

Insights Gained From Working With Patient Authors on Industry-Sponsored Publications: Case Studies From Japan

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Conclusions



This analysis provides early insights into working with patient authors in Japan and may facilitate working with patient authors in other non-English-speaking countries



When working with patient author(s) on industry-sponsored publications, customisation of the publication processes can be facilitated by input from patient engagement roles



Being an author provided meaningful experiences for the patients involved in these publications and gave them an opportunity to raise awareness of their condition

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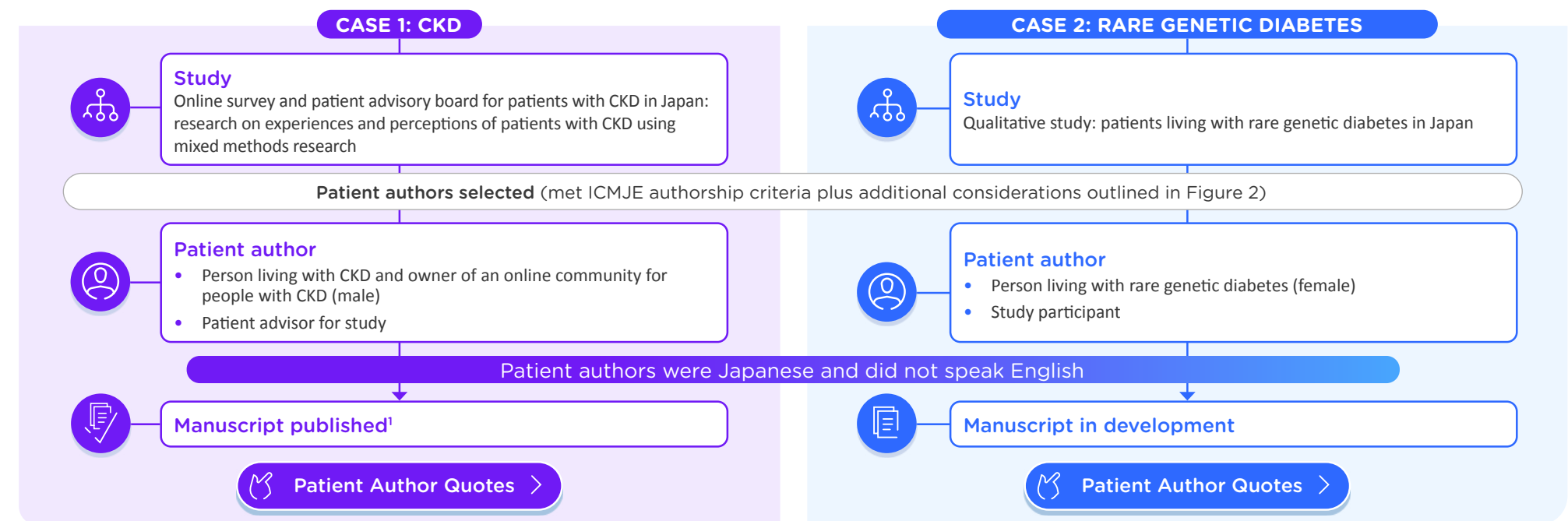
Background and Objectives

- Involving a patient author on industry-sponsored publications is not common practice in Japan
- Patient authors were involved in two publications reporting the findings from two Nippon Boehringer Ingelheim (NBI)-sponsored qualitative studies in Japan involving in-depth interviews with patients (Figure 1). To broaden reach of the findings, the primary publications were submitted in English, with a secondary publication in Japanese
 - Both patient authors were Japanese and did not speak English
- The objectives of this analysis were to:
 - Share experiences of medical publication professionals working with non-English-speaking patient authors on industry-sponsored publications in English and Japanese
 - Gain feedback from the patient authors on their involvement in these publications

