

Introduction

- Patient-reported outcomes (PRO) and patient preference studies frequently require insight into lived experiences and stakeholder perspectives. For example, PRO measure development relies on understanding symptoms and impacts of a condition; discrete choice experiments (DCEs) draw on factors influencing decision-making; and time trade-off (TTO) studies require health state descriptions that meaningfully reflect patient experience. While literature reviews and clinician input contribute to this understanding, qualitative research is widely regarded as essential for informing health economics and outcomes research (HEOR) methods [1].
- However, traditional qualitative approaches can be resource-intensive and reliant on participant recruitment, which may be challenging in some populations. In practice, this may lead to increased reliance on literature reviews and expert opinion, potentially limiting direct insight into patient experience.
- Netnography is an emerging qualitative approach focused on the study of online interactions within digital environments. Unlike traditional qualitative methods, which rely on researcher-elicited data, netnography captures naturally occurring, unsolicited accounts and discussions, providing insight into how patients describe symptoms, impacts, and decision-making in real-world contexts [2,3]. Although concerns have been raised regarding inconsistent reporting and ethical considerations, netnography may offer practical advantages in terms of efficiency and access to patient perspectives. Recent applications have also explored the integration of netnography with AI-assisted approaches to data analysis [4].
- However, there is limited guidance on whether netnographic data can meet the specific data requirements of established HEOR methods such as PRO development, DCE, and TTO studies, or how such approaches should be applied in practice.

Objective

This study had two main objectives:

- To assess whether a non-participatory netnographic approach is feasible for use within PRO development, TTO, and DCE studies,
- To develop a draft framework outlining key considerations for the use of netnography within these studies.

Methods

- A focused literature search was conducted in March 2026 to identify key methodological guidance on the conduct of netnography, alongside established guidance for qualitative research in HEOR, including PRO and patient preference studies. This involved targeted searches for relevant methodological and guidance literature.
- A draft framework was developed through synthesis of this literature, outlining key methodological, ethical, and practical considerations for the use of netnography in HEOR. This included considerations relating to platform selection, sampling approach, online data characteristics, and data requirements for PRO development, DCE attribute development, and TTO vignette construction.
- The framework was illustrated and refined through application to an exemplar netnographic dataset obtained from a publicly accessible online community platform; Reddit, r/lungcancer. Posts were reviewed in reverse chronological order to provide a structured and reproducible sampling approach. Threads were screened for relevance to predefined domains aligned with PRO, TTO, and DCE data requirements, specifically symptoms, impacts, severity, and decision-making.
- Data were mapped to predefined domains reflecting key evidence requirements for PRO development (symptoms, impacts), TTO health state construction (severity, lived experience), and DCE attribute development (decision-making and trade-offs). AI-assisted extraction (ChatGPT, OpenAI) was used to support rapid, structured exploration of the dataset. Outputs were reviewed and interpreted by the research team to assess the extent and nature of relevant data available, and its alignment with PRO, DCE, and TTO data requirements.

Discussion & Conclusion

- This work represents an early-stage exploration of the feasibility of using netnography within PRO and preference elicitation studies, alongside the development of a conceptual framework to support decision-making.
- Within this case study, a substantial volume of patient- and caregiver-generated content relating to disease and treatment experiences was identified, providing useful insight for selected applications within PRO and preference research. However, content was often narrow in scope, frequently focused on users seeking specific information or advice, or sharing perspectives on treatment-related concerns, with less discussion of broader symptoms, impacts, and day-to-day living with the condition.
- The oncology case study illustrates the challenges of applying netnography in conditions characterised by multiple stages, subtypes, and dynamic disease trajectories. The feasibility of using data from online open-access platforms may therefore be influenced by both condition-specific and platform-related factors.
- Netnography may offer a practical means of accessing patient experience data without reliance on participant recruitment and researcher-led data collection, which may be particularly valuable in hard-to-reach populations or early-stage research. Its role within HEOR is likely to vary depending on the research question and context, including use as a standalone source of insight or in combination with traditional qualitative methods.
- This case study employed a non-participatory approach, relying solely on researcher observation. Future research may explore the potential of more interactive netnographic approaches, which could enable tailored data collection within online communities, although ethical considerations relating to public and private online spaces remain.

