

## 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

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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

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**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**



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# Introduction

## Set the scene

Sheila Khawaja



# Objective of the workshop

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- 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

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## 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

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**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

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- 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( eg review process).



# The Methodological approach to the development of the How to guidance ...

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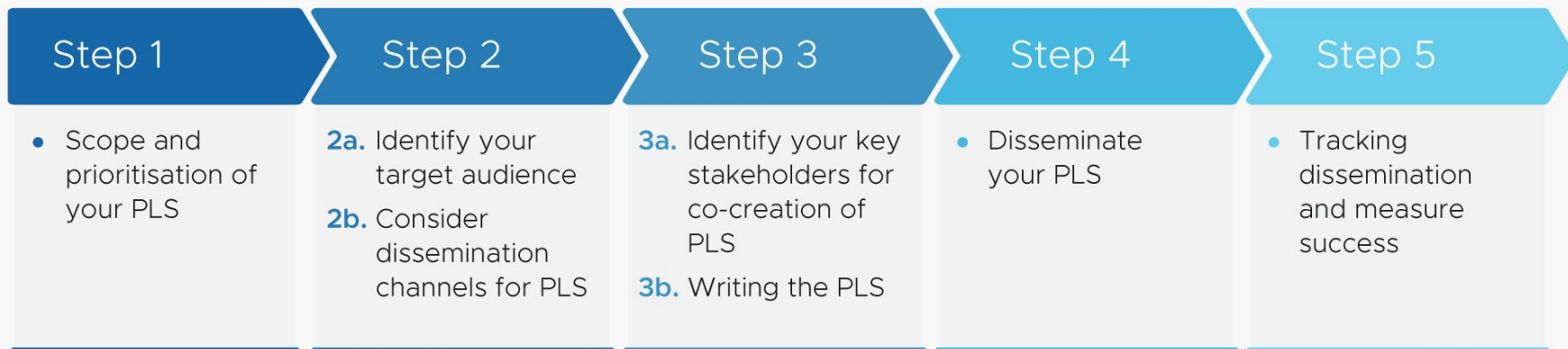
- Co-created by a variety of stakeholders with experience in PLS elaboration and PE: patient representatives, industry members, publishers, researchers, medical communication agencies and public involvement in research bodies.
- The objective was to develop a practical how-to-module guidance that describes 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

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## Working Group 5

## HOW-TO module for PE in PLS of peer reviewed publications

### Co-leads

#### Contributor co-leads



Sheila Khawaja  
WAPO  
([email](#))



Dawn Lobban  
Envision Pharma  
([email](#))

#### PFMD co-lead



Anne Marie  
Hamoir  
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### 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

## Contributors

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Patient advocate/ CAPA, CTO

Sage Publications

eYPAGNet, University of Liverpool

Future Science Group

Future Science Group

GSK

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INVOLVE

Patient advocate

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Patient advocate/ expert

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UCB

Novartis

Santhera

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For more information about the Working Group, please contact the co-leads

This information is for PFMD Working Group contributors only and should not be shared externally without PFMD's consent.