Results

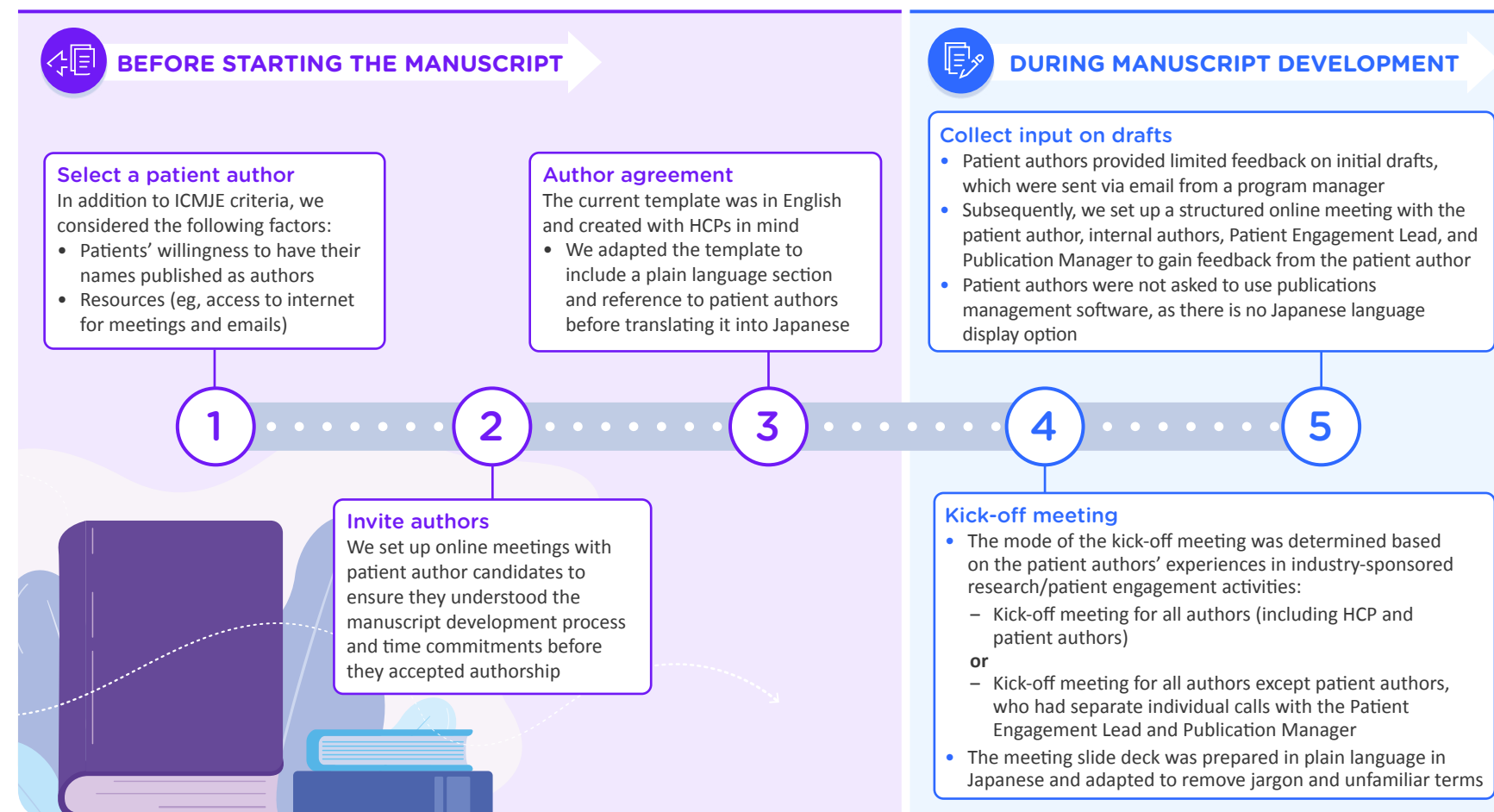
- Considerations for working with patient authors throughout the publication process are summarized (Figure 2)
 - The Patient Engagement Lead worked closely with publication professionals to review and customize the publication processes to facilitate patient author involvement
- There were a few language-specific challenges and learnings (Figure 3)
- Patient authors reported positive experiences and were motivated by a wish to raise disease awareness

