Plain Language Summary of peer reviewed publications:
A step wise approach for co-creation with multiple stakeholders
Welcome to the Patient Engagement Open Forum virtual session

Patient Engagement Open Forum is a series of virtual events (in 2020) where we will work together, in a multi-stakeholder context, to turn patient engagement from an aspiration into reality.

The Forum aims to provide a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation that are often present in patient engagement work.
Before we get started, we ask you

Be present and engaged. We expect your feedback.

All microphones on mute.

Please provide your questions & feedback in the chatbox.

This session will be recorded.

Together let's make it interesting.
Introduction

Set the scene

Sheila Khawaja
Objective of the workshop

• Provide the opportunity to discuss how Plain Language Summaries of publications can be an important milestone for engaging and empowering the patients.

• The multi stakeholder approach in the efforts for co-creation of PLS is important.

• Share with you the perspective of the development of a PLS Guidance.

• Get more familiar with PLS.

• We welcome your input.
Agenda

Introduction/Set the scene  20’
1. Setting the rules
2. Welcome and introduction to the group and speakers
3. Setting the scene and presenting the topic

Part I: Panel discussion  45’
4. Engagement Panel with 3 stakeholders: The Editor, the Industry, & the Patient sharing their perspective on:
   a. Current context and challenges for PLS of publications
   b. Patient Engagement in PLS : what are the benefits ?
5. Q&A session

Part II: Interactive Session (30min) in 3 Breakout sessions with support of one moderator
6. Introduce what is a “good PLS”? (each participant receive a PLS + abstract of scientific article as a reference)
   a. Interactive discussion and Feedback (20min)
   b. Report back to the general meeting: key findings - 3’ per group

Next steps and Close by Editor/ Patient/ Industry  10’
 a. Feedback on the workshop - Satisfaction Survey to be sent
Introduce the Workshop Contributors

Sheila Khawaja
Vice-Chairperson/Patient Advocate
WAPO

Elena Conroy
Senior Managing Editor
SAGE Publishing

Dr Thomas Schindler
Head of Innovation
Medical Writing
Boehringer Ingelheim

Dr Lauri Arnstein
Patient Partnership
Scientific Liaison
Envision Pharma Group
The Context

- Improved patient information was identified as a priority across all phases of Medicine’s lifecycle (PFMD Public consultation).

- Patients can only fully engage if they are well-informed about current medical developments. Therefore PLS of scientific publications are at the core of patient participation and involvement.

- The Plain Language Summary of Publications / Conferences communication allows authors of the research and/or journal editor to reach a broader audience (patients and general public).

- For physicians, Plain Language Summary (PLS) can help generate dialogue and focus communication with their patients.

- Patient involvement and engagement (PE) in the development of plain language summaries (PLS) is generally restricted to later stages of PLS development (e.g., review process).
The Methodological approach to the development of the How to guidance …

- Co-created by a variety of stakeholders with experience in PLS elaboration and PE: patient representatives, industry members, publishers, researchers, medical communication agencies and public involvement in research bodies.

- The objective was to develop a practical how-to-module guidance that describes the process of Plain Language Summary creation and dissemination through a straight-forward 5-step approach to ensure early patient involvement.

- The guidance can be used when planning a PLS to encourage co-creation with the target audience in mind, as well as during the entire process.
Plain Language Summary creation and dissemination through a straight-forward **5 step approach** to ensure early patient involvement
Step-wise approach for PE in PLS

Step 1
• Scope and prioritisation of your PLS

Step 2
2a. Identify your target audience
2b. Consider dissemination channels for PLS

Step 3
3a. Identify your key stakeholders for co-creation of PLS
3b. Writing the PLS

Step 4
• Disseminate your PLS

Step 5
• Tracking dissemination and measure success
# Overview

Co-creation of a how-to module for involving patients in the production of plain language summaries for scientific publications.

- Connecting with other working groups in different phases of meds. discovery, development and delivery
- Connecting with EFGCP and EFPIA’s Roadmap Initiative to Good Lay Summary Practices - workstream

# Next steps

Validation through Public consultation by Sept and feedback PEOF
Dissemination from end of 2020
Starting of Pilots

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**How-To module for PE in PLS of peer reviewed publications**

**Contributors**

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PART I
The Editor, The Patient, the Industry perspective on PLS

Elena Conroy, Sheila Khawaja, Thomas Schindler
Moderator: Lauri Arnstein
An Editor perspective on PLS

Elena Conroy
Senior Managing Editor
SAGE Publishing
Plain Language Summaries – a publishing perspective

Elena Conroy
Managing Editor, SAGE Publishing
London
Clinical practice guidelines for older people with multimorbidity and life-limiting illness: what are the implications for deprescribing?