## 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

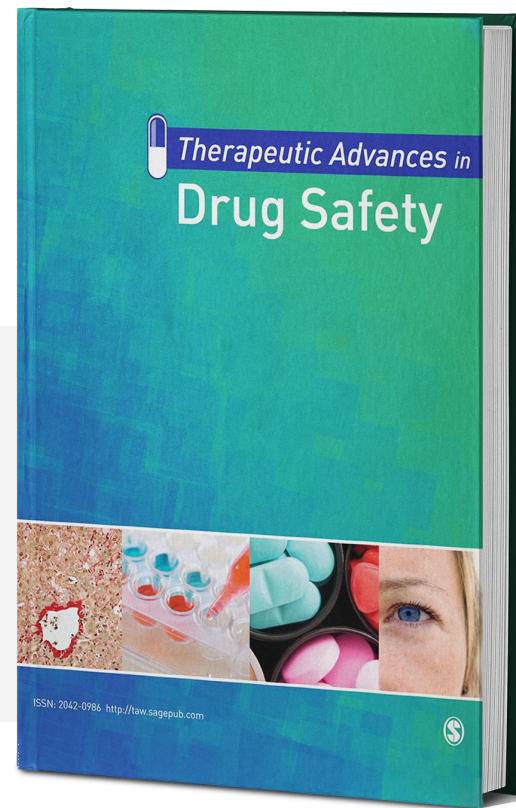
**SAGE Publishing**



# Plain Language Summaries – a publishing perspective

**Elena Conroy**

Managing Editor, SAGE Publishing  
London



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# Clinical practice guidelines for older people with multimorbidity and life-limiting illness: what are the implications for deprescribing?

Daniel Okeowo, Alastair Patterson, Cynthia Boyd, Emily Reeve, Danijela Gjelic and Adam Todd

## Abstract

**Background:** The aim of this study was (1) 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; (2) consider how treatment choices could be influenced by NICE guidance specifically related to multimorbidity; and, (3) ascertain if such clinical practice guidelines describe how and when medication should be reviewed, reduced and stopped.

**Methods:** Based upon 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 new 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 the 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, 4 separate medications (19 dosage units) would be initiated per day; for the treatment-resistant model, 4 separate medications (15 dosage units); and, for the last-line model, 11 separate medications (20 dosage units). None of the guidelines used for the hypothetical patient discussed approaches to stopping 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 steps of care. There is often a lack of information regarding specific treatment recommendations for older people with life-limiting illness and multimorbidity. While guidelines frequently explain how and when a 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

Received: 23 April 2018; revised manuscript accepted: 7 July 2018

## Lay Summary

### Clinical practice guidelines for older people

The aim of this study was (1) 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; (2) consider how treatment choices could be influenced by NICE guidance specifically related to multimorbidity; and, (3) ascertain if such clinical practice guidelines describe how and when medication should be reviewed, reduced and stopped.

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# 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

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# Benefits and challenges

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- 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

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Develop **internal PLS instructions**



**Roll-out** to more Open Access journals



Ensure company **prioritizes** positive impacts on patient education



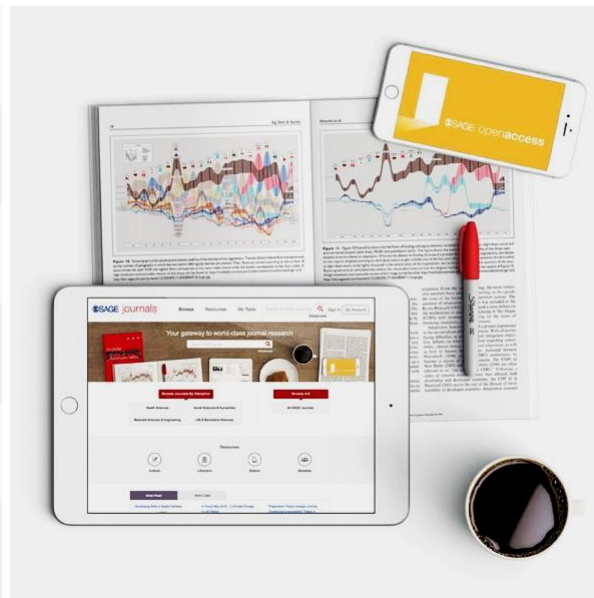
**Increase accessibility** – infographics, translations, patient perspectives



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

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## Challenges

### Individuals

- Finding the platform to access knowledge
- Paywalls
- Language barriers
- Fear of discussing with medical expert
- How to get involved? What skills do I need?

## Challenges

### Patient organization

- Platform accessibility (paywalls?)
- Language variety
- determining best PLS Format and channels
- Getting the organization involved
- Additional workload / skills?

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**



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# 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

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- 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

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- 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



# Practicalities Part II

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## 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  $\geq 18$  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.

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## PART II

# Feedback interactive sessions



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## Next steps and close Satisfaction Survey



# Contact Information

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