Figure 1: Overview of Studies and Patient Authors Included in the Case Studies



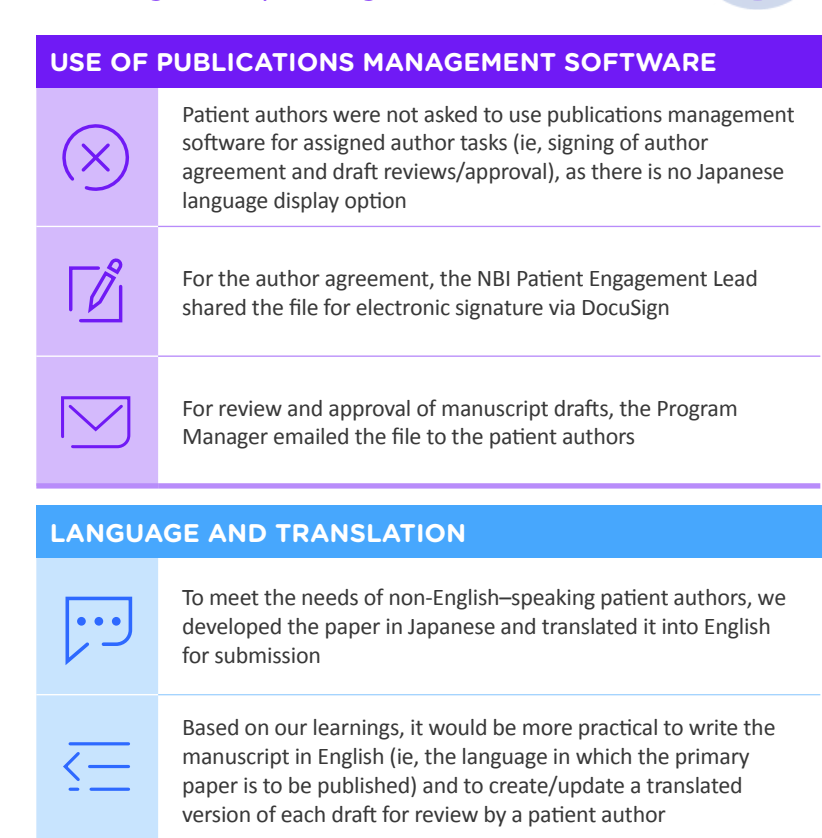
CKD, chronic kidney disease; ICMJE, International Committee of Medical Journal Editors.

Figure 2: Key Considerations for Working With Patient Authors in Japan



HCP, healthcare professional; ICMJE, International Committee of Medical Journal Editors.

Figure 3: Language-Specific Considerations When Developing an English-Language Publication With Non-English-Speaking Patient Authors



NBI, Nippon Boehringer Ingelheim.

Disclosures and Acknowledgments

All authors took part in the research, were actively involved in preparing the abstract, and have approved the final poster. KM and NY are employees of Nippon Boehringer Ingelheim. HE and CE are employees of, and own stock options in, Envision Pharma Group, funded by Nippon Boehringer Ingelheim to support with the analysis. All authors acted in a voluntary capacity. Editorial and graphical support were provided by Helen Donaghy and James Julia of Envision Pharma Group. We would like to express our sincere gratitude to the patient authors for their participation in the publications on which these case studies are based. This encore abstract was previously presented at the 2023 European Meeting of the International Society for Medical Publication Professionals.

Reference

1. Yagi N, Shukunobe T, Nishimura S, Mima A. Experience and daily burden of patients with chronic kidney disease not receiving maintenance dialysis or renal transplantation. *Adv Ther.* 2022;40:853-868.

Presented at the 19th Annual Meeting of the International Society for Medical Publication Professionals (April 24-26, 2023; Washington DC, USA)

