**Table S1: Records identified from databases (N=6,438)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **S. No** | **Search Strategy** | **Hits** |
| **Patient perspective/PRO/QoL** | **1** | ("Patient perspective" or "Patient perspectives" or "Patients’ perspective" or "Patients’ perspectives" or "Patient preference" or "Patient preferences" or "Patient involvement" or "Patient voice" or "Patient insight" or "Patient insights" or "Patient participation" or "Citizen involvement" or "Citizen perspective" or "Citizen perspectives" or "Citizen preference" or "Citizen preferences" or "Community perspective" or "Community perspectives" or "Public involvement" or "Public engagement" or "Public preference" or "Public preferences" or "Patient and public involvement" or "Patient and public preference" or "Patient and public preferences" or "Patient and public engagement" or "Patient and citizen involvement" or "Citizen and Community perspective" or "Citizen and Community perspectives" or "Patient Preference Information" or "Patient advocacy group" or "Patient advocacy groups" or "Patient advocacy" or "Patient/consumer group" or "Patient/consumer groups" or "Patient representative " or "Patient representative" or "Patient representatives" or "stakeholder interviews" or "patient association" or "community engagement" or "citizen participation" or "patient opinion" or "patient organization" or "consumer perspective" or "consumer representative").ti,ab. | **102914** |
| **2** | exp "patient reported outcomes"/ or (PRO or PROM or PREM or "Patient-reported outcome" or "Patient-reported outcomes" or "Patient reported outcome" or "Patient reported outcomes" or "Patient outcome assessment" or QoL or HRQoL or "quality of life" or "Patient-reported productivity" or "Patient-reported general health status").ti,ab. | **1689124** |
| **3** | ("patient input" or "patient inputs" or "patient-based evidence" or "patient-based evidences" or "patient-centric data" or "patient center\*" or "patient organisation" or "patient experience" or "Patient relevant endpoints" or "Patient relevant outcomes" or (("patient-relevant" or "patient-important" or "patient-preferred") and (outcome\* or endpoint\* or parameter\* or indicator\*))).ti,ab. | **82586** |
| **4** | exp quality of life/ or (QoL or HRQoL or "quality of life" or "health-related quality of life" or "EuroQol-5 Dimensions" or "EuroQol-5 Dimension" or EuroQOL-5D or "EuroQol 5-D" or "EuroQol five-dimension" or EQ-5D or EQ-5D-5L or "EuroQol 5-Dimensions-3-level" or EQ-5D-3L or "Short Form" or "Short Form-36" or SF-36 or "Short Form-6 dimensions" or SF-6D or "EQ-HWB" or "EQ Health and Wellbeing").ti,ab. | **1354304** |
| **Socio Keywords** | **5** | ("Social Perception" or "Social Values" or "Social Sciences" or "Public Opinion" or "social support" or "social status" or "Sociological aspects" or "social value judgments" or "Societal perspective").ti,ab. | **177315** |
| **6** | or/1-5 | **2286127** |
| **HTA keywords** | **7** | exp health technology assessment/ or (HTA or "Health technology assessment" or "Health technology assessments" or "Value assessment" or "pricing and reimbursement process" or "pricing and reimbursement decision" or "funding decision" or "market access" or "patient access" or "healthcare access").ti,ab. | **60657** |
| **8** | 6 and 7 | **9172** |
| **Final Hits** | **9** | remove duplicates from 8 | **6438** |