Results

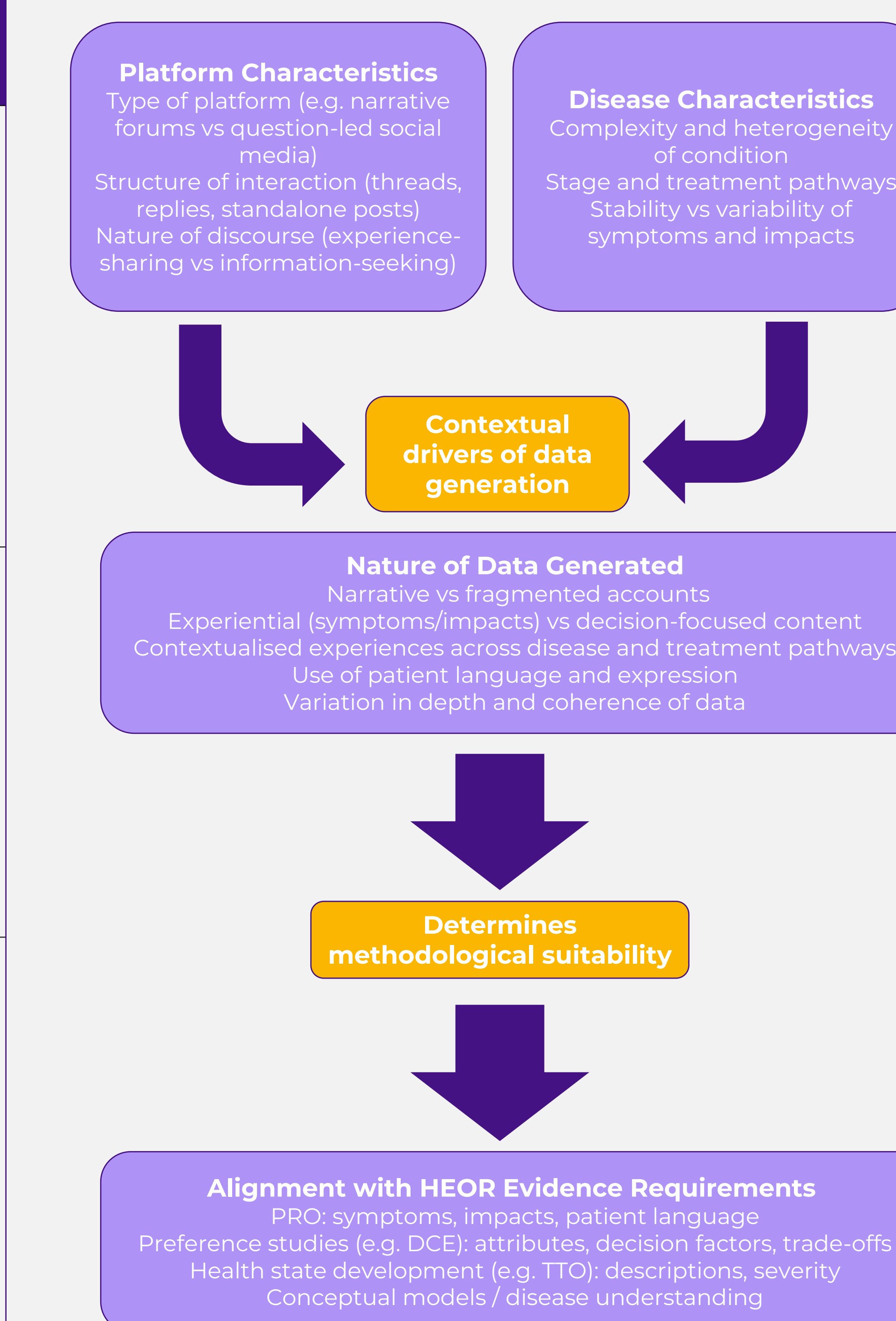
Literature Search: Existing literature highlights key considerations in the use of netnography, including the influence of platform characteristics and the generation of data that vary in form and content depending on the community and interaction [3,4]. The literature also highlights limited availability of demographic and contextual information, alongside ethical considerations relating to the use of publicly available online data (e.g. [3,5]). Methodological guidance for qualitative research in PRO, TTO and DCE studies was also identified (**Table 1**). While detailed guidance exists for PRO development (e.g. FDA), guidance specific to TTO and DCE remains limited.

Table 1. Key Qualitative literature in Patient Reported Outcomes and Preference Studies

Study type	Summary of study method	Purpose of study	Standard data collection methods	Data required
TTO study: Vignette development	TTOs elicit preferences by asking respondents to trade length of life for quality of life, based on defined health state descriptions (vignettes)	To estimate health state utility values for use in economic evaluation	<ul style="list-style-type: none"> • Patient interviews • Expert opinion • Patient representatives [6,7] 	Symptoms, functional impacts, emotional impacts, severity levels, patient experiences [6,7]
PRO measure development	Development of instruments to measure patient experience	To develop instrument capable of measuring patient-reported symptoms and impacts for use in PRO studies or clinical trials	<ul style="list-style-type: none"> • Qualitative interviews: concept elicitation & cognitive debriefing • Focus groups • Expert opinion [8] 	Symptoms, functional impacts, emotional impacts, patient priorities, context & severity [9]
DCE: Attribute and level development	DCEs elicit preferences by asking respondents to choose between hypothetical alternatives defined by attributes and levels	To understand preferences and trade-offs within a particular population for a particular good/service/state	<ul style="list-style-type: none"> • Qualitative interviews • Focus groups • Meta-ethnography [10] 	Experiences, preferences, trade-offs, ranges/variability within preferences (e.g. relating to treatment)

Content mapping: The most recent 100 posts (as of 10th April 2026) from r/lungcancer were analysed by two researchers. Content focused on symptom experiences, treatment side effects, diagnosis, prognosis, and interpretation of medical information, often spanning multiple topics and frequently contributed by relatives. Posts provided rich accounts of symptoms, emotional impact, and treatment decision-making, aligning with key data requirements for PRO, TTO, and DCE studies (**Table 1**). However, content was often fragmented, limiting the ability to map disease stage, and demographic information was often unavailable, with substantial contribution from proxy respondents. **Figure 1** summarises a draft framework outlining key methodological, ethical, and practical considerations for the use of netnography in PRO and preference studies.

Figure 1. Draft framework outlining considerations for the use of non-participatory Netnography in Patient Reported Outcome and Preference Studies.



References

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Abbreviations

DCE, Discrete choice experiment; HEOR, Health economics and outcomes research; PRO, Patient reported outcomes; TTO, Time trade-off

