and validation of the Portuguese version of the Fear of Progression Questionnaire – Short Form. The panel will discuss clinical implications and directions for future research.

S05.1. Fear of cancer recurrence: an updated systematic literature review of self-reported measures from 2012

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Background: Fear of cancer recurrence (FCR) is a common occurrence among cancer survivors. There is a lack of current listings of FCR patient-reported outcome measures (PROMs) to assist in selecting the optimal FCR measurement for use in clinical or research settings.

Aim: To provide an update to the 2012 systematic review of FCR measures by identifying and describing the available PROMs of FCR validated in adult cancer patients, and to provide initial guidance for selecting the most appropriate FCR measure for a specific research or clinical context.

Methods: The COSMIN recommendations were followed. The literature search was performed in the electronic literature databases Medline, CINAHL, PsyInfo, EMBASE, and AMED. Included are cultural validation studies of FCR PROMs published in English. The studies were chosen through a process of peer review using the online software "COVIDENCE." The studies' quality was evaluated using the COSMIN Risk of Bias Checklist.

Results: The initial search yielded 6,524, only 25 of which were retained for analysis. From the 25 FCR PROM studies, we identified three existing FCR scales with cross-cultural validation in nine languages, five new FCR PROMs with varying scale lengths, and validation in two languages, and one presented as a screening instrument.

Conclusion: Our updated systematic review identified new and known FCR PROMs that have been validated in other languages, populations, and at new lengths of scale. These additional scale versions give researchers and clinicians more options when choosing an FCR PROM.

S05.2. The Ottawa Clinical Fear of Recurrence (OCFR) measures for clinical fear of recurrence: First look into the screener and self-report's validity and reliability

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Background: The Ottawa Clinical Fear of Recurrence (OCFR) measures are a set of three new measures being developed to assess clinical fear of recurrence, defined by a recent Delphi study of experts to be a) high levels of preoccupation, b) high levels of worry, c) that are persistent, d) along with hypervigilance and hypersensitivity to physical sensations that result in e) functional impairment. The measures were previously pilot tested and found to be acceptable by a group of cancer survivors.

Methods: Following the pilot study, the screener and self-report will be administered to 300 mixed cancer participants along with established instruments to investigate convergent, discriminant, and incremental validity. This will be assessed using Pearson correlations. Exploratory factor analysis will be used to explore the factor structure, and item response theory will help streamline the number of items on the self-report measure. A subset of 50 participant will complete the measure a second time 2 weeks later to explore test-retest reliability. Using the interview as a gold standard, ROC analysis will be used to establish cut-off scores.

Results: Data collection and analysis is currently underway. Preliminary results will be presented. Next steps will also be discussed.

Conclusion: This first step in the validation of the OCFR measures will allow for a first look into its psychometric properties and thus its place among the measures currently available for FCR. Furthermore, these measures will allow healthcare professionals to assess the presence of clinical FCR and therefore improve services for survivors who struggle with FCR.

S05.3. Portuguese Version of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF)

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Background: Considering that in Portugal, in 2020, 60.000 people were diagnosed with cancer and 50% died of the disease, it is not surprising that the diagnosis and subsequent stages, including survival, are marked by recurrent concerns and fears that the disease progresses negatively or reoccurs, with all its biopsychosocial consequences. Although this Fear of Progression/Recurrence is realistic and is part of the normal response to the disease, valid instruments are necessary to assess and monitor its severity and the evolution. The present study aimed to translate and validate the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) for the Portuguese population with cancer.

Methods: The sample included 220 participants, aged 18 years or over and diagnosed with cancer for at least six months. Cancer patients completed the FoP-Q-SF, the Hospital Anxiety and Depression Scale (HADS), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) and the Post-Traumatic Stress Disorder Checklist-Civilian Version (PCL-C).

Results: The FoP-Q-SF demonstrated high internal reliability ($\alpha = 0.86$). A confirmatory factorial analysis was conducted and supported a modified one-dimensional factorial structure, which allowed the co-variance of errors between some of the items, to improve the fit of the model (CFI=0.96; TLI=0.95; RMSEA=.08; 232 WRMR=0.8). The convergent validity was tested and, as expected, the strongest positive correlation was found between total FoP-Q-SF and anxiety scores. In addition, FoP-Q-SF was also positively and moderately associated with depressive symptoms and post-traumatic stress.

