



OSP3: 3rd Global Open Source Pharma Conference

Science, License, Community

March 21st - March 23rd 2019
Centre de Recherche Interdisciplinaire (CRI)
Paris, France

Crowdsourced Notes and Ideas from Participants

This document contains:

- 1) [Crowdsourced notes from participants on the sessions and discussions, including 3 bears \(Section 1\)](#)
- 2) [Concrete examples of OSP \(Section 2\)](#)
- 3) [Ideas from participants to pursue in the future \(Section 3\)](#)
- 4) [Great lines: lyrical, funny, poetic or otherwise notable lines uttered at the conference \(Section 4\)](#)
- 5) [Conference feedback](#)

Section 1: Crowdsourced Notes

March 21st 2019

Three Bears IceBreakers

Lounge | 12 - 2 pm

Three Bears:

- 1) Think of one small, medium, and big sized idea for OSP.
- 2) Write your name below with your 3 ideas.
- 3) Discuss them in the CRI *Lounge!*

Bruce Bloom

- 1) Big-Hold the OSP4 meeting in 1-3 years at the World Economic Forum in Davos and have at least 3 key leaders from finance and/or government as OSP Forum organizers and funders and ask them to bring in significant additional funders and participant



- 2) Medium-Start OSP groups in every country that can begin to implement the Global OSP strategies from OSP3 and develop their own local OSP strategies, which can then be shared with other country based OSP groups
- 3) Small-write a manuscript with all of the authors being participants at the OSP3 that is published in a reputable peer reviewed journal, and then get parts of it in the lay press

Samir K Brahmachari

- 1) Small— Campaign for MDR TB Drug to be licensed to generic companies to make it affordable—Lawyers to work.
- 2) Medium— Extend OSDD to build a System Biology model for Host Pathogen interaction for TB— Engage students across the world and crowdsource knowledge— Lead by Anshu, Jaleel, & others with guidance from older/ experienced System Biologists.
- 3) Big— Move all open source drug discovery leads for TB to preclinical and clinical trials by putting global resources.— Lead by Jaykumar, Mathew, Bernard & others including TATA trust.

Peter Kolb

1. Big: start a(nother, counting OSM) concrete project to find a drug - learning by doing.
2. Medium: define for which disease areas OSP might work and for which it might not
3. Small: decide on a date for OSP4

Matthew Todd

1. [Big. A funding model incentivizing major investment in open source projects that guarantees a return on investment.](#)
2. Medium. Gather 5 new people together interested in creating Open Source Antibiotics
3. Small. Get OSP on Redbubble! Stickers → revenue!

Mostapha Benhenda

1. Big: Build a “Health-centered economy”: including the transition of the Pharma industry towards open-source and 100% tax-funded R&D. Raise healthcare spending to 50% of the GDP (<10% currently in Europe), mostly for R&D, spent on incentives for various global crowdsourcing R&D platforms. Humanity should collectively spend their wealth on their health.



2. Medium: Build a grassroots movement to support this transition to a “Health-centered economy”, as the big Pharma lobby is opposing this disruption. Connect with related movements across the world (like [Medicare for all](#)). Encourage citizen science and education, with the message: “Learn about the Pharma science and industry, before/after you get screwed by big Pharmas”.
 3. Small: Draft a [roadmap](#) for efficient public spending on Open-Source Pharma (budget: ~\$1Trillion/year), send it to a left-wing newspaper (the Guardian, New York Times...) and send it to the staff of [politicians](#) who could endorse it, and align their agenda with it. Here is the [draft](#), and here is the list of [potential politicians](#).
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OSP 3 Welcome Address

Learning Centre | 2 - 2:30 pm

Ariel Lindner - Welcome to CRI

Jaykumar Menon - Welcome to OSP3 and Thank You!

An Introduction to OSP

Learning Centre | 2:30 - 3 pm

Bernard Munos

What is OSP? What is its history and its future?

Participant Introductions

Learning Centre | 3:00 - 5:00 pm

All participants present themselves to OSP3.

Three Urgent Questions

What are the most important questions you'd like to discuss?

Learning Centre | 5:00 - 6:15 pm

Matthew Todd



Please feel free to contribute thoughts to the below as the session goes.