**Table S2: Abstracts identified from conference (ISPOR n=758 and HTAi n=1312\*)**

|  |  |  |
| --- | --- | --- |
| **S.No** | **Search Strategy** | **Hits** |
| **1** | ("Patient perspective" OR "Patient perspectives" OR "Patients’ perspective" OR "Patients’ perspectives" OR "Patient preference" OR "Patient preferences" OR "Patient involvement" OR "Patient voice" OR "Patient insight" OR "Patient insights" OR "Patient participation" OR "Citizen involvement" OR "Citizen perspective" OR "Citizen perspectives" OR "Citizen preference" OR "Citizen preferences" OR "Community perspective" OR "Community perspectives" OR "Public involvement" OR "Public engagement" OR "Public preference" OR "Public preferences" OR "Patient and public involvement" OR "Patient and public preference" OR "Patient and public preferences" OR "Patient and public engagement" OR "Patient and citizen involvement" OR "Citizen and Community perspective" OR "Citizen and Community perspectives" OR "Patient Preference Information" OR "Patient advocacy group" OR "Patient advocacy groups" OR "Patient advocacy" OR "Patient groups" OR "Patient representative " OR "Patient representative" OR "Patient representatives" OR "stakeholder interviews" OR "patient association" OR "community engagement" OR "citizen participation" OR "patient opinion" OR "patient organization" OR "consumer perspective" OR "consumer representative") AND "HTA" | **165** |
| **2** | (PRO OR PROM OR PREM OR "Patient reported outcome" OR "Patient reported outcomes" OR "Patient outcome assessment" OR QoL OR HRQoL OR "quality of life" OR "Patient reported productivity" OR "Patient reported general health status") AND "HTA" | **479** |
| **3** | ("patient input" OR "patient inputs" OR "patient-based evidence" OR "patient-based evidences" OR "patient centric data" OR "patient center\*" OR "patient organization" OR "patient experience" OR "Patient relevant endpoints" OR "Patient relevant outcomes") AND "HTA" | **56** |
| **4** | (QoL OR HRQoL OR "quality of life" OR "health related quality of life" OR "EuroQol 5 Dimensions" OR "EuroQol 5 Dimension" OR EuroQOL 5D OR "EuroQol 5 D" OR "EuroQol five dimension" OR EQ 5D OR EQ 5D 5L OR "EuroQol 5 Dimensions 3 level" OR EQ 5D 3L OR "Short Form" OR "Short Form 36" OR SF 36 OR "Short Form 6 dimensions" OR SF 6D OR "EQ HWB" OR "EQ Health and Wellbeing") AND "HTA" | **98** |
| **5** | ("Social Perception" OR "Social Values" OR "Social Sciences" OR "Public Opinion" OR "social support" OR "social status" OR "Sociological aspects" OR "social value judgments" OR "Societal perspective") AND "HTA" | **22** |
| **6** | 1+2+3+4+5 | **820** |
| **7** | Number of abstracts (lookback period 5 years) | **758** |

**Table S3: Definition of Parameters**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **THEMES** | | **PARAMETERS** | **DEFINITION** | |
| HOW | H1 | Patient Partnership | **Working collaboratively with the patient community**, relying on patient expertise, evaluating patient engagement in the process, and **opportunities for input throughout value assessment**.  Example: Whether they are being engaged/involved. | |
| H2 | Transparency to Patients | Selection of patient representatives is **transparent**, **method of patient input is described, and results are translated into patient-friendly information.** | |
| H3 | Representativeness of Patients | Representativeness connotes that a sufficient number and types of people are included in the **engagement activity to ensure that those engaged can speak on behalf of the target population**. The objective of the engagement is aligned with the patient representative’s ability to provide useful information, **opportunities** for participation are widely disseminated, and necessary accommodations for representative groups of patients are considered. | |
| H4 | Diversity | Diversity of the **patient population** is acknowledged and considered, coordinated efforts are made to reach populations not always considered for input due to factors such as location or language barriers, and applicability/limitations across sub-populations is acknowledged and considered.  Examples: Age, comorbid conditions, ethnicity, gender, genetics, geographic location, Health literacy, insurance coverage, rural/urban, race, socioeconomic status, severity. | |
| H5 | Patient-centered Data Sources & Methods | Patient’s health privacy is protected**, processes are in place for identifying and incorporating** **patient-generated health data**, existing sources of patient-generated health data (e.g., registries or patient-reported outcomes) are identified and considered. | |
| H6 | Timeliness | Patients provide **input early in the assessment process,** during the scoping phase. Engagement with patients happens at the **appropriate times** throughout the value assessment. | |
| H7 | Governance | Established authority / organization to govern process. Published document on the mandate/involvement of patient perspective (e.g., law, regulation, guideline etc.) | |
| H8 | Mechanism to incorporate patient input and perspective | **Mechanism and process** to incorporate patient input during value assessment process.  Example: written opinion, part of the decision-making committee. | |
| WHAT | | W1 | Outcomes Patients Care About - PRO | Direct patient input is obtained regarding outcomes that are important and relevant from a patient’s point of view, the condition, unmet needs, quality of life issues, subgroups and possible effect modifiers, current treatments, and expectation to new treatments. Outcomes important to patients are identified and incorporated, such as:  PRO o Functional status (mental/physical) o Symptoms o Health-related quality of life, overall and in social, physical, emotional, and functional domains o Well-being o Clinical measures o Survival |
| W2 | Outcomes Patients Care About - Societal perspective | Societal perspectives that are typically indirect impact from payers' perspective, but direct Patient outcomes  o Productivity loss by patients and/or caregivers |
| W3 | Outcomes Patients Care About - Patient preference / expectation | **Patient preference / expectation** o Goals, expectations, aspirations o Preference / considerations in treatment options / disease management  o Patient satisfaction |

Table S4: **Scoring method of mapped parameters**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Parameter 1** | **Parameter 2** | **Parameter 3** |
|  | Tagged 10 times, score = 5 10 tags × 5 = 50 | Tagged 8 times, score = 3 8 tags × 3 = 24 | Tagged 12 times, score = 1 12 tags × 1 = 12 |
| Total score | 50+24+12=86 | | |
| Assume total studies=20 | Average score = 86 ÷ 20 = 4.3 | | |
| Percentage | (4.3 ÷ 5) × 100 = 86% | | |