Daniel Olsson, Alastair Patterson, Cynthia Boyd, Emily Reeve, Denise O'Hehir and Adam Tadd

Abstract

Background: The aim of this study was to apply the current United Kingdom (UK) National Institute for Health and Care Excellence (NICE) clinical practice guidelines to a hypothetical older patient with multimorbidity and life-limiting illness. We considered how treatment choices could be influenced by NICE guidance specifically related to multimorbidity, and, if accepted, whether the clinical practice guidelines should be reviewed, reduced and stopped.

Methods: Based on common long-term conditions in older people, a hypothetical older patient was constructed. Relevant NICE guidelines were applied to the hypothetical patient to determine what medication should be initiated in three treatment models: a naive patient model, a treatment-resistant model, and a last-line model. Medication complexity for each model was assessed according to the medication regimen complexity index (MRCI).

Results: The majority of guidelines recommended the initiation of medication in the hypothetical patient. If the initial treatment approach was unsuccessful, each guideline advocated the use of more medication, with the regimen becoming increasingly complex. In the new patient model, 9 separate medications (15 drug units) would be initiated per day; for the treatment-resistant model, 11 separate medications (25 drug units), and for the last-line model, 11 separate medications (20 drug units). None of the guidelines used for the hypothetical patient discussed approaches to stepping medication.

Conclusions: In a UK context, disease-specific clinical practice guidelines routinely advocate the initiation of medication to manage long-term conditions, with medication regimens becoming increasingly complex through the different phases of care. There is often no information concerning specific treatment recommendations for older people with life-limiting illness and multi-morbidity. The guidelines frequently explain how and when medication should be initiated, there is often no information concerning when and how the medications should be reduced or stopped.

Keywords: clinical practice guidelines, deprescribing, medication utilization, older people

Lay Summary

Clinical practice guidelines for older people

The aim of this study was to apply the current United Kingdom (UK) National Institute for Health and Care Excellence (NICE) clinical practice guidelines to a hypothetical older patient with multimorbidity and life-limiting illness. We considered how treatment choices could be influenced by NICE guidance specifically related to multimorbidity, and, if accepted, whether the clinical practice guidelines should be reviewed, reduced and stopped.

Implementation

- PLS implemented in November 2019
- Open Access journal – PLS accessible to all
- Big collaborative effort
- Creation of Patient Advisory Board
- Developing PLS peer-review process
Benefits and challenges

- Essential for **patient involvement**, education and empowerment
- **Effective communication tool** that allows researchers to reach a wider audience
- Becoming **industry standard**
- Still some **hesitancy** in publishing
- There is still a lot to **learn**!
- Collaboration with **Patient Experts** is essential
## Next Steps

- **Develop** internal PLS instructions
- **Roll-out** to more Open Access journals
- Ensure company *prioritizes* positive impacts on patient education
- **Increase accessibility** – infographics, translations, patient perspectives
- Continued collaboration with **patients & patient organizations**
- **Spreading the word!**
A Patient perspective on PLS

Sheila Khawaja
Vice-Chairperson/Patient Advocate
WAPO
The Patient perspective on PLS
Patient engagement leads to informed choices for a better quality of Life

Opportunity and value

**Individuals**

- Learn about medical research and innovation
- Health literacy
- Explore new roles and collaboration opportunities
- Informed discussion with GP or specialist
- Acquire new skills and networking opportunities

Opportunity and value

**Patient organization**

- Sharing of scientific knowledge to the community
- Empowerment may lead to the identification of gaps leading to new calls for action
- Increasing health literacy levels and establishing new networks
- Determine the best format for the PLS and the most appropriate channel
- Increasing the visibility of researchers and their work to community and stakeholders

EMPOWERMENT

CONTRIBUTION - TRUST - RETENTION
# The patient perspective on PLS

Patient engagement leads to informed choices for a better quality of Life.

