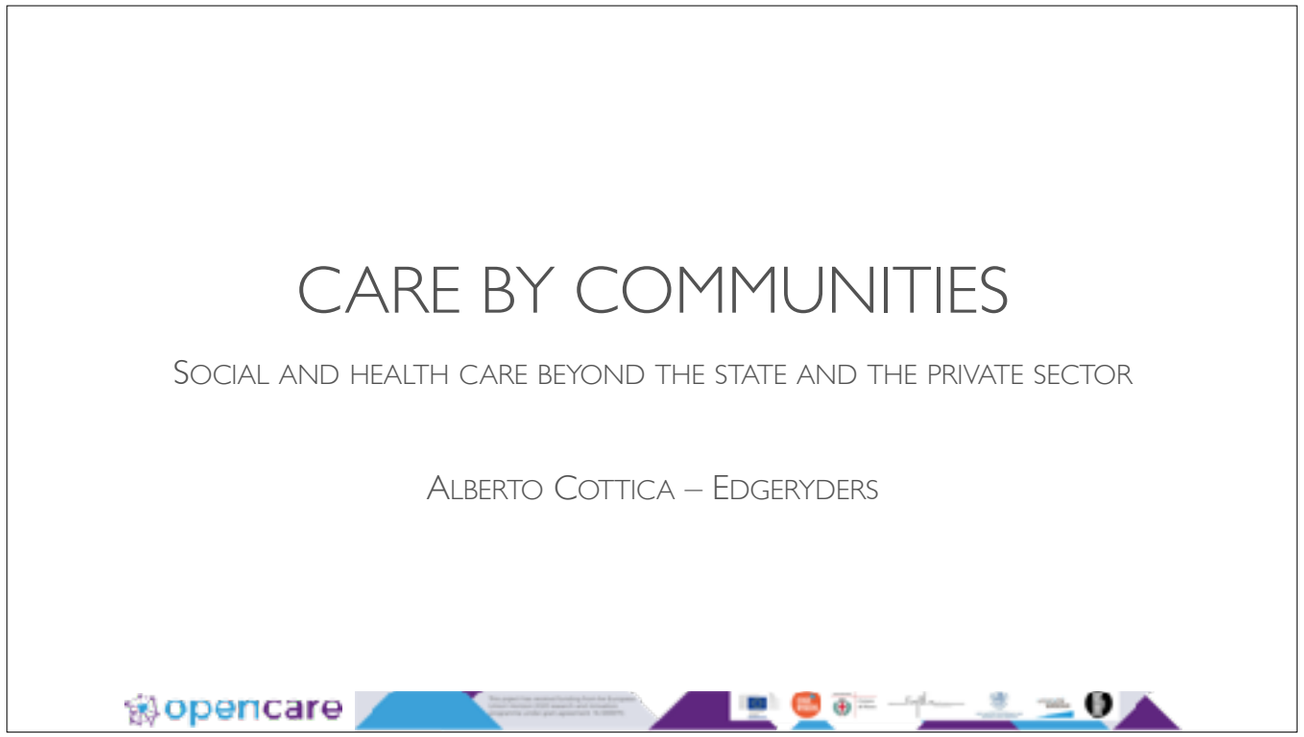
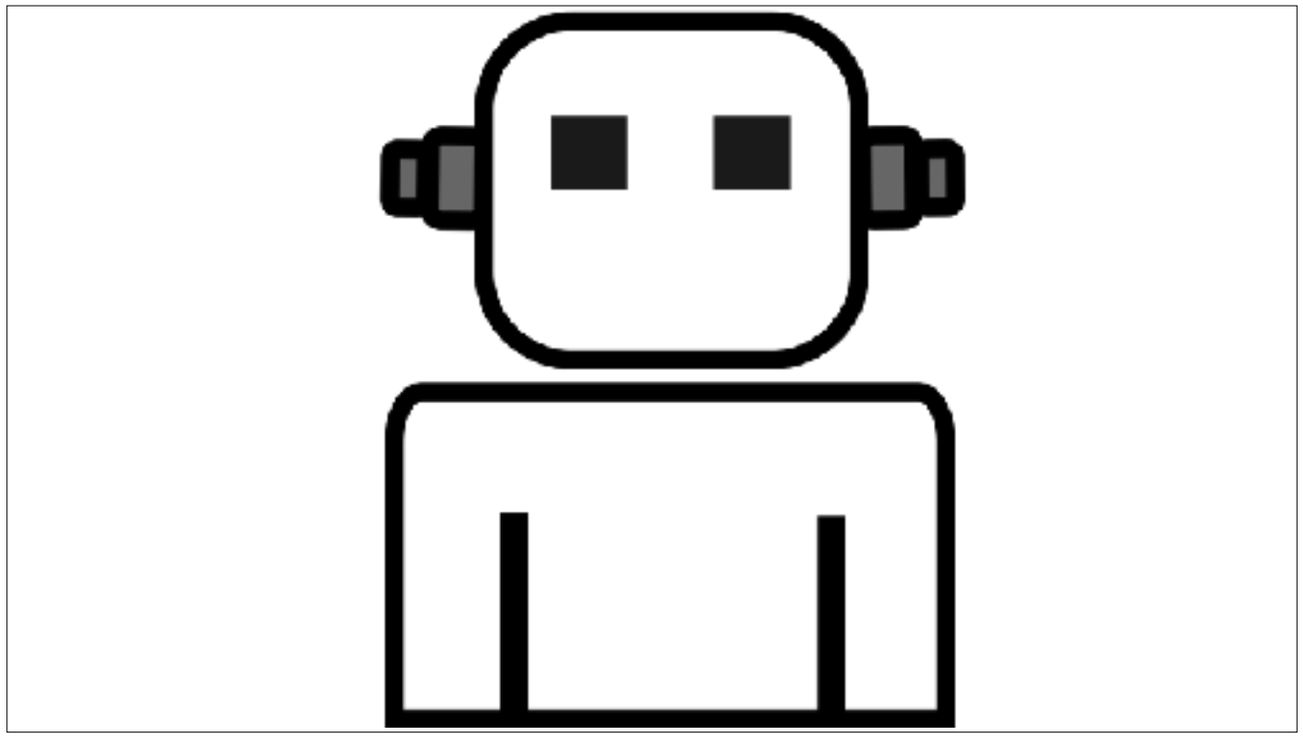


