Before the Federal Communications Commission

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Protecting and Promoting the)	GN Docket 14-28
Open Internet)	
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Reply Comments of Fred Trotter, of the DocGraph Journal

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Fred Trotter
Founder
THE DOCGRAPH JOURNAL
4414 Rockwood
Houston, TX 77004
fred.trotter+fcc@gmail.com

Table of Contents

Who I Am	3
Executive Summary: The New Digital Divide	3
Further Comments	6

Who I am

My name is Fred Trotter. I am a healthcare data journalist and author. I am also the founder of CareSet Systems and DocGraph journal, a technical blogger for O'Reilly Radar, and co-author of the first Health IT O'Reilly book *Hacking Healthcare*, the most popular book summarizing Health IT topics for Meaningful Use (at least according to Amazon).¹

My work has been featured on NPR, *Wired*, *Forbes*, *U.S. News*, and several other publications. I am deeply involved in the e-patient movement and helping patients improve their own health by their own means. I testified in the original hearings on the definition of Meaningful Use—the standard in the Affordable Care Act for the effective use of electronic medical records—and my work designing the Direct Project has now been formally mandated as part of the Meaningful Use standards.

Executive Summary: The New Digital Divide

Transportation is always a political hot potato. In many US cities, affording a car is a sign of wealth. Investments in transportation never treat all citizens equally. People without money tend to use buses, rail, or other public transportation. While the wealthy and privileged are more likely to afford a car.

Transportation has huge implications for healthcare. People who do not own cars spend lots more time trying just to get to healthcare. It is hard enough to get patients to do the preventative care that is needed to ultimately bring down healthcare costs. People who struggle to get to the doctors office skip "unnecessary" visits like screenings. Transportation ends up being a significant social factor in the quality of healthcare a person receives.

Thankfully we are developing methods to make healthcare more accessible for everyone. The US Government has spent \$24 billion buying Electronic Health Record (HER)

3

¹ http://shop.oreilly.com/product/0636920020110.do

systems for doctors. We have developed and standardized projects like Direct,² which will enable secure identification of providers and patients. The FCC has already been charged with ensuring that rural hospitals and other medical providers have access to broadband Internet with the Healthcare Connect Fund.³ We have modified reimbursement codes to enable doctors to be paid when they remotely treat patients.

Why? We all know healthcare costs are crippling this country. The costs for healthcare under Medicare (mostly for old people, some of whom can no longer drive) and Medicaid (mostly for poor people, some of whom cannot afford a car) are crippling our economy. A central tenet of healthcare reform is to enable treatment of patients in their homes, using broadband Internet to allow for remote monitoring.

Pretty ironic, isn't it? Telemedicine is the solution to our current real-world fast lane/slow lane problem. Using telemedicine, we can get the same high levels of treatment to people no matter if they own a car or not.

But all of these programs, presume an Internet built with net neutrality. If we abandon net neutrality, someone is going to have to pay the fast lane tax for patients who want telemedicine solutions to really work. That means either patients are going to pay, or doctors are going to have to pay.

Having an Internet slow lane will ensure that poor patients will not be able to have video telemedicine appointments (which operate just like streaming video) because their doctors do not have the technical expertise or budget to afford the Internet fast lane. Think I am kidding? Already the Office of the National Coordinator of Health IT(ONC) has seen that hospitals and practices that serve in minority communities are late adopters of healthcare technology.⁴

I am fairly annoyed that Netflix and Comcast have become the discussion hub for net neutrality. When Hillary Clinton travels the Middle East giving lectures to dictators about the

³ http://www.universalservice.org/rhc/default.aspx.

² http://directproject.org/.

⁴ http://www.amednews.com/article/20110214/business/302149967/4/

moral value of having unfettered Internet access, she is not defending the ability to stream "The Walking Dead" without a screen stutter.

We have a name for the situation where the elderly, poor, or people with disabilities cannot afford to have the true benefits of the Internet: The Digital Divide. Without strong net neutrality rules, the FCC will create a new Digital Divide. This time it will not be who can afford Internet Access, but who can afford telemedicine, remote ICU monitoring and other critical functions. Under net neutrality, all broadband Internet users would have equal access to these privileges. I urge the FCC to classify broadband providers under Title II, and to ban blocking, technical discrimination, and paid prioritization with bright-line rules, applicable to both fixed and mobile connections. I have absolutely no confidence in any plan which gives vendors the capacity to "self-determine" what net neutrality means.

More detailed comments follow.

Further Comments

It's easy to understand how Comcast's intentional degradation of Netflix's streaming service would continue to resonate among net neutrality experts. But that is the least important illustration of this problem.

