

A Global Social Network to Catalyze Solutions for Chronic NCD



A Case Study on the Young Professionals Chronic Disease Network

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When it comes to dealing with cardiovascular diseases, cancer, diabetes, and other chronic noncommunicable diseases (NCD), we all have our own knowledge, experiences, and personal stories. Yet, these diseases as well as their causes and solutions connect us all together in many complex ways through the social networks we belong to. Defined as a collection of both people and the connections between these people, social networks can employ the power of relationships to solve problems [1]. Each individual's outreach is expanded through social networks, and opportunities for learning are increased [2]. Interconnections within the social network have a strong potential to create a force for good to allow us to work together and connect to achieve what we could not achieve on our own.

With advances in digital communication and global interaction, these social networks have become more complex than ever [2]. An accompanying plethora of tools to understand social networks and how they can be used for impact exist as well. By better understanding 2 key aspects of social networks—connection, the structural ties that describe who is linked to whom, and contagion, ties at the behavioral level that describe how each individual's actions have implicit impacts on everyone else in the network—we can think about how to create collective solutions to the NCD challenges we face today [1].

Social networks can be viewed as both “a methodological tool and a theoretical paradigm” for studying a variety of public health research questions from infectious disease transmission to the influence of social support, networks, and capital on health to the interorganizational structure of health systems [3]. They can help to describe public health problems and catalyze public health solutions. The focus of this paper is the latter: how the world's first and largest organized social network of young health professionals organizes and mobilizes communication and advocacy to address the world's leading causes of death—chronic NCD—and why its structure as a social network is key to its success.

MOBILIZING THE NEXT GENERATION THROUGH A GLOBAL SOCIAL NETWORK FOR NCD

The Young Professionals Chronic Disease Network (YP-CDN) began as an informal meeting of kin from different backgrounds but united by shared values for

social justice, an end to premature and preventable NCD in a generation, and a common vision for the integral role of young people. It began with the need to address NCD as an urgent global health challenge with an intergenerational and cross-disciplinary approach.

Over the years, YP-CDN has straddled multiple virtual and real environments for organizing the social network. We began virtually to share news and ideas with each other: first, through a simple e-mail list with Google Groups, and then, a more interactive online discussion forum hosted by the Global Health Delivery Project at Harvard University. In 2016, we migrated to new platforms to activate the network in new ways. Real social environments of our network have formed through our chapters (initially dubbed “Third Thursdays” or “3T” groups) in cities across the globe. YP-CDN chapters take stock of their own country-context and issues, their own possibilities for solutions, and then implement them—facilitating translation of global policy to local action [4]. This coexistence between virtual and real has proved to be an invaluable strategy for scaling YP-CDN as a social network and creating opportunities for interaction between members across geopolitical boundaries.

We have, in effect, created a unique new community, which Sir George Alleyne, the Director Emeritus of the Pan American Health Organization summed up nicely:

The approach to generating technical and political attention to NCDs through young professionals is a unique one. This is not the first time youth have organized to lend themselves to an issue. But in this case young professionals have the added advantage of having enough knowledge on the issue to be able to articulate the problems more clearly. They have enough skills to be able to educate their peers about both the technical as the social dimensions of the NCD problem. They also have the ability and reach to communicate with policy makers in their respective countries and globally (personal communication, September 2011).

NETWORKS AND NCD

The NCD landscape is complex and changing rapidly, particularly in low- and middle-income countries.

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Therefore, solutions must be iterated quickly and thoughtfully, be context-specific and readily scalable, be driven locally at the grassroots level and attractive globally at the boardroom level, be agile yet directed, and be approached from an ecosocial perspective [5,6]. That social networks exhibit adaptivity, distributed control, emergence, and nonlinearity makes them an exciting prospect as a catalyst for NCD solutions [7].

Adaptive strategies and solutions for NCD

Social networks are adaptive; in fact, they exist in a state of near-constant change in response to information from outside of and within the immediate membership [2,7]. As such, social networks can respond well to the complex and rapidly changing NCD landscape of impacts, causes, populations, rates, and priorities [8,9]. Social networks remain incredibly agile even at scale; they can quickly adopt new goals and strategies as needed, but they can just as quickly pivot away from invalid assumptions and failed solutions.

YP-CDN began adaptively and continues to respond to political events and community needs to address NCD. Our self-determined guiding principles and strategy emerged organically and consensually as a product of the network's collective insights and recommendations for political leaders, captured in the first-ever "Youth Manifesto on NCD" [10]. As another example, we crowd-sourced experiences and ideas from young people across 11 countries to submit in response to the World Health Organization (WHO) Global Coordination Mechanism on NCD discussion paper on "Improving the availability and affordability of essential medicines and basic health technologies for noncommunicable diseases," in collaboration with the Lancet Youth Commission on Essential Medicines Policies in 2015 [11].