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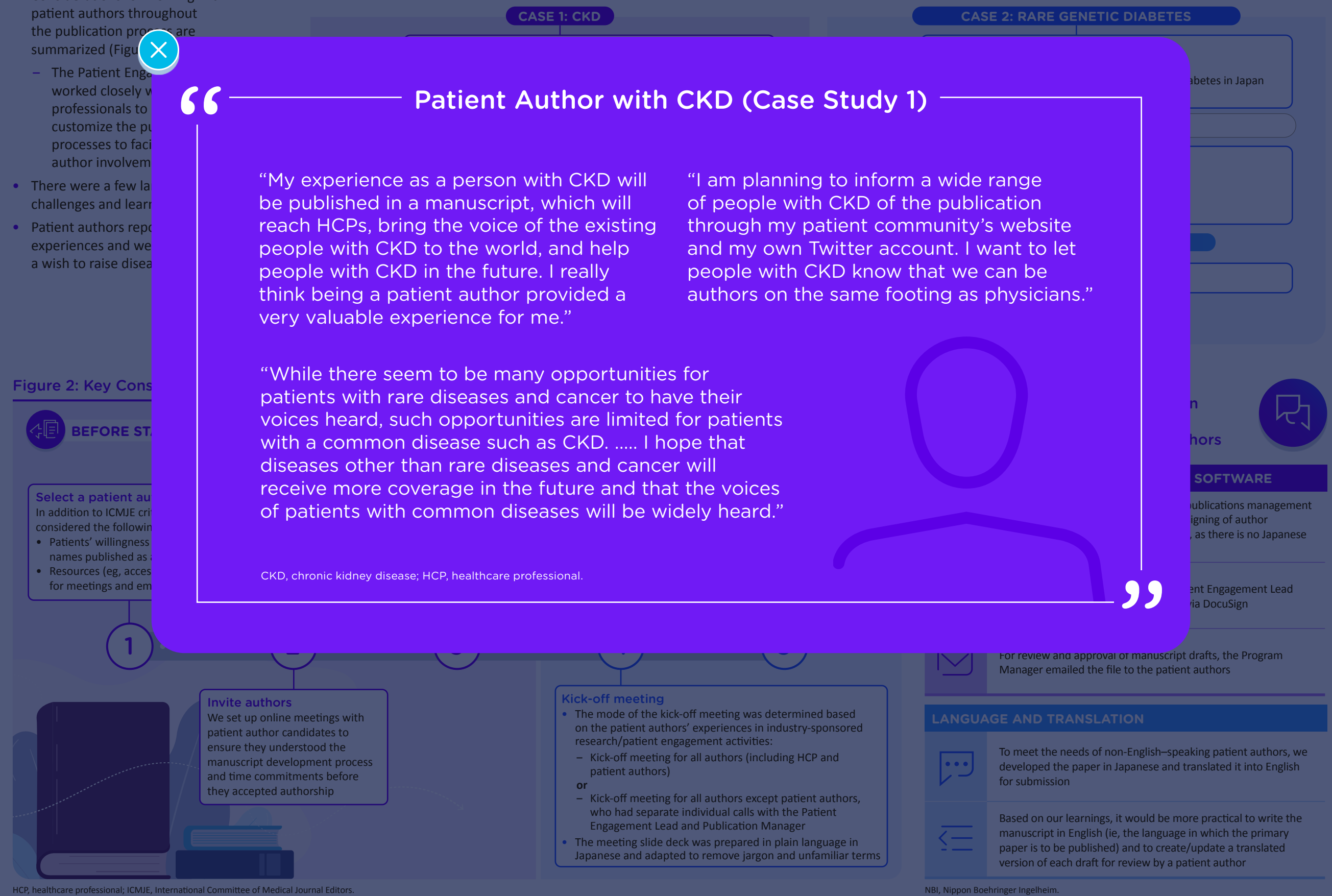
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- Considerations for working with patient authors throughout the publication process are summarized (Figure 2):
 - The Patient Engagement team worked closely with medical publication professionals to customize the publication processes to facilitate patient author involvement
- There were a few challenges and learnings
- Patient authors reported their experiences and we hope to raise disease awareness

Figure 1: Overview of Studies and Patient Authors Included in the Case Studies



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Patient Author with CKD (Case Study 1)

“My experience as a person with CKD will be published in a manuscript, which will reach HCPs, bring the voice of the existing people with CKD to the world, and help people with CKD in the future. I really think being a patient author provided a very valuable experience for me.”

“I am planning to inform a wide range of people with CKD of the publication through my patient community’s website and my own Twitter account. I want to let people with CKD know that we can be authors on the same footing as physicians.”

“While there seem to be many opportunities for patients with rare diseases and cancer to have their voices heard, such opportunities are limited for patients with a common disease such as CKD. I hope that diseases other than rare diseases and cancer will receive more coverage in the future and that the voices of patients with common diseases will be widely heard.”

CKD, chronic kidney disease; HCP, healthcare professional.

