communities (including physicians and other providers)?” “Who and how should key stakeholders (the community members themselves primarily among them) benefit from the discovery of that latent intelligence of the group such that the sharing of ideas and supporting data motivate and benefit both the individual and community at large?”

SOCIAL SUPPORT AND SOCIAL NETWORKS

Escalating technological advancements, globalization of social net-

works, and advanced analytics now make it possible to create a new healthcare service delivery model integrating “connected care” into the care milieu. Connected care is defined by the Alliance for Connected Care as “the real-time, electronic communication between a patient and a provider, including telehealth, remote patient monitoring, and secure email communication between clinicians and their patients”.¹⁵ As healthcare systems move toward more accountable care, remote patient communication and monitoring will be an increasingly important role in patient services for overcoming a variety of care gaps including provider shortages, remote care, access, and the addressing of social determinants to name a few. Connected Care has the potential to improve access to care, helps providers and patients avoid costly healthcare services, and increases convenience for patients.¹⁶

Social networks and the data they generate have spawned new ways to understand how people connect and influence one another including health and health related behaviors.¹⁷ For example, Christakis et al¹⁸ and Alloway et al¹⁹ have produced a fascinating body of work that shows the direct and indirect influences that social networks have on behavior including relationships characterized by several degrees of separation. For example, in their seminal work on the spread of obesity via social networks using Framingham data.² Christakis and Fowler demonstrated that both behavioral and biological traits associated with obesity spread or otherwise develop out of social relationships.

The literature supporting the buffering value of social support is broad and deep.²⁰⁻²² However, social networks are not synonymous with social support. There is no shortage of examples of harm stemming from social networks (e.g, misinformation, “trolling” and “catfishing”). Negative examples notwithstanding, the question arises as to how to create a social environment that facilitates a network that is self-supporting. Elsewhere we have published a framework for organizing support materials by cross-referencing the Lorig self-management model²³⁻²⁵ with the 3 common forms of social support (for those taking specialty pharmacy medications). The Lorig model speaks to four skill sets the chronic condition patient must master. Table 1 displays a cross-referenced heat map whereby the darker shaded cells represent higher cross-referenced content relevance including how content can be tagged and weighted within an initial expert rules engine.

Table 1. Patient Support Heat-Map

	Instrumental Support	Informational Support	Emotional Support
Understand Diagnosis and Treatment			
Work Effectively with the Healthcare Team			
Manage ADLS			
Manage Stress, Neg/Emotions			

Almost by definition support must be personalized. In other words, well-intended but poorly provided or mis-matched support is at best not helpful and at worse can be harmful when it runs contrary to what is needed. The intent then is to help those

being supported search for relevant support materials, tools, resources and/or providers that clearly and quickly match their needs. This begins to give form to how content can be curated for patient-users as they move through the experience to find not only what they need but more importantly what works and to filter information based on patient-expressed needs and the collective small data outcomes data for that need.

CROWDSOURCED COLLECTIVE INTELLIGENCE

Howe²⁶ defined crowdsourcing as the use of large and generally undefined groups to do the work that would traditionally be performed by an agent or class of agents specifically trained for the work purpose. Using this definition, a patient-defined social network could use a crowdsourcing methodology by which to task groups, collect data, and uncover the latent and/or emergent intelligence within a network.²⁷ This assumption can then be applied to a set of individuals coping with and managing one or more chronic conditions (e.g., Patients Like Me). Bucheler et al²⁸ present a framework by placing the methodology of crowdsourcing within a context for rigorously generated new knowledge that defines the elements of collective acting intelligently and is relevant to the validity of the insights and has implications for how to design the experience collective itself.

Levy¹ coined the term collective intelligence to refer to the emergent and creative qualities within these networks that develop as a byproduct of the interactive sharing of experiences. Swarm intelligence occurs in the natural sciences (e.g., bees, fungi, etc.) whereby these lifeforms display emergent intelligence not characteristic of the individual members.¹⁸ Surowiecki's²⁹ best-selling *The Wisdom of Crowds* summarizes the topic in a readable overview. One example of collective intelligence in the life sciences is the online puzzle game Foldit for folding proteins.^{30,31} Foldit was developed at the University of Washington,³² Center for Game Science, in collaboration with the UW Department of Biochemistry.³³ The game's objective is to fold the proteins using

tools and rules provided by the game's design. Scientists use these solutions to better understand and develop interventions for diseases.³⁴ Note that gamers under the scientifically constructed game rules are generating new knowledge). Foldit has over 500 thousand downloads in Google Play alone and has been applied to multiple peer-reviewed publications solving real-world health problems.