Hello all, my name is Alberto. In the past 18 months, my team and I have been working on a project called OpenCare. It turned out to be a journey to the edge of society, where system break down and people suffer, or die, and so they have to do something about it. I am here to tell you what we learned, and reflect with you on what that might mean for all of us.

Let’s start here. You’ve all seen this: health care costs rise faster than GDP. This trend cannot continue indefinitely, because we cannot spend more than 100% of our resources just to stay alive and well. But it has been proven difficult to curb it. The reasons for that are complex, and I do not want to go into them here. I only need to tell you one thing about it. This: there is no central decision behind this trend. It’s not WHO, or some Big Pharma cabal. We cannot simply make a law to stop it.
So what do we do?



Well, you guys are innovation people, so you naturally think about this in terms of innovation. Maybe we could do something with sensors? The Internet of medical things? How about 3D printing? The blockchain, maybe? These are wonderful shiny technologies, they seem to get results in many areas, maybe they will get results here too. So, this is what this problem looks like from this room.

118,000,000

Individuals at risk of poverty and social exclusion in the EU (Eurostat)

But we, in this room, are not representative, even for wealthy countries. Let me ask you a question: hands up those who live in a household with at least two people, and the sum of the income across all household members is less than 15,000 Euro a year. Well, that's 118 million people, or 23.8% of the population. In Europe!


Photo: Paul Lucas on flickr.com

For those guys, the graph I showed you in the beginning looks like a literal life threat. As health care systems try to contain their unsustainable growth, they see system failure. And it’s not so different whether the system is mostly a national health service or a health insurance market. What they see is that the conditions for access to care get steeper and steeper. National health services lengthen the waiting queues, or make access contingent to certain types of employment. Insurance markets raise premiums, try to screen out anyone who might actually need a little more help than others, and lobby Congress to kill anything that provides protection for the less affluent. This is serious, people: if you have diabetes in the United States, your diabetes costs more than your mortgage. It is your number one expense. They can’t get in, but they still get sick. What to do?