## Challenges

<table>
<thead>
<tr>
<th>Individuals</th>
<th>Patient organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finding the platform to access knowledge</td>
<td>Platform accessibility (paywalls?)</td>
</tr>
<tr>
<td>Paywalls</td>
<td>Language variety</td>
</tr>
<tr>
<td>Language barriers</td>
<td>determining best PLS Format and channels</td>
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<tr>
<td>Fear of discussing with medical expert</td>
<td>Getting the organization involved</td>
</tr>
<tr>
<td>How to get involved? What skills do I need?</td>
<td>Additional workload / skills?</td>
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Patient engagement leads to informed choices for a better quality of Life.
An Industry perspective on PLS

Thomas M Schindler
Head Innovation Medical Writing
Boehringer Ingelheim
Patient Lay Summaries of scientific and medical publications – a viewpoint from industry

Thomas M Schindler, PhD; Boehringer Ingelheim Pharma Head Innovation Medical Writing
## PLS offer many opportunities

- Improve the understanding of science and clinical research in patients, caregivers and the general public
- Increase reach and visibility of clinical data and disease-stage information
- Increase the audience of important medical findings and new therapies
- Reduce the risk of misinformation and misunderstanding
- Foster trust between pharmaceutical companies, patients, patient advocates and the public
- Foster exchange and collaboration between patients and clinical researchers, e.g. by co-creation of PLS
- Facilitate communication and shared decision making between patients and physicians
PLS – open questions and challenges

- PLS are still new and not all journals encourage PLS, different formats and standards.

- Should all scientific articles have a PLS (early research, pre-clinical data)?

- Writing a good PLS is difficult and requires special skills, therefore scientific authors need to be trained to write PLS. How to best organise PLS review by patients?

- What are the appropriate ways of distributing PLS to health care providers, non-experts and patients?

- Can PLS be posted on the web and shared in social media?

- Scientific and medical publications are usually in English but patients and the general public want information in their mother language – translations?

- Establishing company-internal structures for co-creation of PLS
Question & Answers

Moderator: Lauri Arnstein
Patient Partnership Scientific Liaison Envision Pharma Group
PART II
Interactive session
Moderators: Sheila Khawaja, Elena Conroy, Thomas Schindler
3 Break out rooms
Interactive Session in 3 Breakout virtual rooms

Breakout I  Moderators: Sheila Khawaja / AM Hamoir
Breakout II  Moderator: Elena Conroy / Daniela Luzuriaga
Breakout III Moderator: Thomas Schindler / Bonaventure Ikediashi

Introduce what is a “good PLS”?  
(each participant receive a PLS + abstract of scientific article as a reference)

  a. Interactive discussion and Feedback (20min)
  b. Moderator to report back to the general meeting: key findings - 3’ per group
Plain Language Summary Example

Lay Summary

Self-administration of medication: a research study of the impact on dispensing errors, perceptions, and satisfaction

Background: Our aim was to investigate whether self-administration of medication (SAM) during hospitalization affects the number of dispensing errors, perceptions regarding medication, and participant satisfaction when compared with medication dispensed by nurses. Methods: A research study was performed in a Danish cardiology unit. Patients aged ≥18 years capable of SAM were eligible for inclusion. Patients were excluded if they did not self-administer medication at home, were not prescribed medication suitable for self-administration, or did not speak Danish. Intervention group participants self-administered their medication. In the control group, medication was dispensed and administered by nurses. Participants were allocated between groups by chance selection.

The primary result of interest was the proportion of dispensing errors collected through observation of participants and nurses. Secondary results of interest were explored through telephone calls to determine participant perceptions regarding medication, participant satisfaction, and deviations in their medication list two weeks after discharge.

Results: Significantly fewer dispensing errors were observed in the intervention group compared with the control group. At follow up, those who were self-administering medication had fewer concerns regarding their medication, found medication to be less harmful, were more satisfied, preferred this opportunity in the future, and had fewer deviations in their medication list after discharge compared with the control group.

Conclusion: The reduced number of dispensing errors in the intervention group indicates that SAM is safe. In addition, SAM had a positive impact on (a) perceptions regarding medication, thus suggesting increased medication adherence, (b) deviations in medication list after discharge, and (c) participant satisfaction.
PART II
Feedback interactive sessions
Next steps and close
Satisfaction Survey
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