Malone et al³⁵ the founder of the Center for Collective Intelligence at MIT, raises the decisive question:

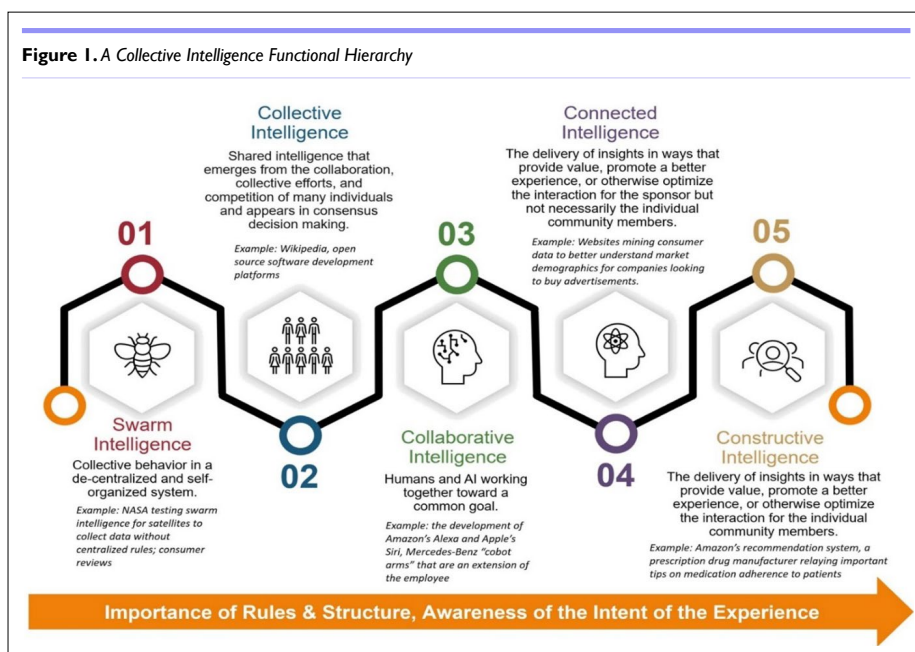
“How can people and computers be connected so that – collectively – they can act more intelligently than any person, group, or computer has ever managed to do previously?”

To expand on Malone's question relative to chronic condition management:

“How can we create an environment (i.e., network) in which targeted patient populations interact, share, and communicate their experiences in ways by which each member is an “experiment” and the aggregated findings are fed back to the community for replication, confirmation, innovation and/or revision?”

CONNECTIVE INTELLIGENCE

One goal of collective intelligence could be to create an environment that would invite the discovery of latent collective intelligence and accelerate innovation by way of connection, collaboration, and construction (Figure 1). Connective intelligence results from the functional attributes of the shared experience that allows for the coordination of network members to connect around a specific problem. Research has shown that conditions can promote collective and connected intelligence and others which can undermine its effectiveness.³⁶ Creating an experience promotes collective intelligence and accelerated it requires it to organize and through 3 additional steps or developmental stages. The first is facilitated connective intelligence by which group members can find



and interact with each other bi-directionally with ease and safety. A connective group contains elements that facilitate the interaction and sharing among members that set the stage for a liquid context.³ Additional developmental layers and functions add facilitation, aggregation, analytics, and interpretive feedback capabilities to the group nested within the experience.

COLLABORATIVE AND CONSTRUCTIVE INTELLIGENCE: FACILITATING THE EXPERT PATIENT

While collective and connective intelligence is useful methods to generate new ideas and fuse ideas and behaviors into new knowledge and applications, they have not proven to be good mediums by which to evaluate the ideas in practice. A third type of aggregate intelligence is one that can collect individual experiences and evaluate them in ways that promote replication, revision, or rejection of findings based on other comparable experiences and statistical evaluation. The experience design guides the individual contributions toward optimal effectiveness thereby creating a collaborative network. Collaborative intelligence in this context is then defined as a medium that leverages individual cognitive diversity to create and evaluate an optimal group experience and share the evaluated collective experience with the group.