Conclusion: The results indicated that the Portuguese version of the FoP-Q-SF is a reliable and valid measure for assessing Fear of Progression in cancer.

S06: Work-related experiences and adverse work outcomes in rare cancer patients, their caregivers and health care professionals

Moderator: *Saskia F.A. Duijts*

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One in five patients diagnosed with cancer receives a rare cancer diagnosis, defined as those with an incidence of <6/100,000 people per year. While most of these rare cancer diagnoses occur in adults, tumors in children, adolescents and young adults are rare as well. Rare cancers have a great impact on the health care system as they bring unique challenges that are linked to rarity. Specifically, patients with a rare cancer are more likely to be misdiagnosed or diagnosed at a more advanced stage, have more problems finding adequate treatment, and experience higher levels of distress and lower quality of life often related to the unknown prognosis. Being diagnosed with a rare cancer also has an enormous impact on caregivers, because of e.g. high insecurity, and limited access to information and peer support. It is hypothesized that the specific challenges that patients with a rare cancer are confronted with impact their and caregivers' work ability. Further, providing adequate support can be a challenge for health care professionals.

In this symposium, we aim to inform IPOS participants about work-related experiences and adverse work outcomes in patients with a rare cancer, their caregivers and health care professionals, and to discuss adequate work-related support options for these patients and those involved. Three research abstracts will be presented: (1) a register-based study, in which adverse work outcomes in patients with a rare cancer were compared to patients with a common cancer, pre-diagnosis and up to five years post-diagnosis, and in which patients with a rare cancer at highest risk of these adverse outcomes were identified, (2) a qualitative study, in which interviews were conducted to explore work-related experiences and unmet needs of patients with a grade II-IV glioma, and the experiences and needs of relevant (healthcare) professionals in providing work-related support to glioma patients, and (3) a register-based study, in which the risk for adverse work outcomes among parents who lost a child with cancer compared to a matched cohort of parents was examined, and in which factors associated with the bereaved parents' work affiliation were assessed.

S06.1. Adverse work outcomes up to 5 years after a rare cancer diagnosis: a nationwide registry-based study with a common cancer reference group

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Objective/purpose: Patients with a rare cancer have a more complex illness trajectory and poorer prognosis than patients with a common cancer, potentially negatively influencing their work outcomes. Little is known about differences in work outcomes between patients with a rare versus common cancer. We explored whether rare cancer patients experience adverse work outcomes pre- and post-diagnosis more often than common cancer patients, and which rare cancer patients are at highest risk.

Methods: Linking data of the Netherlands Cancer Registry and Statistics Netherlands, employed patients with a rare (n=13,934) and common i.e., breast or colorectal (n=20,348) cancer were compared on adverse work outcomes, e.g., work disability, pre (-2 years) and post (5 years) -diagnosis. Chi-square tests and multivariable Cox regression analyses were performed.

Results: Compared to patients with a common cancer, patients with a rare cancer were younger (<45 years: 22% vs. 46%) and more often male (14% vs. 53%). Controlling for covariates, patients with a rare cancer had a higher chance (Hazard Ratio (HR) 1.83; 1.30-2.58) to become work disabled pre-diagnosis, and self-employed post-diagnosis (HR 1.32; 1.03-1.68). Within the rare group, various factors were associated with increased risk for adverse work outcomes, e.g., higher tumour stage, systemic therapy, and stem cell transplantation.

Conclusion and clinical implications: Although patients with a rare cancer appear relatively well-protected against adverse work outcomes pre- and post-diagnosis, slight yet relevant differences exist.

S06.2. Work-related experiences and unmet needs of patients with a grade II-IV glioma and relevant (healthcare) professionals: the BrainWork study

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Objective/Purpose: Many glioma patients are of working age at time of diagnosis. In this study, we explored: 1) the work-related experiences and unmet needs of patients with a malignant (grade II-IV) glioma, and 2) the