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Contents

Executive Summary.....	3
Introduction	3
Preparation of the UPGx Personalised Medicine Public Day.....	3
Development of the scientific program.....	3
Participants	4
Conference Hall.....	4
Hotel accommodation	4
Catering for lunch and coffee break	4
Local media coverage	5
Endorsement.....	5
Printing material	5
Communication and Advertising	5
Timetable of the organization of the UPGx Personalised Medicine Days.....	6
- Six (6) months prior to the meeting:	6
-Five (5) months prior to the meeting:	6
-Four (4) months prior to the meeting:	6
- Three (3) months prior to the meeting:	6
- Two (2) months prior to the meeting:.....	6
- One (1) month prior to the meeting:.....	6
Description of the 1 st U-PGx Personalized Medicine Public Day	6
Advertisement of the event.....	10
Summary/Conclusions	12



Executive Summary

In this document, we report the organization of the 1st patient/general public-oriented PGx information event in London, UK, as part of the dissemination activities of the U-PGx project. The document describes the approach that has been undertaken for the organization of the event, that includes the selection of the theme of the event and the topics to be discussed in the scientific program and the overall organizational aspects of this event, such as local logistics details of the event, reservation of conference hall, arrangement of catering, setting up of the website and the overall advertisement of the event.

Introduction

The U-PGx Personalized Medicine Public Days are dissemination activities of the U-PGx project, specifically aimed to raise pharmacogenomics awareness mainly among patients and the general public, but also among regulators, and local healthcare professionals about pharmacogenomics and the U-PGx project in particular. These events are different from the U-PGx Personalized Medicine Days that are held in each one of the 7 clinical implementation sites of the U-PGx project and specifically target the general public and patients but also regulators and healthcare professionals, so that they are better informed about the notions of genome-guided treatment modalities and pre-emptive pharmacogenomics, one of the hallmarks of the U-PGx project in order to make the right treatment decisions to improve patients' quality of life and at the same time reduce the overall healthcare expenditure.

Preparation of the UPGx Personalised Medicine Public Day.

Development of the scientific program

The U-PGx Personalised Medicine Public Day is usually a half-day event, organized in the evening so that participation is maximized, usually starting after working hours (~6:00 p.m.) and finishing in the evening (~9:30 p.m). There are approximately 4-6 speakers in the scientific program, most of whom are local scientists in the field of Pharmacogenomics. The speakers should be nationally renowned scientists in the field and with research interests closely related to PGx. The theme of each event is broad and always related to genome-guided treatment interventions.



Participants

The participants of these events are mostly patients and members of the general public. Also, regulators, representatives from payers, national healthcare systems, pharma and biotech companies, and healthcare professionals also participate in these events.

Conference Hall

The U-PGx Personalized Medicine Public Day usually takes place in a conference hall of a centrally located landmark venue that can be easily accessed by the general public and the patients. The capacity should be approximately between 80-150 seats.

Hotel accommodation

Hotel accommodation for one night is reimbursed for speakers that are U-PGx members. For non-U-PGx speakers, one night (for speakers coming from Europe) or two nights (for speakers coming from overseas) accommodation and travel expenses are reimbursed. The communication between the members of the organizing committee and the speakers need to start 6 months prior to the event. The speakers from abroad will stay in a hotel that will be conveniently located close to the conference hall and if it is possible centrally located in the city. Participants coming from abroad need to book their own accommodation directly.

Catering for lunch and coffee break

Three different offers should be sought for catering that includes 2 coffee breaks and light lunch for all the participants during the event. The selected option should offer excellent quality and variety at a reasonable price and should be the best value for money option among the 3 different options. Alternatively, as indicated in the Grant Agreement, if the beneficiary is using the services of a certain (sub)contractor, then the beneficiary needs to be able to show that this (sub)contractor (a) has the best price/quality ratio (needs 3 offers), (b) offers the lowest price (needs 3 offers), or (c) is the usual provider for that service.



Local media coverage

The organizer(s) advertise the event at the local and regional level so that participation to the event is maximized. Usually, the local organizer reaches out to local media, including TV, radio and newspapers and news websites to spread-out and regularly updated information related to the event.

Endorsement

Usually, and in order to maximize visibility of these events, the organizer(s) seek endorsement from various local, regional and international organizations.

Printing material

Printing of the name badges and the scientific program in a pre-determined format is centrally arranged by the Golden Helix Foundation. Preparing folders for participants including the scientific program, notes, pen, and name badge are given to the participants and speakers by the local secretariat at the day of the event.