Here’s what they are doing: they are trying to come up with their own systems, bypassing both the state and the private sector. A few examples:

Here’s what they are doing: they are trying to come up with their own systems, bypassing both the state and the private sector. A few examples:

This is the pharmacy at the Metropolitan Helliniko community clinic, on the outskirts of Athens. Free health care for the Greeks that have no access to the public system. No incorporation: this is not an NGO. It’s unemployed people using their time to take care of each other, with some voluntary help from a number of doctors (150 + 150 doctors) They don’t touch cash. They work out of a building that the Helliniko municipality was not using. Provides free medicines, baby food and nappies. Got into a fight with the European Parliament about European Parliament European Citizen's Prize 2015, but they very publicly turned it down. Reason: "Europe is an important cause of the problem we exist to address. Don't give us awards, change your policy”. No management or bureaucracy, they work through a Google Group. 40,000 treatments issued 2012-2015. We have news of 68 similarly organised clinics in Greece.

This is Gent, Belgium. These guys run a biohackerspace called ReaGent. They are working with two likeminded crews called Counter Culture Labs in San Francisco, USA, and Biofoundry in Sidney, Australia, to devise an open source system to make human insulin. Anthony Di Franco started this in San Francisco. He is himself type-1 diabetic. His insulin is expensive, and will stay expensive because of patent strategies. The San Francisco crowd managed to make a proof-of-concept precursor of insulin called proinsulin using a genetically modified bacterium. In Gent, they are working on validating the results and improving the efficiency of the “last mile”, where the precursors bond and result in actual insulin. These guys cooperate globally by sending genetically modified bugs to each other’s basement, and they coordinate via Skype.

Photo: Matthias Ripp on flickr.com

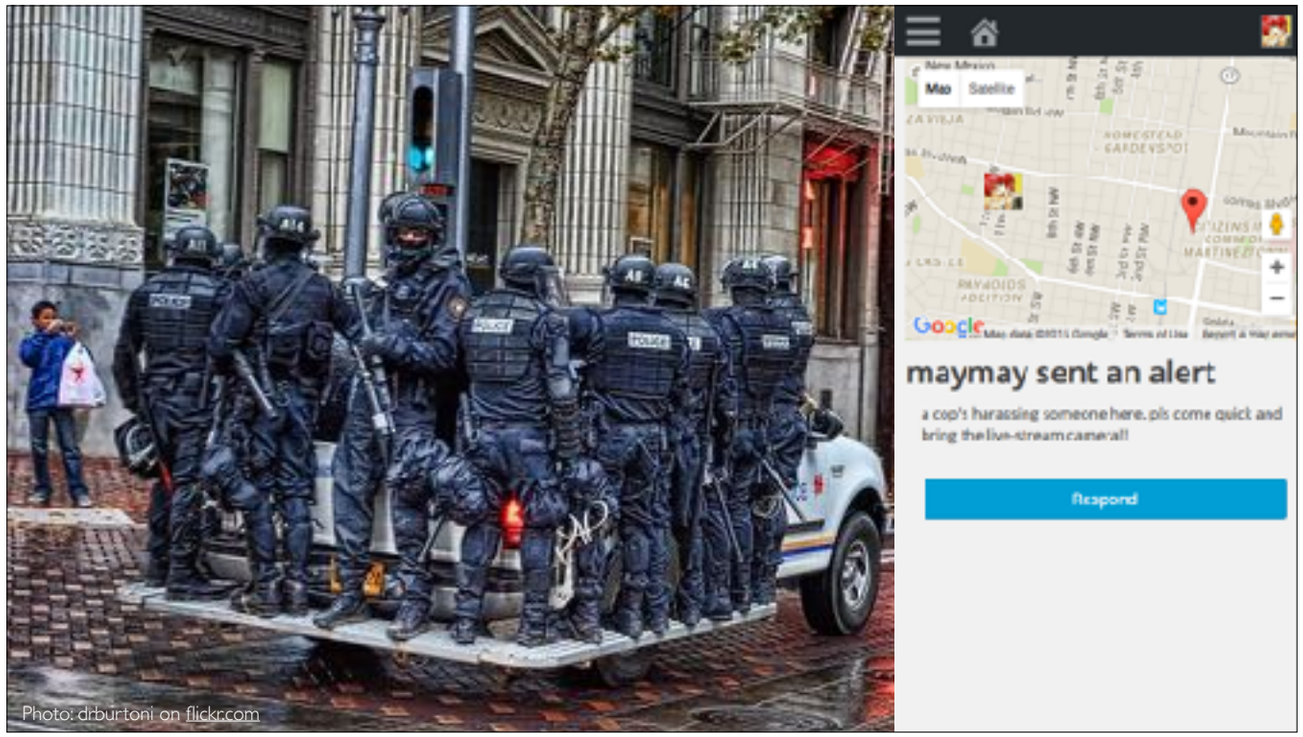
Romania. The health care system got seriously dysfunctional after 2009, for reasons that we will not go into. Part of the dysfunctionality manifested as a complete disappearance of a category of drugs called cytostatics. These are life-saving drugs, used in treating blood cancer. They are normally quite cheap, but were not available in Romania. A young economist living Vienna called Vlad Voicolescu set up an underground network that bought cytostatic in Vienna and elsewhere in Europe and smuggled them into Romania, in the private luggage of ordinary Romanians traveling abroad. This was technically illegal, but people took the risk: it was that, or people had to die. At Bucharest airport, the couriers of the Cytostatic Network were met by a taxi driver called Valeriu, who took point in delivering the drugs to the people in need. Voicolescu was later appointed minister of health of Romania.

