



Open PHACTS

Deliverable 8.3.1

Run OPS Workshop 1

Prepared by UniVie, RSC, LUMC Approved by AZ, LUMC, Pfizer, RSC, UniVie

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Definitions

• Partners of the Open PHACTS Consortium are referred to herein according to the following codes:

Pfizer – Pfizer limited – Coordinator UNIVIE - Universität Wien - Managing entity of IMI JU funding **DTU** – Technical University of Denmark – DTU **UHAM** – University of Hamburg, Center for Bioinformatics **BIT** – BioSolveIT GmbH **PSMAR** – Consorci Mar Parc de Salut de Barcelona LUMC – Leiden University Medical Centre RSC – Royal Society of Chemistry VUA – Vrije Universiteit Amsterdam **CNIO** – Spanish National Cancer Research Centre **UNIMAN** – University of Manchester **UM** – University of Maastricht ACK – ACKnowledge USC – University of Santiago de Compostela **UBO** – Rheinische Friedrich-Wilhelms-Universität Bonn AZ – AstraZeneca **GSK** – GlaxoSmithKline Esteve - Laboratorios del Dr. Esteve, S.A. **Novartis** – Novartis ME – Merck Serono HLU – H. Lundbeck A/S **E.Lilly** – Eli Lilly

- **Grant Agreement**: The agreement signed between the beneficiaries and the IMI JU for the undertaking of the Open PHACTS project.
- **Project**: The sum of all activities carried out in the framework of the Grant Agreement.
- Work plan: Schedule of tasks, deliverables, efforts, dates and responsibilities corresponding to the work to be carried, out as specified in the Grant Agreement.
- **Consortium**: The Open PHACTS Consortium composed of the above-mentioned legal entities.
- **Project Agreement**: Agreement concluded amongst Open PHACTS participants for the implementation of the Grant Agreement. Such an agreement shall not affect the parties' obligations to the Community and/or to one another arising from the Grant Agreement.

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1 Introduction

The first Open PHACTS workshop,co-organised by <u>GEN2PHEN</u>, was held in Volendam in The Netherlands on September 19 and 20, 2011. Its main topic was "Solving bottlenecks in data sharing in the Life Sciences", aiming predominantly at incentives for licensing and long term sustainability models for scientific data. The first day focused on tutorials by licensing and sustainability experts and the second day participants boarded traditional Dutch sailing ships and, divided into 3 groups and assisted by the experts, worked in Masterclasses on developing a bullet point licensing/sustainability plan for their own data sources.

2 Aims of the Workshop

The workshop aimed to explore two directly related topics: data sharing (pushing data outwards from its source to one or other online resources) and data access (pulling data from one or other online resources for additional use). The goal is to maximally enable and promote 'open' data sharing, i.e., precompetitive, unencumbered, unrestricted, universally equitable dissemination of datasets generated by academia and (to a certain degree) by industry. Therefore, focus was restricted to datasets that are ethico-legally 'safe' to share, or can be made safe to share by some pre-processing, aggregation, anonymisation or via advanced data access methods designed to protect the data. It is accepted that certain other datasets will not be possible to share in any kind of 'open' fashion.

3 Keynote speakers

Three short presentations by data owners about 'their issues':

- Evan Bolton from PubChem
- Frank Schacherer from Biobase
- Christine Chichester from Open PHACTS

Keynotes:

- "Introduction of IMI Ju" by Ann Martin, Principal Scientific Manager Knowledge Management IMI JU
- "Open Access and Open Source: no free lunch!" by Jan Velterop, Open PHACTS and AQknowledge
- "Open Source licensing and sustainability models for effective data sharing in the Life Sciences" by John Wilbanks, Creative Commons and SageBioNetworks
- "Forms of OPEN Sharing that avoid data disclosure, and methods to make CONTROLLED sharing equivalent to OPEN sharing" by Anthony J Brookes, GEN2PHEN Co-ordinator

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4 Participants

Organisation	first name	name
TopQuadrant (member of SAB of OPS)	Dean	Allemang
Univ. Santiago (OPS Consortium)	Filipe	Areias
Phenosystems (GEN2PHEN)	David	Atlan
European Institute of System Biology and Medicine (EISBM)	Stephane	Ballereau
GSK, Open Innovation	Michael	Barnes
TralT	Jeroen	Belien
AstraZeneca (OPS Consortium)	Niklas	Blomberg
Eli Lilly (OPS Consortium)	Micheal	Bodkin
TralT	Jan-Willem	Boiten
(PubChem), NCBI	Evan	Bolton
TNO	Jildau	Bouwman
University of Leicester (GEN2PHEN)	Anthony	Brookes
Institute Molecular Medicine Finland (FIMM) (GEN2PHEN)	Myles	Byrne
Univ. Santiago (OPS Consortium)	Marian	Castro
Leiden Univ. Medical Center (OPS Consortium) + ConceptWiki	Christine	Chichester
(VIVO)	Mike	Conlon
Eli Lilly (OPS Consortium)	Hans	Constandt
Univ. Santiago (OPS Consortium)	Emiliano	Cuadrado
University of Leicester (GEN2PHEN)	Raymond	Dalgleish
EBI/ChEMBL	Bernard	de Bono
Leiden Univ. Medical Center (GEN2PHEN)	Johan	den Dunnen
Orphanet/Inserm	Ferdinand	Dhombres
Fundació IMIM (GEN2PHEN)	Carlos	Díaz
Bio2RDF, Carleton University, Ottawa, Canada (CWA)	Michel	Dumontier
Univ. Vienna (OPS Consortium)	Gerhard	Ecker
Univ. Maastricht (OPS Consortium)	Chris	Evelo
Karolinska Institute (GEN2PHEN)	Martin	Fransson
Univ. Vienna (OPS Consortium)	Franz	Gatterer
Univ. Manchester (OPS Consortium)	Carole	Goble
San Diego University	Jeff	Grethe
Global Health Equity Foundation	Athol	Harrison
Pistoia	lan	Harrow
Leiden Univ. Medical Center (OPS Consortium)	Rob	Hooft
Leiden Univ. Medical Center (OPS Consortium)	Mascha	Jansen
RSC (OPS Consortium)	Richard	Kidd
Elsevier	Adriaan	Klinkenberg
NBIC	Ruben	Kok
BioSolve IT	Christian	Lemmen
PSMAR	Oriol	Lopez Massaguer
Technical Univ. of Denmark (OPS Consortium)	Ole	Lund
(HCLS,W3C) (CWA)	Scott	Marshall
IMI	Ann	Martin