Here we introduce the concept of constructive Intelligence which takes the design further by adding another layer to the architecture. Here facilitation occurs at a level that contains both the analytics and subject matter expertise as an interpretive and contextualizing layer in terms of clinical delivery orchestrated to meet the care needs of the network. This knowledge can be digital in nature or within human SMEs or both. This represents an architectural layer where providers of all disciplines would have configured access by which to play a critical role in the correction of misinformation and the translation and application of novel insights and findings. The critical distinction here being that the overall design within a constructive model is one in which evaluation is straightforward, interpretively clear, actionable, and rigorous in its logic at the individual and aggregate level. (e.g., Foldit). When applied to a chronic condition network the net result should be facilitation of the “expert patient”:

A “...patient with a chronic disease whose knowledge and experience about it

*empowers him/her to play a part in its management...*³⁷

The expert patient assumes that by virtue of their daily experience with the condition and its management harbor deep experiential information for how to live and cope with the condition. Most of these insights remain latent within a patient community at the level of the patient and family/friends because each data point remains unconnected and untested within each individual’s experiences and as a community member.^{38,39} Cordier³⁸ has provided a vision for how the expert patient could be engendered and applied in ways consistent with the concepts discussed here regarding small data and constructive intelligence.

Today, technological and analytical advancements provide tools and opportunities by which we can reach into the collective experience of a given community and harvest the collective data of to allow experts to gain wisdom from those shared experiences. But if people are truly to become expert patients, the wisdom from their collective experiences needs to be captured and shared back to the individual patients as well. For this reason, systems should develop constructive intelligence defined as the delivery of insights in ways that optimize the interactions and outcomes for the community members.

RECOMMENDATIONS FOR A CONSTRUCTIVE INTELLIGENCE

The collective intelligence of individuals interacting with each other, and mathematical algorithms that help drive social networks have already shaped everyday life.⁴⁰ These forms of intelligence have proven they can indeed produce new knowledge and make it valuable to the network. The means by which to develop and facilitate such an environment and extract the latent intelligence from within the network is already being explored by companies such as Foldit and Patients Like Me. Further development lies within the ability of clinical, behavioral, and data sciences to come together to create “engagement” within an environment where needs can be addressed uniquely by the group. Table 2 lists considerations for developing programs that facilitate constructive crowdsourced environments by which emergent intelligence is promoted and mined.

Table 2. Experience Design Considerations for Promoting Constructive Intelligence in Networks

Considerations	Objective	Risk/Challenge
Clearly define the target network	Clearly define the population or network of interest and its primary needs or goals.	Chronic condition management. Management of highly comorbid conditions and risk
Channel communications mapping	The experience architecture begins with communications and functionality that reaches the network and draws them in.	Lacking a clear and phased strategy that loses message and channels focus (scattered, unclear, diluted messaging).
Design experience elements to promote network participant rapport	The functional attributes of the network environment are created and a communications map created.	Failure to develop rapport via an effective experience that is Longitudinal, Conversational, Relational and Trusted.
Operationalize KPIs within the network	Social networks promote new constructive knowledge among a defined patient group in a context.	Operationalize the right metrics a priori that include both process and outcomes arranged in leading to lagging order.
Evaluate and mine for replicated solutions.	The experience architecture guides for systematic self-observations to promote valid and actionable insights.	Evaluation and findings are filtered for “value” and returned to the network for additional replications and translation into practice.
Visualize feedback to the network and other key audiences	Communication and data insights economically delivered via smart data visualization.	Confusing, non-intuitive, and/or overly complex data feedback.

Clearly Define the Target Network

Defining the boundaries of the population and the target needs and goals helps determine the content, function, and structure of the experience. Individuals living with one or more chronic conditions have selected by circumstance (including a pattern of biological and behavioral risks) to share a common set of experiences and goals but adapt uniquely. When the target population is clear then their needs and group-defining behaviors (typical treatments, clinics, doctor visits, etc.) are identified, and prioritized within need domains (Figure 1). This model provides a face-valid and testable heuristic by which to design key social support features within a social network. Furthermore, when elements are appropriately tagged and evaluated at the individual network member level (e.g., helped/did not help) that leads to better network-driven constructive intelligent self-management and that better self-management^{24,25} leads to improved outcomes. When cross-referenced with structural/functional domains of social support the overall program design gets clearer.

Channel Communications Mapping

The communication architecture for a target social network should be deeply informed by the needs, goals, and supports currently available among the network members. The architecture must consider what needs to be communicated among the network members and at what level of relationship type. Figure 2 represents a communications strategy map for developing a Social Network Dialogue architecture and facilitation strategy. Communication sources operationalize the universe of speakers within the network that can also signify a role and related level of access to bi-directional functionality (patient, caregiver, provider, etc.). Relationship type defines who the sender and receiver audiences are. Depending on the relationship type, the communication channel can be dictated through a strategic communications campaign. Lastly, the message's intent describes the reason, goal, or objective of the message itself.

