

group are information specialists. SuRe Info is updated twice a year by experienced information specialists. Publications on information retrieval methods are identified by running topic-specific search strategies in relevant databases. Publications fulfilling the SuRe Info inclusion criteria receive a structured abstract together with a brief critical appraisal prepared by one SuRe Info information specialist and checked by another. The key messages from the appraisals are summarized in topic-specific chapters.

**Methods.** The structure and work of SuRe Info is presented on the basis of the chapter “Value of using different search approaches”.

**Results.** The chapter “Value of using different search approaches” was last updated in September 2018. It examines various alternative search approaches in bibliographic databases beyond the conventional Boolean search. According to this chapter, the most well-known approach, offering the most evidence, is citation searching (direct or indirect citation relationships). In contrast, little research has so far been conducted on other approaches such as full-text searches, automated retrieval methods or hand searching.

**Conclusions.** SuRe Info is an important resource for information specialists to keep up-to-date with the literature on information retrieval. In particular when information specialists work alone and not within a larger team, it is necessary to rely on collaboration projects such as SuRe Info.

## OP27 Engaging Patients: The EuroCAB Programme

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**Introduction.** When developing a health technology that requires clinical studies, developers institute working relations with clinical investigators. In certain diseases areas, patients’ representatives create their own advisory boards, which proved their utility in the early 90s, in particular for the development of products to treat HIV infection. Inspired by this model, where patients with a same disease join and meet with relevant developers and discuss all aspects of the research, the European Organisation for Rare Diseases (EURORDIS) proposes a new programme of such Community Advisory Boards for Rare Diseases (CAB).

**Methods.** For this programme, EURORDIS invites developers to sign a Charter of principles when engaging with patients, and provides guidelines on CABs, together with a mentoring programme for patients’ networks that are less experienced with the development and the evaluation of health technologies. CABs are driven by patients who set their agenda, who sign a Memorandum of Understanding with each developer, and who organise the sessions. Sessions typically last for two to four days during which different meetings with different developers can take place, or trainings. All meetings can take place under confidentiality arrangements, and minutes are written to keep track and to follow-up with all points discussed. Participants and agendas are made public

**Results.** As of 2018, four CABs exist and operate (for tuberous sclerosis complex, for scleroderma, for cystic fibrosis, for Duchenne muscular dystrophy) and 18 others are in discussion

with many due to start in 2019. Topics discussed cover the target population, the study feasibility, the endpoints including patient reported outcomes, the comparator choice and/or the acceptance of a placebo controlled trial, the quality of life, the practical aspects of the trials, and the identification of previously unknown or unmet patient needs/preferences. For products which are more advanced in their life-cycle, discussions can also cover compassionate use, pricing policy, relative efficacy etc.

**Conclusions.** This represents a well-structured programme for the engagement of patients, where collective thinking and exchange between different patients ensure high quality dialogue with developers and can inform HTA also.

## OP28 Patient Involvement at AQuAS: Experiences And Reflections For Future

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**Introduction.** AQuAS is gradually incorporating patient involvement in health technology assessment (HTA). We present two experiences conducted during 2018 and the different methods and approaches used. The aim is to reflect on learnings from those experiences to improve ways for increasing patient involvement with HTA at AQuAS.

**Methods.** We conducted two experiences using different quantitative and qualitative techniques (mix-methods approach). The first, a focus group discussion regarding the use of 3D-technologies for maxillofacial reconstruction with a selection of hospital patients that received maxillofacial reconstruction, which included the use of a quality-of-life retrospective self-assessment tool. The second, a sequence of email correspondence regarding cataract surgery technology (femtosecond laser-assisted cataract surgery (FLACS), in the context of an EUnetHTA Joint Assessment) with a patients’ association representative, to learn their opinion regarding the use of laser technology.

**Results.** Main learnings were: (1) patients and associations have different levels of knowledge and expertise to consider when planning an HTA; (2) sharing experience and knowledge among peers (i.e. focus group) proved to have a positive impact on patients and worked as a resource for some to improve knowledge on their condition; (3) critiques were received regarding a specific Patient Reported Experience template for HTA patient involvement (iv) quality of life retrospective self-assessment tool provided unexpected positive and negative results.

**Conclusions.** Recent patient involvement in HTA at AQuAS proved to be useful to complement HTA reports. We believe that patients’ experiences and opinions can help decision-making regarding the use, disinvestment or incorporation of health technologies, contribute to the improvement of tools and survey accuracy and improve doctor-patient communication. Their involvement might be beneficial for them to gain more knowledge, share experiences, reflect on their health situation and improve communication with the professionals that treat them. Future patient-involvement in HTA is needed, e.g. considering the social perspective in economic evaluations or including patients in recommendation consensus panels.