1. Who will invest in OSP?
2. How come nobody will take your idea and run with it?
3. Voted question by participants. *Please write your ideas, or add your support to others, below.*

MT: Do we have to limit ourselves to investors who do not want a return?

Keith: We need collaborative networks, this works for OS software.

MT: We have had in-kind contributions from pharma, but never money.

Amanda: Linux Foundation assets of > 50M USD. Companies first feared LF, now they give big money. Why? It's in their interest. They saw this as a way to become more efficient & attract devs. Can consume what LF produces. Money buys them a seat at the table for governance. IT and pharma are different, however. 20 years for this change to happen. Monetize services, network equipment. Lot of advantages in sharing the resources.

Keith: Pharma example. 2013: trans?? Foundation. Facilitating translational medicine. In areas that they consider pre-competitive. We have to find areas that are precompetitive.

Gelbhart: You need to access the correct one.

BP BIG Question 3: How do we ensure maximum collaboration within the OSP community, and more importantly, avoid duplication of efforts, particularly in the evaluation of OS mechanisms?

Big question: At a technical / scientific level, how can we make a convincing argument that an open source approach is as efficient / more efficient than a market-driven pharma approach to any given problem?

Building an advocacy kit which would support open source pharma evangelists in their respective environments would be a very valuable asset for the community. There might be versions for people in academia who are reluctant to go open, and versions for pharma which would put the emphasis on the fact that it might be very compatible with their business interest to go more into OSP.



Lessons Learned: Perlara Orphan Drugs

Learning Centre | 6:15 - 6:30 pm

>> I was very interested to hear about Perlara, and that a Public Benefit Corporation was able to attract institutional investors. The story is cautionary though, as one of the initial investors reneged on a licensing deal, and caused the company to go into default. I wonder if the lesson is to not rely upon institutional investors to fund a public benefit corporation, but rather to appeal to social venture capital, government and non-profit sources of capital that are better aligned with the mission. Nice quote though “Don’t run outside of your headlights..”

- Keith Elliston

Evening Reception

Learning Centre | 6:30 - 7:30 pm

Day 1 Words of Thanks

Invitation to join us at **Frog Revolution**

March 22nd 2019

Breakfast and Unveiling of Art Installation

Lounge | 8 - 9 am

Eric Anderson

Welcome and Recap

Amphitheatre | 9 - 9:15 am

Liesl/Prateek/Peter: three basic points we were discussing yesterday evening:

- Do we need a single model that fits all disease areas or are there certain areas where we could already work today because the boundary conditions are somewhat different.



- Depletion of chemical space: how can we make sure we channel the massive efforts going on in academia and not just waste these
 - Is pharma like Coca Cola, which worries about distribution and not development. What role could marketing play in maintaining market share even without exclusivity?
 - We are talking a lot about “money in”. What are the strategies for “money out”? Advertising?
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Session: Open R&D: Across The Stages

Amphitheatre | 9:15 - 10:45 am

Matthew Todd - Open Source Malaria (moderator)
Tomasz Sablinski - Transparency Life Sciences
Sitta Sittampalam - National Institutes of Health (NIH)
Nadine Bongaerts - CRI
Bruce Bloom - Cures Within Reach

- Need to lay out the cost of each stage of the clinical trials - breakdown of Tufts \$2.6B
 - Colin Pillai: Less than 2% of the world’s clinical studies done in Africa - why aren’t we moving research there?
 - How can PDP put site analyzation in public domain?
 - How to change the mentality of trialists to become more open
 - Tomasz: Clinical trials can be professionally done with regulatory standards at a much lower cost - human labour most expensive - if we can digitize certain things
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Session: Open R&D: Across The Stages

Amphitheatre | 10:45 am - 12 pm

Bruce Bloom - Cures Within Reach (moderator)
Alice Motion (Williamson) - University of Sydney
Anshu Bhardwaj - CRI
Samir K Brahmachari - Open Source Drug Discovery (OSDD)/ AcSIR

Mat T: Alice is talking about [Breaking Good](#), funded by Google Australia. It builds on a [pilot with Sydney Grammar School](#) that involved the synthesis of Daraprim, the medicine that was price-hiked by Martin Shkreli’s company Turing pharma. Alice and I are interested in working with people who would like to empower school students, or



junior undergrads, to make molecules that are part of real research projects, open source. In the UK I'm in touch with [IRIS](#) and a couple of schools.