Design Experience Elements to Promote Network Participant Rapport

The functional attributes of the network's architecture *via* the com-

munications map are not simply tools to streamline transactions but rather intended to facilitate the development of supportive relationships among the network members. For a relationship to develop in-depth (even *via* a virtual medium) there must be some form of sharing or exchange of the persona in a protected and trusted context. Below is a short list of high-level shared activities that might be relevant to the relational needs of a patient population.

- Shared Activities (including treatment protocols)
- Shared Goals (including treatment goals and treatment plans)
- Shared Experiences
- Shared Challenges
- Shared Enemies
- Shared Friends/Family

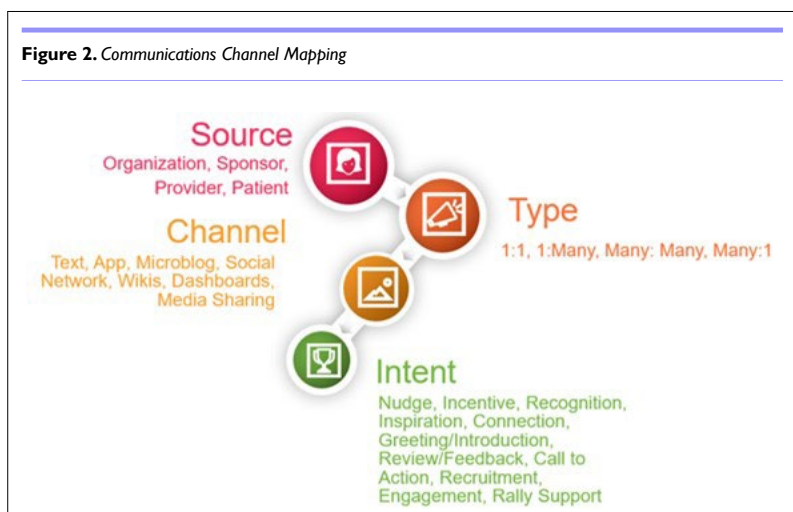
Operationalize Key Performance Indicators within the Network

Social networks to promote new constructive knowledge will generate various forms of structured and unstructured data. Under the collaborative, and constructive models, the shared network has a shared Uber goal(s). Informational feedback is a critical requirement under these models to disseminate and replicate new ideas and ultimately to access progress to the shared Uber goal(s). For example, crowdfunding for causes generally have mechanisms by which to share the end product of the funding with the funding network.

Evaluate and Mine for Replicated Solutions

Architecture logic should clearly articulate the ideal "Happy" path and align related metrics. These measures follow the theory-driven confirmatory pathway of evaluation. Carefully selected constructs for profiling and data mingling should also be selected. These follow an exploratory path for yielding insights not suggested by existing theory. Evaluation and related findings are filtered for "value" and returned to the network for additional replications (support), modification/innovation, or even failure based on reaching thresholds of evidence.

The use of logic and experience mapping are techniques for determining what is and is not working within an integrated



system or program to be evaluated.⁴¹ Laying out the overall process along a series of steps each with an input and an output that relates to the outcome but also to subsequent steps along the overall experience path is essential. Figure 3 shows a very simple example to illustrate. A target population's overall experience is broken down into four simple steps. 1. Concerns about reaching the target group and recruiting them into the network. 2. Engage them longitudinally in the experience encouraging them to share, experiment, and interact with others. 3. Monitor for improving self-management skills (at least in part *via* network participation) that manifest meaningful changes in biometric values and behaviors relevant to the condition and its treatment. 4. Satisfaction of 1-3 leads to the desired outcomes.

