

The Impact of Summary of Information for Patients (SIP) on Patient Advocacy Organization Engagement in Health Technology Assessment: A Literature Review

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BACKGROUND

- Health Technology Assessment (HTA) is playing a more prominent role in U.S. healthcare.
- Patients and patient advocacy organizations (PAOs) are increasingly engaged in HTA and value assessment.
- Meaningful participation of patients and PAOs requires clear, understandable scientific evidence.
- An information gap remains, limiting effective patient engagement.

What is a SIP?

A Summary of Information for Patients (SIP) is a concise, plain-language, transparent, non-promotional evidence summary about a disease and a medicine that treats it — written so patients and PAOs can understand and use it as appropriate.

5-10 pages

6th-8th grade

Non-promotional scientific rigor

Public data no new evidence

OBJECTIVE

Evaluate published evidence on the impact of Summary of Information for Patients (SIP) on patient advocacy organization (PAO) engagement in Health Technology Assessment (HTA) and value assessment.

METHODS

- Design:** structured narrative literature review.
- Databases:** PubMed and PubMed Central, HTAi publications, SIP development materials.
- Time range:** 2017 to 2026.
- Search terms:** patient involvement in HTA; plain-language summary; patient advocacy group engagement; value assessment; Summary of Information for Patients.
- Inclusion:** peer-reviewed studies on patient and PAO involvement, plain-language information tools, and measured engagement outcomes.
- Supplementary:** reference lists of included studies hand-searched for additional sources.

Evidence Reviewed:

Identified 2017-2026

Screened peer-reviewed

Organized by theme & Synthesis

Included 13 studies + 2 HTAi

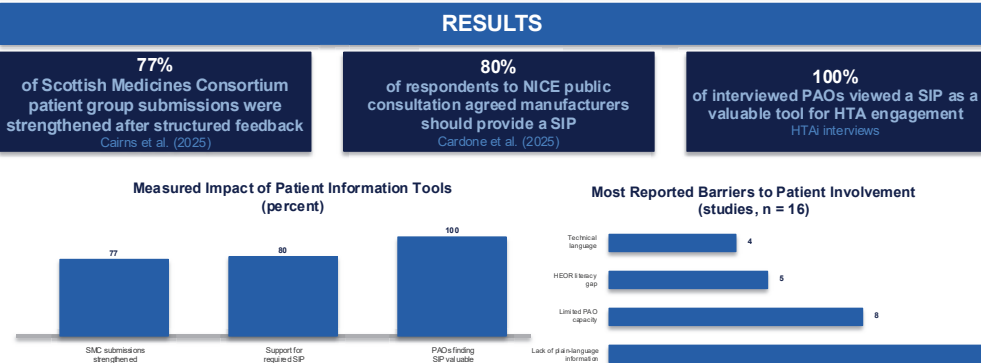


Table 1. Selected evidence on the impact of the SIP and patient information tools

Study (Year)	Focus	Key finding
Cook et al. (2021)	International SIP template	Developed an international template to support patient submissions in HTAs.
Wale et al. (2021)	Patient and public involvement	Described patient and public involvement needs in health technology assessment.
Single et al. (2021)	Patient advocacy involvement	Observed patient advocacy group involvement in health technology assessments.
Arntsen et al. (2022)	US value assessment	Examined patient engagement in US value assessment.
Lopez Gousset et al. (2024)	Impact framework	Characterized the impact of patient involvement in health technology assessment.
Cairns et al. (2025)	SMC feedback process	77% of SMC patient group submissions were strengthened after structured feedback.
Cardone et al. (2025)	Plain language in HTA	80% of respondents agreed manufacturers should provide a SIP.
ICER (2025)	US patient perspective	Described centering the patient perspective in the US healthcare system.

SIP USE CASES

IRA program

PDABs

ICER

Supports evidence-informed patient input for drug price negotiation.

Supports patient and PAO input in prescription drug affordability reviews.

Supports patient engagement in value and cost-effectiveness reviews.

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DISCUSSION

- The evidence converges on a single barrier — the absence of clear, plain-language information — and the SIP is fit for purpose to overcome it.
- Structured information tools measurably strengthen patient and PAO submissions, raise confidence, and reduce preparation time.
- International precedent is strong and sustained: both the SMC and NICE embed plain-language summaries as a mandatory part of submissions.
- Because three US use cases align with the SIP, a single standardized tool can serve the IRA program, PDABs, and ICER at once.
- The SIP shifts patient participation from testimony alone toward evidence-informed engagement on equal footing.

CONCLUSIONS

- SIP is a standardized, evidence-based tool that reduces the most cited barrier to patient involvement in value assessment bodies.
- Adapting the SIP for the US may strengthen the patient voice and support fair, patient-centered decisions on coverage, pricing, and access.
- Because it consolidates publicly available data and requires no new evidence, the SIP is scalable across diseases and therapies.

LIMITATIONS

- Literature-based synthesis; no original outcome data were generated.
- Heterogeneous study designs limit direct comparison across studies.
- Most quantitative evidence is from outside the US; the US SIP is new, so long-term US outcomes are not yet available.
- Barrier frequencies reflect a thematic synthesis across the reviewed studies.

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