The most important illustration is the creation of a new type of Digital Divide. At first glance, the Digital Divide seems to be getting smaller. The Pew Research Internet Project is the gold standard for considering the Digital Divide. Everyone should be familiar with their work on the topic, here is a short link for a great summary video on their latest results: http://bit.ly/digitalDivideVideo2013.

The good news from the research is that broadband Internet access has become more common for everyone. The bad news?

- The people who are on the "wrong" side of the divide still tend to be poor, black,
 Hispanic, elderly or disabled. This remains a social problem.
- It's getting worse to be on the wrong side of the divide. More and more decent resources are only available on the Internet—for example, most good jobs now only accept applications over the Internet.

My concern is not with the Digital Divide proper, but with the healthcare impacts of the Digital Divide. At least two big problems become apparent when you consider healthcare and the Digital Divide at the same time. First, our healthcare system still does a very poor job of accounting for social determinants of health, and most of these social determinants are connected to the Digital Divide.

We have this expectation that people can deal with a chronic disease, for instance, without considering that they are going through a divorce, or they are stressing in response to a new crappy boss. Not having home broadband Internet access (which is, for better or for worse,

the only kind available anymore) deeply impacts life stressors and life stressors deeply impact health. But that is really just a spin on the original problem of the Digital Divide, which brings us to my second problem.

I design digital healthcare interventions. What happens when digital healthcare interventions are placed in the digital slow lane? Lots of research has shown that people want their healthcare providers to provide help navigating the other social determinants of health.

There is a ton of dry research about this, but I love listening to the incomparable Alex Drane as she frames these issues as "unmentionables": http://bit.ly/Health20AlexDraneRocks.

Alex and I are emblematic of a new breed of entrepreneurs who are trying to use the Internet to improve the lot of everyone online. Not just the rich and privileged. It is becoming apparent that with the deregulation of the Internet there is a new Digital Divide coming, a divide between those who can leverage healthcare resources online, and those who cannot.

The Digital Divide was originally framed as the simple question: "Do you have Internet access?" This first formation of the concept was useful because it makes a lot of productive assumptions. For instance, the question does not make any sense for a person who did not have any kind of personal computer. It presumes that the resources on the Internet were equally available to anyone with Internet access. In many cases, there were specific caveats in place where these presumptions might be false.

Future formations of the Digital Divide concept must become more nuanced. We need to start evaluating what will and what will not be parts of the Internet that represent part of the social good that we expect from online access. Finland, as well as other European countries, have gone so far as to claim that Internet access is a human right. As we start to consider the Digital Divide using more and more radically humanitarian terms, we need to take a moment and stop kidding ourselves by what we mean by this.

And Netflix access does not cut the mustard here.

Digital healthcare interventions are designed to relieve the types of problems that make life unlivable. These interventions will include using the Internet to monitor complex healthcare devices. They will include telemedicine between not only doctors and patients, but patients and mental health professionals, and patients with other patients. They will include innovative audio solutions, social media systems and health focused websites.

It is impossible to overestimate the importance of these digital interventions. The expenses in the US healthcare system are out of control, if they continue to raise unchecked they will cripple our entire economy. The quality of the US healthcare system is substantially lower than other first world countries, despite many of the most modern medical techniques being born in the US. These concepts are already deeply embedded in the policies of the Obamacare healthcare reform efforts. Obamacare has made significant investments in Health IT, spending over \$24 billion on the effort. Health IT investments are one of several areas where Romneycare and Obamacare did not differ.

There is bipartisan support for the simple idea: "We can use Internet-based technologies to regain control of our healthcare system." Make no mistake, the digital interventions that I am discussing are not some pie-in-the-sky business plan. The United States has bet its entire economy that these digital interventions will work.

Obamacare, through its Meaningful Use incentive program, is expecting to create a Health Internet: a new layer of the Internet designed specifically to enable healthcare communications. There are two relevant Internet protocols that have been fundamentally endorsed by the Meaningful Use regulations. The first is the IHE stack, which is a complex "solve it all" approach to healthcare information exchange. The second is the Direct Project, which is a very thin specification detailing how secure email should be leveraged in healthcare settings. Both of these protocols, to varying degrees, are mandated by Meaningful Use. I have written about both of these extensively in *Hacking Healthcare*, but I am far more familiar with the Direct Protocol which I helped design.

Meaningful Use is the standard that Electronic Health Records must meet in order for a doctor to qualify for federal funding. The Meaningful Use standards are released by the Office of the National Coordinator for Health IT (ONC for short). In reality these are two sets of standards, one set that EHR vendors must comply with in order to be able to sell "Meaningful Use certified EHR systems" and then another set of standards that providers must meet once they have purchased a certified EHR. An Electronic Health Record is intended to be a kind of operating system for Health IT operations.

