

PATIENT/CAREGIVER AUTHORSHIP



INTRODUCTION

Per Good Publication Practice (GPP) guidelines,¹ plain-language summaries (PLS) should be considered for all publications to facilitate informed shared decision-making

There is an unmet need to include the experiences and voices of patients and caregivers as authors, particularly of those who are often underrepresented



METHODS

ARASENS, an international Phase 3 trial, evaluated the efficacy and safety of darolutamide in metastatic hormone-sensitive prostate cancer²

The primary paper was published in February 2022.² A PLS was written by diverse patient and caregiver authors in collaboration with healthcare professionals who authored the original paper³

Medical writing services were provided by Tracey Lonergan of Adelphi Communications Ltd (Bollington, UK) and Daniel Booth on behalf of Adelphi Communications Ltd (Bollington, UK), funded by Bayer, in accordance with Good Publications Practice 2022 guidelines

GPP, Good Publication Practice; PLS, plain-language summary

References:

1. DeTora LM, et al. *Ann Intern Med* 2022;175:1298–1304;
2. Smith MR, et al. *N Engl J Med* 2022;386:1132–1142;
3. Smith MR, et al. *Future Oncol* 2022;18:2585–2597.

IF WE “SHARE THE DECISION” WE MUST SHARE THE LANGUAGE: PATIENT/CAREGIVER-AUTHORED PLAIN LANGUAGE SUMMARIES

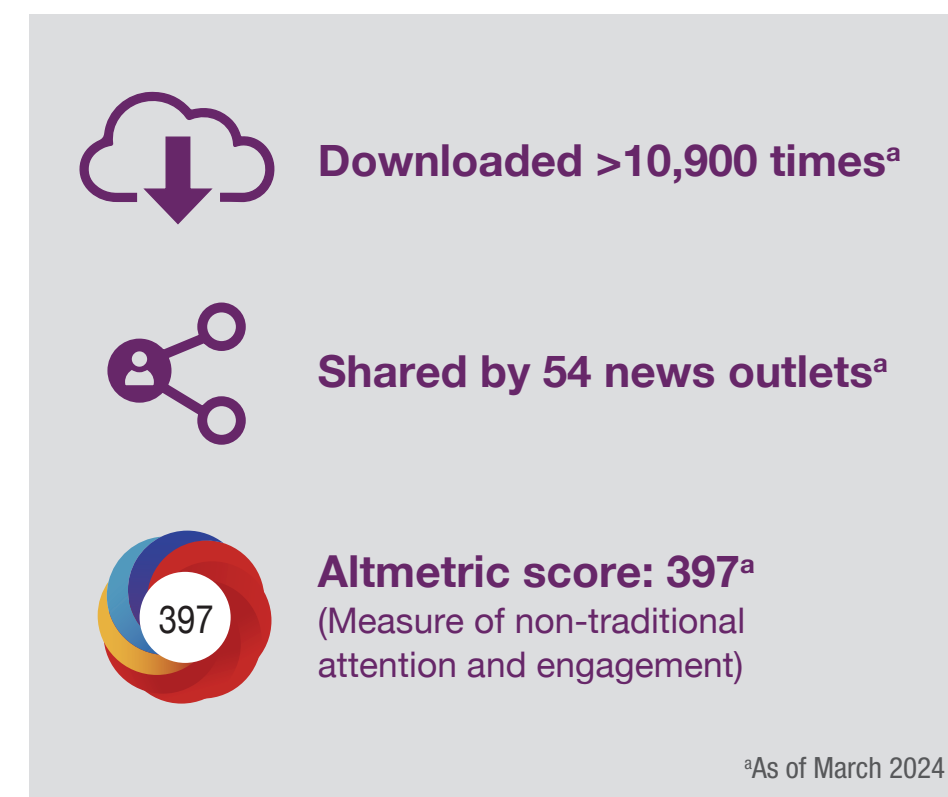
Jan Manarite,¹ Thomas Farrington,² and Rebecca Cowens-Alvarado³