Visualize Feedback to the Network and other Key Audiences

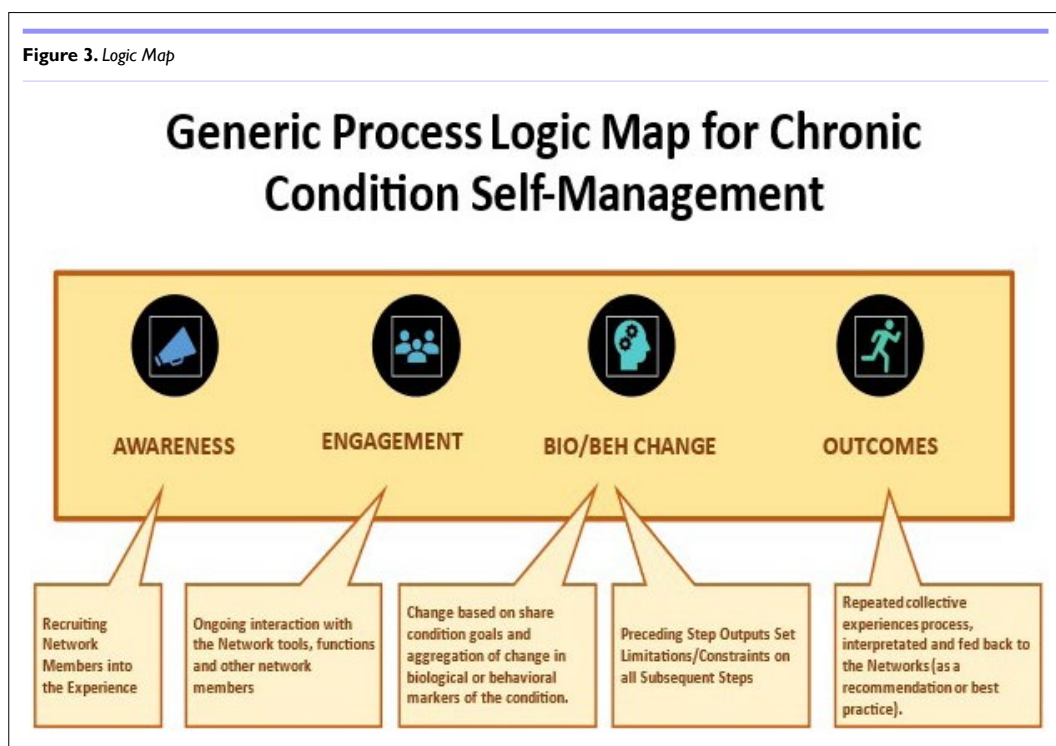
Feedback is critical in making the constructive intelligent system work. Therefore, the design of this enabled community must make the data-driven feedback intuitively consumable. Strong design and infographics, smart dashboarding, etc. can help the network (particularly when composed of non-subject matter experts) now make aligned sense of the meaning of the data. Knaflitz⁴² has written a nice guide for those new to data visualization that lays out common mistakes and best practices.

A real-world hypothetical of constructive intelligence is a smartphone app for those with chronic pain could promote improved self-management of chronic pain by sending ecological momentary assessments at common high pain points throughout the day (e.g., first thing in the morning for people living with inflammatory conditions or end of the day for people experiencing neuropathic pain). Through timely assessments, pain experts discover a different way of treating pain, one that accounts for the daily fluctuations in pain including and importantly self-pacing.

The experts then share this information back to the patients using the app so the patients can apply it to their daily lives. The app users can use the community chat within the app to continue to fine-tune this new treatment based on the fluctuations and support each other as a community of expert patients.

CONCLUSION

The technology is now in place to collect, integrate and aggregate data at the level of the individual managing a condition or condition and the network and connect them in ways that generate data by which to discover new insight to help support patients managing one or more specific or highly comorbid conditions. Patient networks and advocacy groups have started to leverage technology to better connect specific patient communities⁴³ and are well-positioned to construct, promote and deliver the value of the network back to the network. Experiences that connect and evaluate small data, as well as Big Data, have the potential to discover new insights of high value by way of a facilitated expert patient. The trend in healthcare today is to create patient-centered strategies intended to empower and enable individuals to take greater care and responsibility for their own health when connected to a Subject Matter Expert provider layer allowing for the feedback system to more optimally translate innovation. This digital twin concept envisioned the instantiation of digital technologies that would facilitate in situ assessment and intervention based on the clinical attributes of the patient and their biometric readings, biobehavioral risks, and current context related to treatment goals and treatment response. The concept of digital twins focuses heavily on the value of measurement-based care⁸ and analysis of clinical data at the level of the individual patient (i.e., small data). If the platform could share those experiences back into the community, it would be truly possible to create not only “*expert patients*” but “*expert communities*”. These concepts remain largely conceptual and therefore



await implementation and testing in whole or part. It is the intent of this paper to guide our thinking as to what could be.

CAUTIONARY STATEMENT

Even though crowdsourcing was found to hold some potential in this context more future studies are however needed to validate the method.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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