The adaptive features of our global network have also led to direct local action and progress, for example, in Mexico and Uganda. As part of a larger civil society effort, YP-CDN's Mexico City chapter led a digital advocacy strategy that contributed to successfully maintaining the soda tax in Mexico in 2015. Although "Big Soda" companies and their political allies attempted to decrease the tax by half, YP-CDN mobilized key national and international opinion leaders to support the tax, and research shows that the tax has resulted in a 12% reduction in purchases of sugary beverages—particularly among the poor who are at highest risk for NCD [12].

Distributed control for social change

A key feature of our social network is distributed control: all members of the network have influence or control over its behavior as opposed to one or a few [1,7]. This is a consequence in part of feedback loops, an inevitable dynamic of social networks as complex adaptive systems, where each member influences all other members in the network even if it is in some infinitesimal, perhaps immeasurable way. As a result, members can address NCD

with context-specific solutions as local expertise held by one or a few members is shared with and influences the whole network globally, and with democratic solutions that have support at the grassroots level, unhindered by the barriers of bureaucracy.

Since 2011, approximately 600 young professionals in Kenya have joined YP-CDN, many through the active chapters in Nairobi, Thika, and Eldoret. In the past 5 years, they have worked outside the reaches of formal health policy and programs and instead built intergenerational partnerships involving Ministry of Health, county governments, local nongovernmental organizations, and faith-based organizations to achieve impressive results. They have developed and shared opportunities for mentoring and training in research and policy for other young health professionals, led NCD awareness campaigns and intimate dialogues alike to ensure control is distributed to the public, and helped communities mobilize and advocate for smart NCD solutions across the country. For example, medical student volunteers led community NCD screenings with local partners, and chapter leaders received grants to develop their careers and present at the United Nations and other global conferences [4].

The distributed control of the network functions globally as well, helping YP-CDN to advocate for a greater representation of NCD medicines on the WHO Model List of Essential Medicines, an international list that guides mass drug procurement and priority needs. YP-CDN members and other NCD providers, patients, and advocates have successfully petitioned for the addition of nearly 2% of medicines—and 15% of NCD medicines—on the WHO Model List of Essential Medicines, which include statins and beta-blockers for cardiovascular disease, glucagon for diabetes, and imatinib and trastuzumab for cancers [13-17].

Emergent outcomes for NCD and social change

Social networks are also emergent, meaning known interactions between known members can lead to the emergence of ideas, insights, or something else entirely which is unpredictable, sometimes unrecognizable, and unique [18]. This characteristic allows social networks to more easily capture and scale new ideas for NCD that result from perhaps seemingly meaningless interactions that would otherwise go unnoticed or would fail to be encouraged in the first place. These networks allow structure and precision to unlock the hidden potential of these relationships. In addition, social networks are organized by surprisingly simple rules: there is little if any "red tape," or entrenched policies and processes. For NCD solutions, this means social networks can be more inclusive, more creative, and more lean in their management. Because social outcomes are often emergent instead of planned, a social network for NCD is a potential key facilitator of enduring social change.

Numerous outcomes and innovations in NCD service delivery, movement building, and partnership building

have emerged from the YP-CDN network. For instance, Nigeria's Bone Marrow Registry emerged from the vision, ambitions, and interactions between YP-CDN board member Seun Adebisi, a leukemia-lymphoma survivor and bone marrow transplant recipient, and other YP-CDN members. It is the second in Africa and is now funded and operating [19].

CONCLUSIONS

The adaptive, distributed, and emergent qualities of social networks are instrumental to not only mobilization of support for, and execution of, national NCD policies in countries that have not yet adopted them, but also the implementation of current national NCD policies, strategies, and programmatic activities to deliver NCD prevention and care to traditionally excluded populations. Emerging leaders and young people have started to make valuable contributions to achieving the global NCD targets and remain driven and dedicated to act in shaping the future health of their nations. YP-CDN has offered a network and a platform for young people to initiate, ideate, and contribute to action and solutions for NCD in meaningful ways.

Discovering new ways for our social network to fuel improvement of NCD prevention and control, particularly through strategic interaction and behavior, is a continuous process requiring constant collective input [2]. The creations of social networks belong to the collective, not just to one or a few individuals alone. Insights from individual nodes (members) can be shared through social contagion and coordinated to amplify and power social action and political pressure to drive real-world, measurable impact (as in the case of the bone marrow registry described). The physician and sociologist Nicholas Christakis defines these social networks as commonly owned forests where we all stand to benefit but must work together to ensure it is healthy and productive [1]. As individual nodes, the members of YP-CDN are valuable, but, collectively, we animate the powerful application of social networks and consequential social action for health as a powerful global health tool.