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University of Aveiro (GEN2PHEN)	Sérgio	Matos
VUMC	Gerrit	Meijer
Fundació IMIM (GEN2PHEN)	Eva	Molero
Leiden Univ. Medical Center (OPS Consortium)	Barend	Mons
Leiden Univ. Medical Center (OPS Consortium)	Albert	Mons
Univ. Vienna (OPS Consortium)	Daniela	Past
Univ. Manchester (OPS Consortium)	Steve	Pettifer
INSERM (GEN2PHEN)	Anna	Pigeon
Novartis (OPS Consortium)	Maxim	Popov
Eagle Genomics	Glenn	Proctor
NBIC	Theo	Reijmers
Univ. Vienna (OPS Consortium)	Anika	Robl
University of Oxford	Susanna	Sansone
BIOBASE (GEN2PHEN)	Frank	Schacherer
Leiden Univ. Medical Center (OPS Consortium) + Sequenomics	Erik	Schultes
IUPHAR	Joanna	Sharman
Univ. Hamburg (OPS Consortium)	Katrin	Stierand
British Library (GEN2PHEN)	Allan	Sudlow
Rijks Universiteit Groningen	Morris	Swertz
Technical Univ. of Denmark (OPS Consortium)	Olivier	Taboureau
Biocomputing Platforms (GEN2PHEN)	Päivi	Tikka-Kleemola
Univ. Amsterdam (OPS Consortium)	Frank	van Harmelen
Science & Technology Experts Pool	Bart	van Mierlo
Erasmus University Medical Center/EU-ADR/CALBC (CWA)	Erik	van Mulligen
(LUMC/BBMRI) (CWA)	Gertjan	van Ommen
Netherlands Metabolomics Centre	Merlijn	van Rijswijk
Leiden Univ. Medical Center (OPS Consortium)	Willeke	van Roon-Mom
Acknowledge (OPS Consortium)	Jan	Velterop
Data Dyrad (GEN2PHEN)	Todd	Vision
Carealliance	Peter	Walgemoed
John Hopkins University	Jing	Wang
Stanford University/NCBO (CWA)	Trish	Whetzel
Univ. Maastricht (OPS Consortium)	Kim	Wiersma
Creative Commons/Sage Bionetworks (CWA)	John	Wilbanks
DataCite (GEN2PHEN)	J Max	Wilkinson
RSC (OPS Consortium) + ChemSpider	Antony	Williams
Pfizer (OPS Consortium)	Bryn	Williams-Jones
CNG Data Sharing	Diana	Zelenika
UBO (OPS Consortium)	Marc	Zimmerman
NMC/NBIC	Gooitzen	Zwanenburg

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5 Summary / outcomes from the Workshop

The meeting was well attended, signalling considerable interest in the topic. This probably also indicates that a kind of a tipping point is being reached regarding the sharing of data as a common and expected activity. This itself is clearly driven by the emergence of -omics technologies and large scale studies, which demand new research business models and data management structures. These things, however, are typically not the expertise (nor the interest) of scientists, but require specific professional knowledge.

A related matter that is tightly intertwined with any consideration of data sharing and data access is that of sustainability of online data resources. In short, how can resources be made sustainable if the primary commodity (the data) are deemed 'valuable' and so often not shared to the online resource in the first place and yet have to be handed on openly (here, meaning 'free') by that resource. These issues were debated in the workshop, but those discussions did not extend to the question of sustaining the data generation activities themselves, nor to enabling the radical further development of online resources. It was felt that sustainability challenges cannot be resolved in a 'silo-ish' manner, and so a coordinated approach to the problem is desired, with exemplar sustainability models being part of the way forward. As part of this, funders need to allocate more money to data stewardship in research grants, but only distribute those funds given evidence of actual delivery on promises (via local or outsourced approaches). Lastly, projects themselves need to realize that starting sustainability efforts cannot be left as a low priority or started too late to be in effect once the lifespan of the project is over.

The results of the workshop will be addressed in a general perspective summary paper or publication, targeting Human Mutation.

The general conclusions will also be used by the participating sponsoring projects to inform future project approaches.