Communication and Advertising

This includes all the necessary arrangements to promote the event and actively mobilize the local, regional and international partner's network, such as the use of social media, email campaigns, advertisements in scientific journals. Promotional documents describing the objectives of the U-PGx Personalized Medicine Public Day, such as HTML mails, clearly defining the aims of the event, is sent to the local and international scientific community by (a) mass email campaigns to targeted recipients, e.g. involved in pharmacogenomics research and/or attended previous conferences on Genomic Medicine and Pharmacogenomics organized by the GHXF, (b) ads in social media, such as Facebook, Instagram, LinkedIn, etc. (c) international scientific journals, such as *Public Health Genomics*, the official journal of the Genomic Medicine Alliance, (d) leaflet distribution to participants in related international conferences, (e) raising awareness about these events by lead partners during their presentations in conferences that they participate/lecture (e.g. as a concluding slide in their presentations), (f) engaging the invited speakers (both U-PGx partners and most importantly speakers outside the U-PGx Consortium) to attract attendance from their own academic/scientific network.



Timetable of the organization of the UPGx Personalised Medicine Days

- Six (6) months prior to the meeting:

The organizing committee develops the scientific program and invites the speakers.

-Five (5) months prior to the meeting:

The meeting hall and the auxiliary space (including but not limited to foyer, sponsors area if applicable, registration spot) is reserved.

-Four (4) months prior to the meeting:

(1) The First Announcement of the meeting is sent, (2) The scientific program is finalized, (3) The first round of invitations for participation are sent by e-mail and all promotional material regarding the specific event is developed.

- Three (3) months prior to the meeting:

(1) The online registration form is opened and the online registration system customized, (2) The list of the registered participants from the online registration system is created and regularly updated and communicated to the scientific organizing committee, (3) Catering (meals, cocktail) are organized, (4) The event is promoted by using any proper marketing channel at the international, regional and most importantly local scientific level.

- Two (2) months prior to the meeting:

(1) Accommodation for speakers is arranged, (2) Reminder invitation to the participants are sent, (3) Badge names are designed.

- One (1) month prior to the meeting:

On-site secretariat is selected and organized.

Description of the 1st U-PGx Personalized Medicine Public Day

The 1st U-PGx Personalized Medicine Public Day, the first of a series of dissemination events for the general public and patients that will be organized for the U-PGx project has been successfully organized on Wednesday December 6th, 2017 in London, UK. The theme of the event, that was organized in the Wolfson Library of the Royal Society, was “Is Personalized Medicine available for every citizen?”

There were 92 registered participants and speakers coming mostly from London but also from other cities in Britain. A dedicated website was set for this conference (**Figure 1**), where information about the venue, the organizing and scientific committees and invited speakers, as well as the scientific program was available. Online registration was also available from the same website.

Guest lectures were given by Prof. Sir Munir Pirmohamed (Liverpool, UK), who gave to keynote lecture, Dr. Darrol J. Baker (London, UK), Dr. Anneke Seller (Oxford, UK), Dr. Jayne Spink (London, UK), and Dr. David Haerry (Brussels, Belgium; Scientific Program in **Figure 2**).

The conference started with the welcome addresses from the Dr. Darrol Baker, Director of the Golden Helix Foundation (London, UK), who gave an excellent outline of the HORIZON 2020 U-PGx project and of the Golden Helix Foundation activities. Subsequently, Prof. Sir Munir Pirmohamed (Liverpool, UK) delivered the keynote lecture, who gave an overview of the most characteristic examples of adverse reactions that can be avoided by drug treatment rationalization, as a result of pharmacogenomics.