Photo: Alex Levene

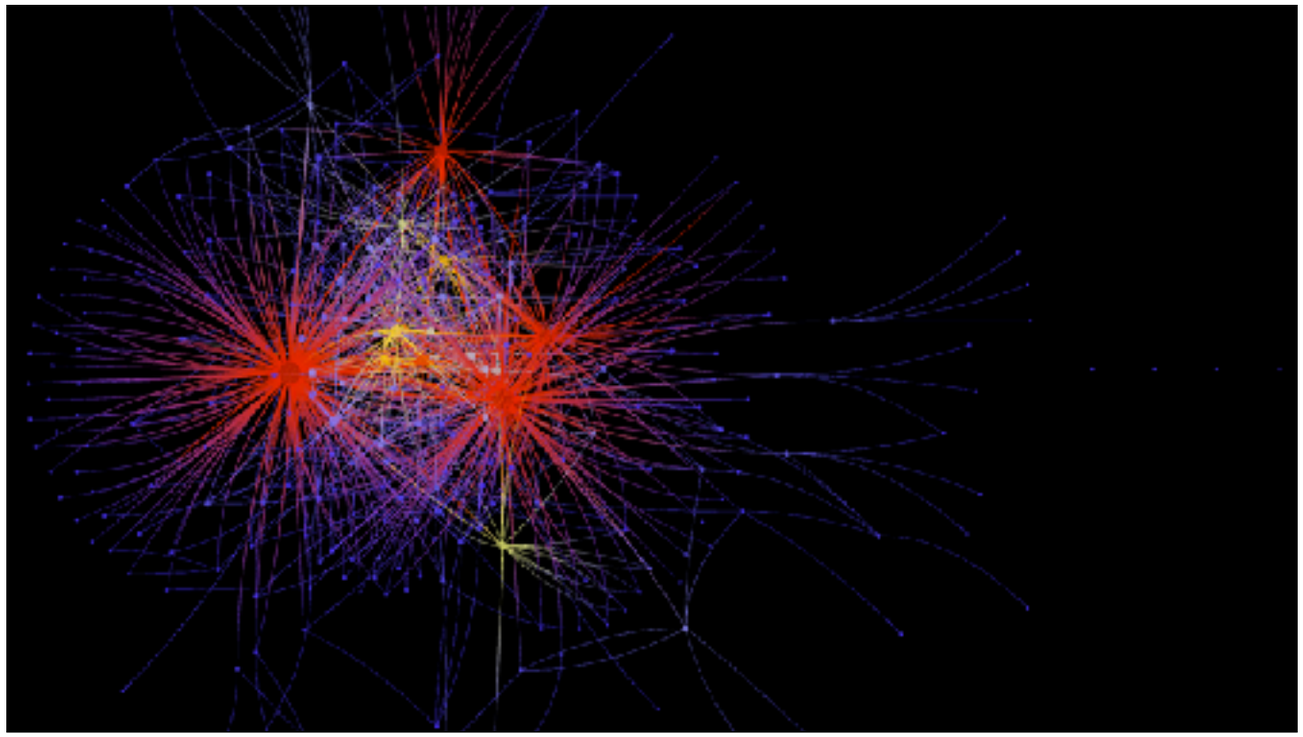
Even the people that appear most desperate show substantial initiative. This picture was taken a year ago at The Jungle, the infamous massive semi-official refugee camp in Calais, in the north of France. It hosted predominantly Syrians, Pakistani and Afghans who wanted to go to the UK, but could not get past the Channel and got stuck. At its largest it was home to 6,000 people, including hundreds of unaccompanied children aged 12-16. At one point, the French police was sort of OK with people taking materiel into the camp. And by God, did people build! Community kitchens. Small businesses providing things like SIM cards. Informal restaurants, like this. Even a library and a theatre. Then the police changed its mind. The building stopped. And then they evacuated it, and that was that.

