

technologies; therefore, ultra-orphan technologies may require a distinct appraisal process/framework but the HST may not (yet) represent best-practice.

## OP20 Has The New HST Process Improved The Recommendation Chance In England?

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**Introduction.** The National Institute for Health and Care Excellence (NICE) in England has a separate appraisal process for drugs for very rare conditions, i.e. Highly Specialised Therapies (HST). In April 2017, the HST process has been changed to incorporate a quantitative approach: automatically fund treatments with incremental cost-effectiveness ratio (ICERs) up to GBP 100,000 (EUR 113,008 based on the 2018 average GBP / EUR exchange rate) per quality-adjusted life year (QALY). For treatments with an ICER above GBP 100,000 per QALY, NICE will consider treatments that offer a substantial magnitude of improvement, with additional QALY weighting. We investigated the impact of this more quantitative approach on the likelihood of a HST receiving a positive recommendation.

**Methods.** All HST appraisals and draft guidance documents were reviewed (up to November 2018) and data were extracted on ICERs, incremental QALY gain, budget impact, and recommendations. The extracted data from each HST were assessed based on the interim HST guidance.

**Results.** Eighteen products have been or are currently going through the NICE HST process. Of these, 8/18 (44%) have received a positive recommendation, while 5/18 (28%) have received a draft negative guidance, and for 5/18 (28%) products, no recommendations have been published. For the products with a positive outcome, 5/8 (63%) had incremental QALY gain of at least 10, qualifying these products for additional QALY weighting. For the products that received a draft negative recommendation, the negative decision was related to the cost-effectiveness estimates being higher than GBP 100,000 per QALY (5/5 reported) in all cases, while none of these products were eligible to receive a 'QALY modifier'.

**Conclusions.** It has become more difficult for HSTs to get recommended by NICE under the new guidance, which requires cost-effectiveness analyses, whereas previously there was no official ICER threshold. The additional weighting of QALYs may be insufficient to meet an ICER threshold of GBP 100,000 per QALY for many products.

## OP21 Enhancing Capability: Patient Impact In Ultra-Orphan Conditions

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**Introduction.** Written evidence is submitted to the National Institute for Health and Care Excellence (NICE) by patient organisations for all ultra-orphan evaluations. To enhance the

capability of patient involvement at NICE and to further develop understanding of how patient generated evidence and input in ultra-orphan conditions can support the Health Technology Assessment (HTA) agencies beyond 2020, the Public Involvement Programme systematically reviews the impact the evidence has on committee decision making.

**Methods.** This study captured data from September 2017 to August 2018 for seven ultra-orphan evaluations. A paper questionnaire was given to each committee member to complete for each evaluation and entered in to an online system for analysis. Findings were used to inform the committee views which were highlighted in feedback letters to the patient groups. The questions included: how much impact and what sort of impact the patients had; both qualitative and quantitative data; and, a specific question on clarification of quality of life data

**Results.** We obtained 83 responses showing the submissions: had a moderately high or high impact; gave the committee particular insight into quality of life data not provided elsewhere; provided new evidence; interpret the data from other sources; and, demonstrated consistency with other sources

**Conclusions.** Patient evidence is particularly useful for ultra-orphan conditions where other forms of evidence are limited. Patients can provide a unique insight into the burden of disease, the patient population, any updates of treatments and the impact on patient and carers. They provide real life data to the committee including information that standard Quality Adjusted Life Years measures do not. Evidence varied by condition with impact themes highlighting the effects on patient and carers including fear, stress and anxiety. The examples are recorded, updated annually and will be shared with national patient groups and offered internationally through the HTAi Interest Group on Patient and Citizen Involvement.

## OP22 Patient-Based Evidence: Its Role In Decision-Making On New Medicines

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**Introduction.** The Scottish Medicines Consortium (SMC) advises NHS Scotland on the clinical and cost-effectiveness of new medicines. Since 2014, evidence from patients and carers on end-of-life and orphan medicines has been gathered during Patient and Clinician Engagement (PACE) meetings. The output is a consensus statement which describes the added value of a new medicine from the perspective of the patient/carer and clinician. This study investigates the importance of factors identified through PACE to committee members and how these are used in their decision-making.

**Methods.** Survey methodology was used to gain an understanding of the factors from the PACE statement that are most likely to influence members (n=26) in decision-making. The survey instrument was informed by a literature review and observation of PACE and SMC meetings. Likert scale questions were used to determine the relative importance of factors in the PACE statement, including information relating to eight prominent 'quality of life' themes (family/carer impact, health benefits, tolerability,

psychological benefit, hope, normal life, treatment choice and convenience), that were identified by an earlier thematic analysis of these statements.