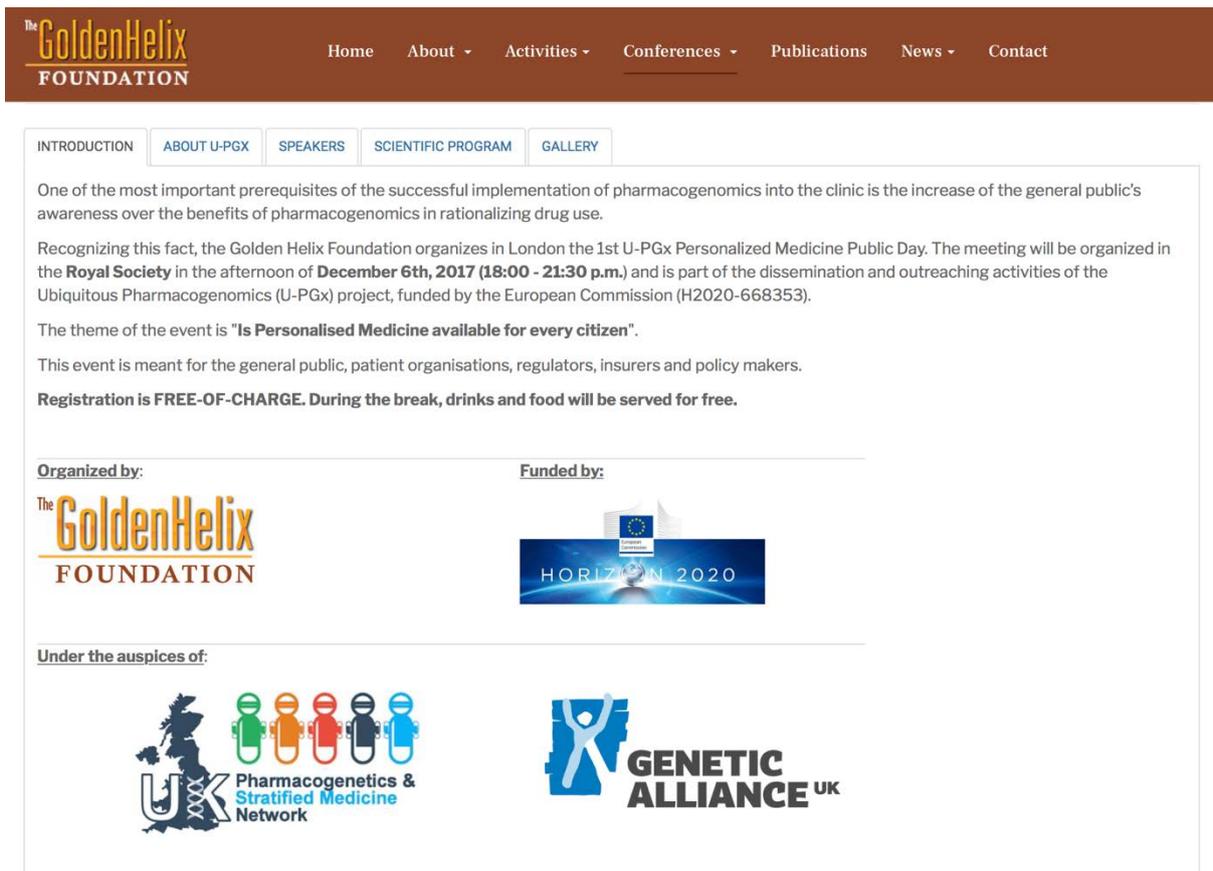


Figure 1. Overview of the 1st U-PGx Personalized Medicine Public Day, where

information about this conference was available.

The next talk was delivered by Dr. Anneke Seller (Oxford, UK), who gave a succinct overview of the various educational activities of the UK National Healthcare System related to genomic medicine, emphasizing the focus on the interinstitutional graduate courses and e-training on genomic medicine. This lecture was followed by Dr. Jayne Spink (London, UK), who presented the patients’ views related to the genetic basis of rare diseases. Dr. Spink also presented the various activities of Genetic Alliance UK, that also endorsed this event. Lastly, Dr. David Haery (Brussels, Belgium), member of the Scientific Board of the U-PGx project, presented that various collaborative aspects and opportunities between patients and pharmaceutical companies as far as drug development is concerned, focusing in particular on companion diagnostics.



Figure 3. Overview of the front and back side of the scientific program format of the 1st U-PGx Personalized Medicine Public Day. Special emphasis was given to the fact that these conferences are funded by the H2020 project under the 668353 Grant Agreement (bottom right part of the front page).

The session ended by Prof. Sir. Munir Pirmohamed, who coordinated a lively general discussion, in which all speakers and the attendees participated. At the end. Prof.



Pirmohamed analyzed the outcome of the questionnaires distributed and anonymously filled in by the attendees of the event. The questionnaires aimed to familiarize the attendees with the notion that some usual phenotypic trends, such as taste of some vegetables, the smell of armpits, *etc*, is genetically determined. After the event, a cocktail was organized at the adjacent, to the conference hall, cocktail room, where participants interacted with the speakers.

