WORKSHOP 3
The role of patients in co-designing Plain Language Summaries

Patient Engagement Open Forum
19.9.2019
## Workshop agenda

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<td>15:10</td>
<td>Introduction of workshop and speakers</td>
<td>Danielle Derijcke</td>
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<td>15:15</td>
<td>Introduction to the PLS and target audiences</td>
<td>Paula Wray</td>
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<td>15:45</td>
<td>PLS Toolkit</td>
<td>Dawn Lobban, Lauri Arnstein</td>
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<td>16:15</td>
<td>Dissemination</td>
<td>Sheila Khawaja, Laurence Rouxhet</td>
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<td>16:45</td>
<td>Feedback session</td>
<td>Danielle Derijcke</td>
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<td>Next steps and <strong>closing the workshop</strong></td>
<td>Danielle Derijcke</td>
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<td>17:00</td>
<td><strong>End of workshop - Farewell drinks in the Plenary room</strong></td>
<td>Danielle Derijcke</td>
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Speakers

Sheila Khawaja
WAPO

Dawn Lobban
Envision Pharma

Lauri Arnstein
Envision Pharma

Paula Wray
INVOLVE/ NIHR

Laurence Rouxhet
GSK

Danielle Derijcke
PFMD
A good Plain Language Summary is the face of your work.
Importance of a Plain Language Summary

It can:

• build trust
• facilitate shared decision making
• increase awareness around research and its outputs/findings
• reduce the risk of misinformation
• raise profile with stakeholders

Mandated to share research outcomes for regulatory and funding bodies.
Patient empowerment.
Reducing health inequalities.
What needs to be done?

- Improve the quality and consistency of the information within summaries.
- Identify the target audiences and why they would need this information.
- Consider the different formats for accessibility and ensure the health literacy level of the content for the general public.
- Create opportunities for patients and the public to inform and develop the plain language summaries.
What needs to be done?

Provide mechanisms for the wider public to access the PLS information – a trusted source of robust information that not only reports the findings of the research but the implications to the patients and clinicians.

PLS and research outputs are intended to be used to inform discussions with health care professionals.

Example:

Ramsay Hunt Syndrome, understood clinical significance of symptoms, with atypical presentation, confirmed with doctor and discussed with consultant before changing treatment approach.
Sequential model to co-create and disseminate Plain Language Summaries

1. Identifying target audience and partners
   Who is the right target audience to your publication and why are they important? Planning the PLS from the beginning will form the basis of wider dissemination activities.

2. Plain language summary toolkit
   Toolkit and templates for the creation of the Plain language summary.

3. Dissemination
   Plain language summaries can play a role in decreasing health inequalities. How to disseminate impactfully?
Plain language summaries and the importance of choosing the right target audience
Questions for group discussion

• Who are potential target audiences of research outputs?
• Why they may be important?
• How they can be involved in developing a PLS?
Reviewing the Plain language summary toolkit

What is missing?
How can we improve?
Insights into optimal co-creation of PLS

Workshop: London Nov 2018
BROUGHT KEY STAKEHOLDERS TOGETHER TO DISCUSS

The Workshop was a ‘tools fest’ not a ‘talk fest’
Agreement and recognition of the need to prioritise patient preferences and take an evidence-based approach
A collaborative event where the voice of the patient was powerful throughout the day

- Patients
- Industry
- Publishers
- Publication professionals

Evidence relevant to PLS
Real-world case studies
Co-creation of practical tools for PLS
How to ensure access, quality and integrity of PLS
The Envision PLS of Publications Toolkit

**PRACTICAL TOOLS**

1. PLS of publications template
2. PLS of publications QC checklist
3. PLS cover sheet to help patient reviewers
4. PLS cover sheet to help sponsor reviewers
5. PLS glossary guide

**QUICK READS**

6. Why should sponsors fund PLS of publications?
7. Metrics for PLS: Quick and easy ways that Datavision can help you

**RESEARCH AND REVIEW**

8. PLS evidence bibliography
Activity: we welcome your input!

- **Top-line review of the toolkit contents**
  - Please refer to printouts on the tables

- **Moderated group discussion to answer the following:**
  - *How useful would you find the Toolkit?*
    - Which elements are more useful than others?
  - *What would you change?*
  - *What other tools would help you in developing PLS?*

Please note that post congress, additional feedback can be provided via the website [https://www.envisionthepatient.com/plstoolkit/](https://www.envisionthepatient.com/plstoolkit/)
Dissemination

Determining the best solution for different audience types
Objectives and purpose

In this session we aim to analyse the best dissemination methods, channels and formats of the lay summaries based on audience type (and disease)

• Consider that different audiences may require different formats

• Dissemination may be dependent on audience (& purpose of use)

• Determine the key point why the audience need this; how and where this information will be retrieved and shared.

Charts will be provided to help you complete the information; feedback will be shared with all participants at the end of the exercise.
Now that you have identified your audience and what you want to say...

- What would be the most appropriate format to reach your audience (support, layout,...)?

- What would be the best channels to do so? How would the users access such information?

- Which partners might help you access those channels?

- What challenges do you think each group might face?

Please use the table provided to help you sort out and complete the various sections, based on audience.
Feedback on key points from each table

- Target audience
- PLS toolkit
- Dissemination
Thank you for joining us today!

For more information please contact pfmd@thesynergist.org