Question: can students tinker in their own time. A: not really, it's chemistry. But how could we do that more? In silico, gamification.

Breakout Session: Cluster Group Discussions

[Place des Vosges](#) and [Quais de Seine](#) | 1:30 - 2:45 pm

Participants break out into small groups (5-8 people/group) on various themes that are detailed below (45 minutes), and then summarize in plenary session (30 minutes)

Cluster Group Themes:

1. Computational Drug Discovery
2. Pre-Clinical Drug Discovery
3. Clinical Trials
4. Incentives
5. Funding Sources
6. Business Models
7. Intellectual Property
8. Modes of Organisation
9. Collaboration
10. IT Infrastructure
11. Citizen Science
12. Other

Computational Drug Discovery Group Discussion Notes

Crowdsourced Preclinical Drug Discovery Group Discussion Notes

Clinical Trials Group Discussion Notes

Funding Sources + Business Models + IP Group Discussion Notes

Linda: Interesting (and sensible in my view) that these three groups coalesced into one. It is hard to talk about IP or funding or business models each in isolation because these topics are interrelated and context dependent. One idea that came out of the group discussion was the possibility of creating a rating or accreditation system for OSP that would be used to classify various drug development efforts according to how well these efforts align with the principles of OSP. Rather than ranking the drugs themselves, the ranking could be applied to the nonprofit and for-profit entities by evaluating their drug portfolio. Such a ranking system could give OSP greater visibility and potentially influence investment in non-profit and for-profit entities by investors who value the



principles of OSP. A possible model would be the Access to Medicines Index (<https://accesstomedicinefoundation.org/access-to-medicine-index/results>)

Collaboration Group Discussion Notes + Motivations and Incentives Group Discussion Notes + Modes of Organisation Group Discussion Notes

Alice: One of the main discussions was focused on the necessity for a 'platform' that helps to unite OSP efforts and hosts project/information and helps us to collaborate and prevent duplication within our community.

IT Infrastructure Group Discussion Notes

Citizen Science Group Discussion Notes

Panel Session: OSP Business Models and Sustainability

Amphitheatre | 2:45 - 4:00 pm

Benjamin Perry - DNDi (moderator)

Bernard Munos - FasterCures

Guy Rouleau - Montreal Neurological Institute and Hospital

Ellen 't Hoen - Medicines Law and Policy

Stephen Friend - Sage Bionetworks

Ellen: multiple kinds of non patent exclusivities, of longer duration

Many top selling drugs have orphan drug designation, which gives one exclusivity over the entire disease space

"Curing patients is not a sustainable business model."

"Delinkage" was an approach recommended by the UN High Level Panel on Access to Medicines.

Ellen- -pilot delinkage maybe on antibiotics and TB (MDR), WHO could be platform on negotiations, or just move forward with a coalition of countries. New Innovation Hub started at WHO tefros DG

Bernard--laser, internet founders--very difficult to know what form it will take

Guy Rouleau. M4 model. For-profit companies held by a trust (Agora). No patents. Exclusivities.

Exclusivity on all the data used to file for an IND. Commitment to affordable pricing. 1st company is M4K Pharma. Virtual company, started with \$ from government and disease associations. In preclinical.

Now M4ND is for neurological disorders. 1st project Parkinsons. Krembl foundation.



Now starting two other projects.

Ben Perry, DNDi. Partnering with Atomwise, an AI company, who are contributing for free. DNDi developed fexinidazole, recently approved for sleeping sickness (Els Torreele spoke about this in OSP2).

Bernard - the current pharmaceutical system will never produce affordable drugs. It will produce the same number of drugs as it did 30 years ago.

OSP & Education: Nobel Laureate Lee Hartwell

Amphitheatre | 4:30 - 4:45 pm

Panel Session: Blockchain and Open Source Pharma

5:00-6:15 pm

Amphitheatre

- Keith Elliston (moderator) - Open Source Pharma Foundation
- Niclas Nilsson - LEO Pharma
- Paul Kohlhaas - Molecule Foundation
- Bryn Bellomy - Axon

Mat T. Blockchain describing a molecule synthesis, which is immutable. Is this like a patent? Does it obviate the need for the patent, meaning the same thing as a patent, that you can be granted rights in return for public disclosure?