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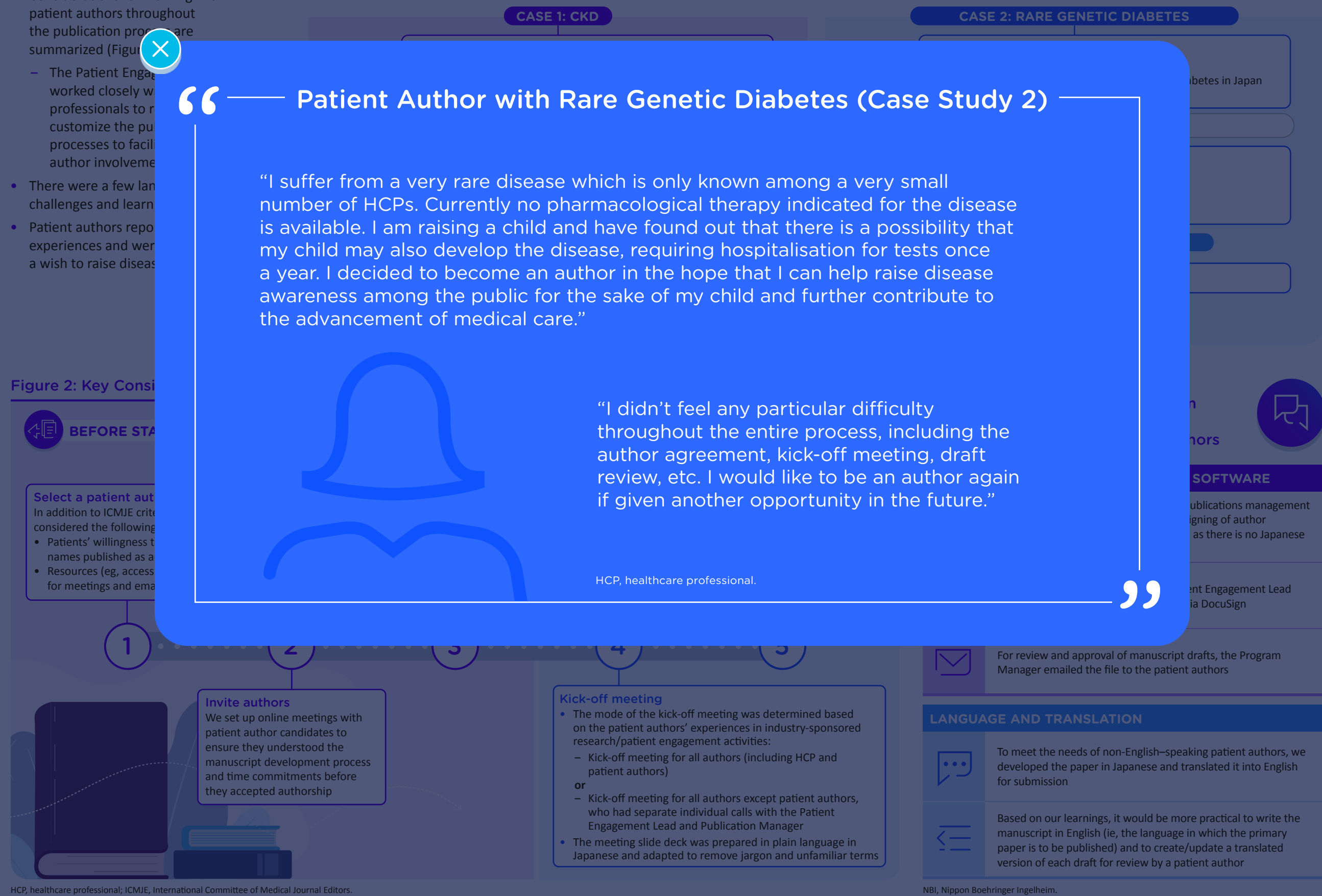
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Results

- Considerations for working with patient authors throughout the publication process are summarized (Figure 2)
 - The Patient Engagement team worked closely with medical publication professionals to not only customize the publication processes to facilitate patient author involvement but also to ensure that the patient authors' experiences were captured
- There were a few language challenges and learning opportunities
- Patient authors reported positive experiences and were able to raise disease awareness

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Disclosures and Acknowledgments

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