Which is to say that I spend a lot of time trying to predict and guide how the Internet will leverage healthcare specific Internet protocols in order to impact patient care. I wish I could be more confident, given what I have already worked on, in predicting exactly how the digital health revolution will play out, but I do understand common elements of how these new paradigms will work.

Healthcare Protocol	Relies on	Not unlike
Direct Protocol	Encrypted peer-to-peer connectivity	Encrypted chat protocols
Telemedicine	Encrypted peer-to-peer real time video capabilities	Netflix or skype
Remote Medical Device Monitoring	Encrypted, Low bandwidth, low latency, peer-to-peer connectivity	Video Game connections

As we consider these interventions, we notice how many of them are marked by encryption (a legal requirement in healthcare) and peer-to-peer connectivity. We also have specific healthcare related applications that require low-latency and high bandwidth.

Even under the previous net neutrality rules, ISPs have consistently filtered or otherwise obstructed peer-to-peer protocols. Comcast specifically was shown to be interfering with the BitTorrent protocol, and then even more problematically denying that they were doing so through support requests for months.

If ISPs are able to slow down content based on protocols, they will be forced to cripple healthcare related services. There is no way to determine if encrypted video streaming is "The Walking Dead" or a telemedicine appointment with your psychologist. There is no way to tell the difference between encrypted UDP traffic to run Halo, and the encrypted data required to run a home ICU remotely.

ISPs have shown an indication to block traffic that "might" be illegitimate rather than go to the expense to determine what traffic is legal and proper, and which represents inappropriate use. As we invest in Health IT systems running over the Internet, a substantial portion of them will be indistinguishable with other forms of encrypted high bandwidth traffic. For instance, peer-to-peer encrypted WebRTC traffic can be used to stream "The Walking Dead," or it can be used to stream medical records interfaces and video chat with your physician. If the market can decide who gets priority, we can be certain that the rich and privileged will be able to afford reliable telemedicine services, but the poor, who need them more, will be unable to use telemedicine features because of unreliable ISP service.

Already the Office of the National Coordinator of Health IT (ONC) has seen that hospitals and practices that serve in minority communities are late adopters of healthcare technology. As they strive to solve that adoption problem, they are presuming that the patients that attend those hospitals have access to the same Internet that everyone else does. As the ONC strives to convince hospitals in minority and underserved areas to adopt this technology will they also need to explain that they need to ensure that they pay for priority access to the Internet?

Already, many healthcare providers shun Medicaid insurance.⁵ Medicaid is for people who are at or just above poverty levels of income, and with Obamacare Medicaid is expanded into a massively important component of universal healthcare. Healthcare providers who do take Medicaid learn to avoid any unneeded expense. All indications is that they would never

⁵ http://www.kevinmd.com/blog/2013/11/physicians-hesitant-medicaid-patients.html.

choose to get "fast lane" access to the Internet, even if providers who avoid the terrible margins of Medicaid do elect to pay in to a fast lane program.

The ONC is hardly the only organization that has been charged specifically with ensuring that telemedicine works effectively for patients everywhere. The FCC has already been charged with ensuring that rural hospitals and other medical providers are given access to broadband Internet with the Healthcare Connect Fund.⁶ Will the Internet connections funded under that program be assured access to the "fast lanes" of an Internet without net neutrality? Or have taxpayers been duped into subsidizing "mere" Internet access for these telemedicine programs?

It is easy to model hospitals as "big business", but most hospitals in the US have razor thin profit margins. The belief that doctor groups and hospitals will need to buy priority service in order to provide telemedicine and device monitoring will do little but ensure that telemedicine and device monitoring are rare. These costs will ensure that smaller practices and smaller hospitals are not able to light up the types of services that their patients need. In many cases, these smaller hospitals and practices provide the majority of care for patients who are poor, minorities, or people with disabilities.

ISPs simply do not provide phone-based service to their customers. Their business model relies centrally on not taking calls and when they do receive calls they provide levels of expertise that are incapable of articulating the types of issues that patients will encounter in the slow lane. I have called both Time Warner and Comcast multiple times about latency related problems and have spent the vast majority of time speaking to support staff who have no idea what network latency is or how you measure it.

Netflix has a very different relationship with Verizon. The majority of the conversations between Netflix and Verizon are between high-level network engineers on both sides. Netflix is in a position to precisely measure, and critique the performance of Verizon's network. Google is in a similar position with its video-based services.

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⁶ http://www.universalservice.org/rhc/default.aspx.

The average hospital in the United States outsources all of its network connectivity. Not unlike the average consumer, they rely heavily on the support from their ISP to ensure that their connection to the Internet is functional. They are struggling with the portal and health information exchange requirements in Meaningful Use (both of which require them to offer Internet services of various kinds). In general the IT resources available to the average group practice are less than those available to a hospital. There will be no engineer to engineer debugging of the Internet for healthcare protocols.