Paul K makes the valuable point that a problem with patents is the question of why people would contribute to patented research when one organisation holds all the value. Can issue bounties for things that are needed in a project.

Geoffrey Siwo asks: what about linking physical resources?



March 23rd 2019

Welcome and Recap

Learning Centre | 9 - 9:15 am

Panel Discussion: Can We Develop an Open License

Learning Centre | 9:15 - 10:30 am

Andy Updegrove - Gesmer Updegrove LLP (moderator)

Linda Kahl - BioBricks Foundation

Keith Elliston - i2b2/tranSMART/ Open Source Pharma Foundation

Andy - Before we talk about licensing, we have to talk about what we're licensing.
"We need Uber for pharma"

There is a huge propensity to ignore the wheel and reinvent the past

Ideas for moving forward:

- 1) List all the projects and contact info
 - 2) Create working/contact groups in several areas
 - a) Clinical trials
 - b) E coli TB project
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Participant Reflections

Learning Centre | 10:30 - 11:25 am

Participants will be asked here to share some insights from OSP3. This can include:

1. What has been learnt?
2. What has been inspirational?
3. What has been motivated to push forward?

Mat: Lens (?) project - The value of maps

- Try to move towards publishing things about these questions
- Turns it into something concrete
- Encourages group to publish something discussed

Hans: how can you tap into this without the funding and money



- How to consolidate different business models
- Can be confusing for newbies
- Have a manual
- Experience of do's and don't - has to be fool proof

Andy: someone to do a paper - landscape of OSP

- Come up with something more coherent
- Would be hugely popular - give people point of departure into the future

Niclas: what should openness entail?

Marc: what kind of material can get?

- OSP is not just something made by enemies of ours/ big pharma

Prof Brahmachari: 4 stages of OSP

- Organization says they want to do something in the open, gets funding from government
- CSR
- Open source software
- Monetizing
- Most critical/difficult part - how do legal people see OSP?
- Need for citizen science

Nadine: how OSP can be more practical/ hands on

- Virtual incubator - visual as drug development pipeline
- Everyone can fit into one part of the pipeline
- Use community to increase visibility and attract investors
- Apart from publishing - need mentors to help us move forward

Anne-Marie: very valuable to publish papers

- In order to get traction - go beyond academic community
- Need people outside of pharma
- Talk to people from other institutions/ consultants - willing to mentor
- Aim for the goal, don't worry about business models
- Get skills you don't have

Liesl: use tools to communicate and traditional routes to speed up process of publishing

Hans: pros and cons of using the tools

- Openness with function of gate keeping



Bruce: if get lawyers involved, could slow process down

- We need to break past what seems impossible

Alice: helpful to have paper about principles we agree to for OSP, and tiering of different types of framing for OSP - blueprint

- Different tiers for organization working as mentors
- Allow to follow different routes with different commitments

Bill: os software is a procedure to solve problem - ultimately the goal

- As a procedure, have people help develop many different procedures - can apply to biology

Andy: Linux was a safe way for OS to grow up

- Purpose was to preserve, promote, protect OS software
- We have many great questions - need to figure out how to preserve, promote, protect OSP to turn this into a bigger reality
- Come up with governance and membership model

SKB: does CRI have legal background to protect openness created

Ariel: CRI - move forward and see where things form

- Is an NGO to get and have building funded
- Researching is associated to university
- Present work to INSERM, passes through evaluation, receives funding
- For students, open spaces to use - grey zone for funding
- The open code is not a religion but a practice
- Should follow best way to license it in best way possible to scale up project

Mat: shouldn't affiliate it to one institution

Andy: one organization needs to show what we mean by OSP

Ariel: need correlation work, safety.. Need an organization to help us do this

- Need to increase membership

Karmen: there are technical challenge - how to collaborate and exchange info

- Legal challenges
- Whoever wants to join can contribute a different skill - no one can do everything A-Z.. find place in the sausage chain



- With OSP3, we can develop shortlist with what identified as challenges and form working groups

Urmi: we can't solve all cases at the same time

- Have small working groups and come up with pilot project
- Do a microblog and twitter to share what we've discussed
- Fund OSP fellowships - recruit to carry out OSP projects

Keith: Linux defined relationship with industry - funding comes from industry

- Experience with big pharma: where did you find compound for drug?
- Pre-competitive research
- Take homes: we have to work on relationship with pharma
- Talk to people about what we're doing and get feedback - will define success

Thank You!