¹YourProstateCancer.help, USA; ²Patient author, Prostate Health Education Network, Quincy, Massachusetts, USA; ³Bayer HealthCare Pharmaceuticals, New Jersey, USA

The ARASENS PLS is placed in the top 5% of research outcomes tracked by Altmetric^a

Patient/caregiver authors volunteered through involvement with patient organizations and were educated on GPP

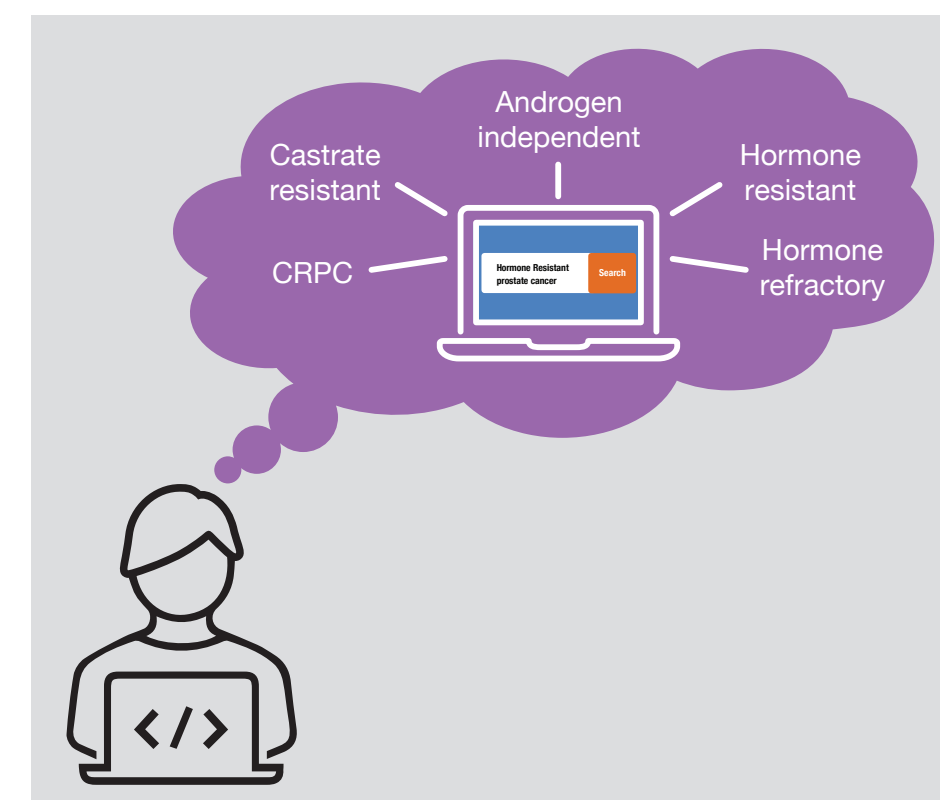
The PLS and accompanying animated video were published in a peer-reviewed scientific journal in June 2022



Downloads of the original paper tailed off after publication but increased again after the PLS was published

CAREGIVER AUTHOR EXPERIENCE

Use of multiple different terms for the same concept can make shared decision-making extremely challenging for patients and caregivers



Consider referencing one phrase when using another and use the same phrases from beginning to end

Almost every drug and treatment has two names, a brand name and a generic name. Both names should be used together whenever possible



CONCLUSIONS



Integrating patient/caregiver voices and insights into publications empowers others in their shared decision-making journey and ensures equitable access to the information needed to make informed decisions

PLS should be an integral part of scientific publications

SCAN ME FOR MORE INFO



PLS allow patient/caregiver perspectives to be incorporated where the language used is critical to ensure access and engagement by non-healthcare professionals with an interest in clinical trial outcomes

Poster presented at the 20th Annual Meeting of the ISMPP, Grand Hyatt Washington, Washington, DC, USA; April 29–May 1, 2024.