credit: Marie Moe, "Unpatchable", 2015

We met Marie Moe at a hacker conference in 2015. She is an information security analyst, used to work for the Norwegian intelligence, now into academia. She has a heart condition, and was implanted a pacemaker. After an incident, she realised that the pacemaker's software had bugs. And that the bugs were unpatchable, because the code is proprietary. So she mobilised the infosec community into auditing medical devices from a security point of view. The effort is ongoing: I can tell you already that medical devices are not very secure at all. There are quite some horror stories. In fact, to pursue this work Marie had to switch jobs: as an intelligence officer, she could have been hacked by adversaries, who could literally have stopped her heart, because the Bluetooth link to her pacemaker is vulnerable.



This is a project called Buoy. Here's the idea: you are walking home after a party, late at night, and notice someone is following you. What are you going to do? Are you going to call the police? The police are not going to come, unless a crime is committed first – in other words, *after* you have been mugged. Or raped. Also, the Buoy crowd is in America. Many are black. They *really* don't trust the police. So, the idea is that people would cluster into "response teams": I am in your team, you are in mine. When one of us is in danger, she thumbs a big red button on the Buoy app, and the whole team receives a geocoded emergency signal.



You get the idea. We collected hundreds of these stories in the course of OpenCare. And we asked ourselves: what do they have in common? Are there patterns to community-based solutions? So we invited people running these initiatives, and anybody else who was interested, to compare notes on the edgeryders.eu platform. We ended up with a very large scale online conversation: at last count we had 280 participants from all over the world, about 500 posts and 2,500 comments, 600K words. This was a dense conversation: I'm showing you the interaction network, where dots represent people and arcs connecting them represent interactions.

IT'S ALL ABOUT HUMANS

We processed this body of data using a method we call semantic social network analysis. I wont talk about it here; if you are curious hang around for the presentation by Guy Melançon and myself later in the day. One thing we learned is this: it's all about humans. The people who are driving community care consistently reach for…more people. Better prepared volunteers. Practices that prevent them from burning out as they go about their very difficult work.

Take a moment to consider this. These people believe they are part of the solutions. We believe that too. Their work is, frankly, intimidating. They run rings around institutional and corporate actors. And what do they want? They practically *never* say they need more technology, more blockchain stuff or IoT stuff. In fact, in some cases they are working to fix the mess left behind by innovation in care. Innovation by the private sector, like the vulnerable pacemakers; innovation by the public sector, like the procurement arrangements that run the risk that pharma will simply stop delivering life-saving medicines. So, as you consider your next moves, I would encourage everyone here to stop and wonder. Will what you are planning to do help these people do what they are trying to do? Or will it incapacitate them, as you drive a solution incompatible with their activity? Me, I stand with Maria in Helliniko. Winnie in Ghent. Vlad and Valeriu in Bucharest. The entrepreneneurial refugees of The Jungle. Marie, in Trondheim. Mey in New York City. And the many unsung heroes we met in Opencare. I am looking forward to find out where this "care by community" strand goes.