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REFERENCES

- Christakis NA, Fowler JH. *Connected: The Surprising Power of Our Social Networks and How They Shape Our Lives*. New York, NY: Little, Brown and Company; 2009.
- Easley D, Kleinberg J. *Overview*. In: *Networks, Crowds, and Markets: Reasoning About a Highly Connected World*. Cambridge, UK: Cambridge University Press. p. 1–20. Available at: <https://www.cs.cornell.edu/home/kleinber/networks-book/>. Accessed August 3, 2016.
- Luke DA, Harris JK. *Network analysis in public health: history, methods, and applications*. *Annu Rev Public Health* 2007;28:69–93.
- Matheka DM, Nderitu J, Vedanthan R, et al. *Young professionals for health development: the Kenyan experience in combating non-communicable diseases*. *Glob Health Action* 2013;6:22461.
- Kauffman S. *At Home in the Universe: The Search for the Laws of Self-organization and Complexity*. New York, NY: Oxford University Press; 1995.
- Krieger N. *Theories for social epidemiology in the 21st century: an ecosocial perspective*. *Int J Epidemiol* 2001;30:668–77.
- Plsek P, Lindberg C, Zimmerman B. *Some Emerging Principles for Managing Complex Adaptive Systems* [Plexus Institute working paper]. Available at: http://216.119.127.164/edgeware/archive/think/main_filing1.html. Accessed July 25, 2016.
- Bloom DE, Cafiero E, Jané-Llopis E, et al. *The global economic burden of noncommunicable diseases*. *World Econ Forum* 2011:1–46.
- Daniels ME, Donilon TE, Bollyky TB. *The Emerging Global Health Crisis: Noncommunicable Diseases in Low- and Middle-Income Countries*. The Council on Foreign Relations: Independent Task Force Number 72. 2014.
- Kishore SP, Siegel KR, Ahmad A, et al., for UP-CDN. *Youth manifesto on non-communicable diseases*. *Glob Heart* 2011;6:201–10.
- YP-CDN. *Expanding Global Access to Affordable Essential Non-communicable Medicines and Technologies: A Next Generation Perspective on the WHO Discussion Paper*. Available at: http://www.ncdaction.org/joint_consultation_with_yp_cdn_redirect. Accessed July 25, 2016.
- Colchero MA, Popkin BM, Rivera JA, Ng SW. *Beverage purchases from stores in Mexico under the excise tax on sugar sweetened beverages: observational study*. *BMJ* 2016;352:h6704.
- Jarvis JD, Kishore SP. *WHO Takes a Big Step to promote Cancer Treatment Worldwide*. *Lancet United States Heal Blog*. Available at: <http://usa.thelancet.com/blog/2015-05-18-who-takes-big-step-promote-cancer-treatment-worldwide>. Accessed August 2, 2016.
- Kishore SP, Kolappa K, Jarvis JD, et al. *Overcoming obstacles to enable access to medicines for noncommunicable diseases in poor countries*. *Health Aff (Millwood)* 2015;34:1569–77.
- Kishore SP, Aisola M, Lopert R, Koney N. *Proposal for the Inclusion of Imatinib Mesylate for the Treatment of Chronic Myelogenous Leukemia in the WHO Model List of Essential Medicines for Adults*. Available at: http://www.who.int/selection_medicines/committees/expert/19/applications/Imatinib2_8_2_A_Ad.pdf?ua=1. Accessed July 25, 2016.
- Balasubramaniam T, Kishore SP, Love J, et al. *Proposal for the Inclusion of Trastuzumab in the WHO Model List of Essential Medicines for the Treatment of HER2-Positive Breast Cancer*. Available at: http://www.who.int/selection_medicines/committees/expert/19/applications/Trastuzumab2_8_2_A_Ad_Final.pdf?ua=1. Accessed July 25, 2016.
- Kishore SP, Shafae MN, Vedanthan R, Reidenberg MM. *An Application to Recommend That Beta-Blockers Be Added to the WHO Model List of Essential Medicines for Heart Failure (12.4) and That the Representative of the Beta-Blocker Class Be Switched to Bisoprolol From Atenolol*. Available at: http://www.who.int/selection_medicines/committees/expert/18/applications/BetaBlockers.pdf?ua=1. Accessed August 2, 2016.
- Byrne A, Vincent R. *Evaluating Social Change Communication for HIV/AIDS: New Directions*. UNAIDS discussion paper. Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaids_publication/2009/20111101_JC2250_evaluating-social-change_en.pdf. Accessed August 2, 2016.
- Kirby T. *Nigeria's bone marrow registry offers new hope to patients*. *Lancet* 2012;379:2138.