**Results.** Analysis of survey responses will use mainly descriptive techniques to generate percentages and ranges. Correlation analysis will be considered to investigate relationships between members' demographics, type of medicine (end-of-life, orphan) and the importance of different factors in the PACE statement. Preliminary results indicate that key quality of life themes highly valued by patients/carers are also important to committee members in their decision making. Challenges in assimilating qualitative patient-based evidence from PACE alongside quantitative clinical and economic data were highlighted.

**Conclusions.** Findings from this survey will provide valuable insight into how PACE evidence is used by SMC decision makers alongside traditional clinical and economic evidence and will help shape future improvements to the PACE methodology.

## OP23 Smart Searches For Context-Sensitive Topics: Geographic Search Filters

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and Amy Finnegan

**Introduction.** Some systematic review topics are context-sensitive and informed by evidence about a specific geographic setting. Smart information retrieval methods are required to identify such evidence in an efficient manner. This presentation will discuss how validated geographic search filters enable smart literature searching for context-sensitive reviews using the National Institute for Health and Care Excellence (NICE) United Kingdom (UK) filters for MEDLINE and Embase (OVID) as examples. The NICE UK filters were developed in 2016. The filters demonstrated high recall and high precision, however, further research was required to confirm these results.

**Methods.** In 2018, the filters' recall of references from 100 UK-based multidisciplinary reviews was calculated. Reproducible search strategies were identified from twenty-six of the 100 reviews in MEDLINE and from nine reviews in Embase. From this, the precision and number-needed-to-read (NNR) were calculated.

**Results.** The MEDLINE filter achieved 96 percent recall (1401 out of 1454 UK references), 2.1 percent precision and a NNR of forty-seven. The Embase filter achieved 97 percent recall (1520 out of 1560 UK references), 0.7 percent precision and a NNR of 146. Compared to not using a filter, the MEDLINE and Embase filters reduced the number of search results by an average of 87 percent and 80 percent, respectively.

**Conclusions.** The filters retrieve the majority of evidence for UK topics while reducing search result volumes and so enable smart literature searching for context-sensitive topics. Large literature search result volumes can increase development time-frames for systematic reviews. Using the filters can therefore save time for reviews with a UK focus. There are currently two other validated geographic search filters for Africa and Spain. It is hoped that the NICE UK filters' successful retrieval performance will encourage the development of validated search filters for more geographic regions.

## OP25 Organisational Learning Principles Applied To Information Retrieval

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**Introduction.** A key discussion point during HTAi's 2018 Meeting was how Health Technology Assessment (HTA) practitioners might borrow ideas from other industries or academic areas. Organisational learning (OL) is the study of how individual knowledge is shared within an organisation to become institutional/group knowledge. There are several models of OL, all focusing on how tacit knowledge (abstract, personalised, hard to define, action-based) is converted to explicit knowledge (definable, concrete, fixed, information-based). Effective knowledge sharing is crucial to leveraging individual knowledge to drive innovation, efficiency and effectiveness. Information retrieval is a knowledge-intensive field, with many processes requiring both tacit and explicit knowledge. Ideas from OL demonstrate ways to improve practice by increasing knowledge sharing.

**Methods.** Nonaka & Takeuchi's (1994) SECI model describes the cyclical process by which knowledge is shared. The model includes 4 stages: socialisation (tacit-to-tacit), externalisation (tacit-to-explicit), combination (explicit-to-explicit) and internalisation (explicit-to-tacit). Each stage describes how knowledge sharing takes place and highlights ways to ameliorate these processes. Information retrieval involves many elements that require or benefit from knowledge sharing and both tacit and explicit knowledge is required.

**Results.** In the SECI model the Socialisation stage is characterised by face-to-face learning. Peer reviewing of search strategies, open dialogue and team working are ways of facilitating this stage. The Externalisation stage is crucial to OL. This can be seen as the practice-into-research stage; the results of successful experimentation, for example with search filters. The Combination stage is the easiest to understand. Communities of practice and inter-organisational networks can widen knowledge sharing and help refine or increase detail of best practice. The Internalisation stage is the hardest to conceptualise or measure. The extent to which guidelines become adopted in individual practice is one way to gauge Internalisation.

**Conclusions.** Information retrieval practitioners could benefit from thinking about ways to improve knowledge sharing. Models of OL can be instructive in this regard.

## OP26 Search Approaches In Information Retrieval Presented In HTAi SuRe Info

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**Introduction.** It is a challenge to stay up-to-date with the latest developments in information retrieval for health technology assessment (HTA). Summarized Research in Information Retrieval for HTA (SuRe Info) is a well-established open-access website with a selection of up-to-date key papers presented in summarized overviews. SuRe Info is maintained by the HTAi Interest Sub-Group on Information Resources; its main target