This is best understood as a question: "If either the doctor or the patient must pay for access to the Internet fast lanes, which one of them will do it?" And further "Which doctors and which patients will be unable to afford Internet fast lanes?" The answer is simply: "Those that are already on the wrong side of the Digital Divide specifically, and social justice generally".

We come to the end of the argument progression: The Digital Divide is getting narrower but steeper, there are fewer on the 'wrong' side but life is getting worse and worse for those few. Our country is betting on digital health interventions working to rescue our economy but this model relies on consistent connectivity between consumer grade doctor ISP connections and consumer grade patient ISP connections. If we allow for the creation of Internet "fast lanes" we will force at least some patients and doctors into the slow lane. This will deepen the Digital Divide and significantly damage the healthcare reform efforts that are designed to rescue our country's economy.

To put this in perspective. It costs roughly \$70k for an end-stage-renal-disease (ESRD) patient to get dialysis for one year under Medicare. Specifically, Medicare covers 507,326 ERSD patients for a total of \$34.3 billion.⁷ For most of these patients, estimates of million-dollar expenses are not unreasonable. But then ESRD patients are usually just diabetes patients who could not get their diabetes under control. The average costs for a diabetic patient are vary between \$124,700, and \$54,700 depending on how long you have to live with the disease.

12

⁷ http://www.usrds.org/2013/view/v2_11.aspx.

So the costs to the healthcare system for finding a pre-diabetic patient and preventing them from becoming diabetic and/or ESRD are substantial in just dollar terms, without considering the patient's experience at all. Thankfully, I have never been an ESRD patient, and rather than try and have the ignorant educating the ignorant, I will just link to a single slice of the ESRD experience: http://bit.ly/newESRDPatient.

The future I want to avoid is this. A doctor has made a referral to a dietician to consult about some food choice changes that might help a patient (let's call her Debbie) to control her diabetes. The dietician and Debbie make a telemedicine appointment without understanding that the dietician (who works from home) has not paid for the fast lane from her ISP. Debbie and the dietician give up on the telemedicine appointment because they just cannot understand each other talking, much less the YouTube video that the dietician was planning on sharing. Debbie asks her doctor for an in person referral but cannot make an appointment because the new dietician lives an hour away... Debbie chooses to do nothing. In year she will develop diabetes, in 10 years she will lose her foot to infection. In 15 years she will enter ESRD, which will kill her 20 years after she failed to get the video working with the dietician. Of course she will miss her granddaughter's wedding ceremony which will take place 30 years after the flaky video call.

You can see, I hope, why I get annoyed when people talk about Netflix and net neutrality.

Of course I chose a dramatic example with Debbie. But recognize that in the healthcare system, patients traverse from provider to provider in a very unorganized way. Obamacare intends to fix this through the use of what former ONC Farzard calls "flight plans."

Debbie's healthcare flight plan relied on the Internet functioning in a way that it has, under rules which guarantee net neutrality. I spend just about all of my time now thinking about

⁸ http://www.ajmc.com/publications/ajac/2014/2014-1-vol2-n1/four-key-technologies-for-physician-led-accountable-care-organizations.

how to use technologies to fix healthcare flight plans, and a tiered Internet simply does not fit

into those plans. I need to be able to predict that systems that I build for provider-patient,

provider-provider and patient-patient communications will work seamlessly into the far future.

Let's make Debbie into a litmus test. I have contributed to a suite of healthcare protocols

that would enable:

Debbie and the dietician to share a HD telemedicine video connection

Debbie to share her heart rate monitor with her dietician using a low latency

connection in near-real-time.

All encrypted and peer-to-peer without connecting to any central server to protect

Debbie's privacy.

If Debbie and her dietician cannot accomplish this because either one of them cannot afford the

"fast" lane service, then the FCC will have created a new healthcare Digital Divide by

abandoning net neutrality that will cost millions of dollars and untold human suffering.

Make no mistake, this country cannot afford this. Moreover, if the FCC endorses a policy

making this possible, it will clearly be the result of them respecting lobbying dollars over the

health and wellness of the American people. I urge the FCC to classify broadband providers

under Title II, and to ban blocking, technical discrimination, and paid prioritization with bright-line

rules, applicable to both fixed and mobile connections.

I have committed to providing a joke at the end of all commentary submitted to the

federal government, in order to show my sympathy for the poor guy who has to read all of these

comments without a break. I appreciate your service to your country... I couldn't do it.

What did the cat say when it accidentally stumbled into a time machine, went back in time and

met its younger self?

Are you kitten me?

Source: some guy's daughter on Reddit.

14