Learning Centre | 11:30 am

Section 2: Concrete Examples

OSP3 is about discussing obstacles to OSP, and also learning about concrete real world examples of OSP and OSP-related approaches. Use this section to share information about these examples. For each one, write a name or identifier, and if you like, a phrase or two to describe the initiative.

- Generics repurposing- e.g Cures Within Reach, Chicago
- Montreal Neurological Institute - pursuing open science approach, institution wide
- Streptomycin story (TB treatment from \$30k in R&D, no patent incentive)
- Generic drug industry generally, more or less
- Young people in open science



Section 3: OSP Ideas

Please share your ideas for OSP or OSP-congruent ideas or projects which *might* have promise:

- TB in Northern Canada:
 - examine health records of those with TB and without TB in far northern Canada, in communities where TB rates are very high. Ontario has fairly comprehensive records. Run computer analyses on them to see retrospectively what drugs may have had an effect of reducing TB. Analog to Scotland cancer approach.
- Crowdsourced/Open Source Pre-Clinical Drug Discovery for TB
 - E- coli
 - Put key TB genes in E-coli, then study the e-coli, which reproduce much faster ,and are safer to study
 - Distribute these kits--all 100 strains of e-coli, broadly, undergrad and grad students can sue them, they are cheap
 - Computational/other
 - One gets the strains/kits, agrees to contribute data/IP back to the platform
- OSP global fund
- Blockchain for OSP
- Anshu: give prestigious fellowships--that institutionalized OSP
- Anshu: API - listing of all the OSP projects
- Amanda: awareness campaign on open pharma issues. Articles/social media/etc. Can provide incentive for others to get involved and industry perhaps to change.
- A gov't wants advice on what conditions to impose on its public money provided for private r&D--e.g affordability etc - Ellen, KEI, and Universities Allied for Essential Medicines could advise
- Accreditation system to define a company's level of openness, to create awareness about OSP and be more concrete on what open entails. (Niclas mentioned an article about Classification of level of openness in Pharma Open Innovation:
<https://www.sciencedirect.com/science/article/pii/S1359644617303458>)
- Related - someone suggested the idea of a ranking system for medicines according to the extent of openness in their development/data. The relevant mark could be trademarked, and hence could act as a revenue stream for OSP. By stealth this is a form of advertising that OSP exists.
- (Ben Perry) A UNITAID style levy on something (where the increased \$ wouldn't make much difference) to raise funds for OSP projects.
- Sitta: Millions of \$\$ worth of useful medicines are discarded every day worldwide. Mechanism to collect and distribute 1) unused, unopened medicines to communities in need worldwide. A model already exists: www.sirum.org 2)



develop a program to validate expired drugs (similar to the FDA SLEP program) to rescue drugs that are discarded following expiry dates initially established by Pharma and regulatory agencies.

Section 4: Great Lines

Great lines; lyrical, funny, poetic or otherwise notable lines uttered at the conference:

- *There's always a point in your project where you can't be lazy anymore, you have to do the work*
- *There are more potential drug molecules than there are atoms in the solar system*
- *The clinical trial system is broken*
- *I know I cannot find the molecule. But I can find the person who can find the molecule.*
- *DRUILIKE! (drug-like molecule)*
- *Pooja Gupta, age 17, wrote paper*
- *Curing pateints*
- *Goldman Sachs: "Is curing patients a sustianable buisness model?: CNBC 11 april*
- *Curing patients is not a sustainable buisnes model*
- *The model to discover drugs is broken - even industry is broken and we need to take them at their word*
- *Cost savings of 90% and time savings of 50% is feasible*
- *When you come out with a powerful idea like this, it is difficult*
- *We need an Uber for Pharma*

Section 5: Conference Feedback

What worked? What didn't work?

Thank you to all participants for joining us at OSP3! And a huge thank you to organisers, partners and sponsors for supporting and ensuring OSP dialogue continues!

Continue the discussion online >> [OSP Forum](#)