1st U-PGx Personalized Medicine Public Day,
Royal Society, Wolfson Library
December 6th, 2017, London, UK
From 18:30 until 21:00 p.m

[View this email in your browser](#)



About the U-PGx Project

The [U-PGx project](#) aims to address major challenges and obstacles for implementation of pharmacogenomics (PGx) testing in patient care, taking into account the diversity of healthcare systems and citizens across Europe. Specifically, U-PGx will investigate if the emerging approach of pre-emptive genotyping of an entire panel of important PGx markers is cost-effective and results in a better outcome for patients. With the pre-emptive PGx testing approach, data on multiple important pharmacogenes are collected prospectively and embedded into the patients' electronic record. Typically, it alerts prescribers and pharmacists through electronic clinical decision support systems when a drug is ordered or dispensed for a patient with an at-risk genotype. The new model of personalized medicine through pre-emptive PGx-testing will be conducted at a large scale in seven existing European health care environments (The Netherlands, Spain, UK, Italy, Austria, Greece, Slovenia)

Registration is FREE-OF-CHARGE

During the break, drinks and food will be served for free

[Click here to register for the Conference and for the Scientific Program](#)

Advertisement of the event

Figure 4. Part of the email campaign that was sent to a large number of recipients to advertise the 1st U-PGx Personalized Medicine Public Day, where relevant information was available.

During the preparation phase of the 1st U-PGx Personalized Medicine Public Day, the event was duly advertised in various ways, such as (a) email campaigns, available in HTML format (**Figure 4**), (b) social media, such as Instagram, Facebook and LinkedIn (**Figures 5, 6**).



Figure 5. Snapshots of the social media campaign in Facebook (upper panel) and LinkedIn (lower panel) to advertise the 1st U-PGx Personalized Medicine Public Day.

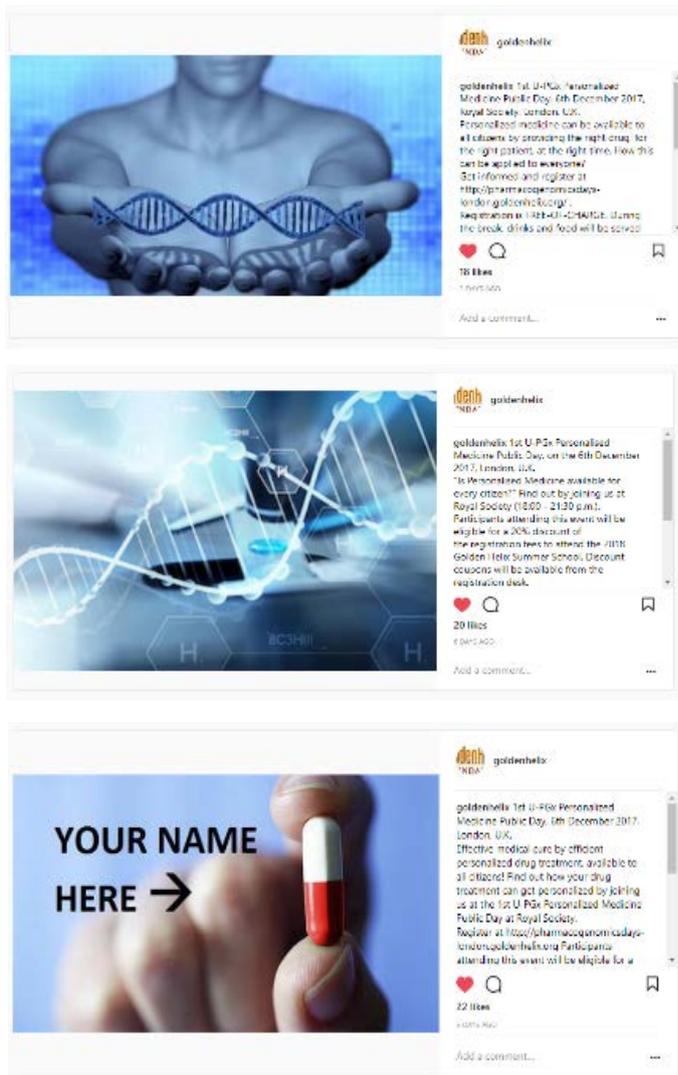


Figure 6. Snapshots of the social media campaign in Instagram to advertise the 1st U-PGx Personalized Medicine Public Day.

Summary/Conclusions

Overall, the 1st U-PGx Personalized Medicine Public Day was successfully organized in London, UK (see photo Gallery in **Figure 7**). The participants who evaluated the event provided a very favourable and useful feedback, which will contribute towards the better organization of the future event in Rome, Italy in December 2018.



Figure 7. Photo Gallery of the 1st U-PGx Personalized Medicine Public Day in London, UK