## IMPAHC 2023 May 23-24, 2023

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**Objective:** To characterize the emotional impact of germline sequencing among parents of children with cancer and to identify demographic, clinical, and psychosocial factors that may be associated with sequencing-related distress. Method: Participants were 104 parents of children with cancer recruited from a pediatric oncology hospital for a prospective study of clinical tumor and germline genomic sequencing. Parents completed psychosocial questionnaires at consent (i.e., genetic knowledge), prior to disclosure of results (i.e., sequencing-related worry), and ≥5 weeks following disclosure of results (i.e., sequencing-related distress). Bivariate associations with distress were tested using t-tests or ANOVAs for categorical variables and correlations for continuous variables. Variables with significant bivariate relations were included in a multiple regression model predicting distress related to sequencing results. Results: Parents' sequencingrelated distress significantly differed across parent relationship status (Mean single=11.55, Mean partnered=7.12; t[39.34]=2.12, p=0.04) and result-type (pathogenic, uncertain, vs. negative results; t[2,101]=3.37, p=0.038), and was significantly correlated with higher predisclosure genetics knowledge (r=0.27, p=0.006) and worry about potential sequencing results (r=0.41, p<0.001). Parents of children with pathogenic results endorsed significantly more distress than those with negative results (p=0.029); however, those with uncertain results did not differ in distress from those with negative results (p=0.548). Pathogenic results continued to be significantly associated with distress (F[4,92]=9.95, p<0.001;  $\beta$ =0.19, p=0.031) even after controlling for relationship status ( $\beta$ =-0.19, p=0.029), genetic knowledge ( $\beta$ =0.20, p=0.022), and pre-disclosure worry ( $\beta$ =0.38, p<0.001). **Conclusions:** Parents of children found to have a genetic variant linked with cancer predisposition may benefit from psychosocial screening or referral to a psychosocial provider for evaluation of distress. Specifically, screening parents' relationship status and worry about sequencing prior to learning results may be informative in identifying parents most likely to benefit from further support. Reporting uncertain results does not appear to yield elevated distress for parents. Further research about the duration of distress following a pathogenic result and the ideal way to disclose these results and support families experiencing distress is warranted.

PA4-3

## PLAY-THE-ODDS: CO-DESIGNING A COMMUNICATION TOOL TO HELP PARENTS TALK ABOUT GENETIC CANCER RISK WITH THEIR CHILDREN

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Objective: Disclosing hereditary cancer risk (HCR) information to children and maintaining an open communication over time is crucial for family psychosocial adaptation. In the absence of available resources to facilitate education or parental empowerment toward open and developmentally appropriate communication with children, both health providers and parents call for robust supplemental tools to assist them in this process. Werner-Linn proposes a model describing the phases for age-specific communication between parents and children. Theoretically framed in this model, our project aims to develop a game-based tool to help parents and children communicate about HCR. The aim of this paper is to showcase the interdisciplinary codesign process of solutions for this tool. Method: Using a participatory and interdisciplinary approach, we brought together people with HCR syndromes and their families, genetic counselors (GC), psychologists, communication designers and gamification specialists, for a total of 20 participants. We followed a human-centered design process, with the combination of agile methods, focusing on Lean and Biodesign methodologies. Over 4 codesign workshops, participants identified priority needs for each dimension (Wks 1), ideated (Wks 2) and validated solutions (Wks 3), and ended by reassessing results and conceptualizing the aggregation of all solutions in a unified resource (Wks 4). Results: The codesign approach in a dynamic and agile environment allowed the participants to feel empowered with strategies to complete the process of finding viable solutions for the needs they identified. Participants expressed gratitude and enthusiasm for being invited and allowed to be part of the solution. At the end of the 4 workshops, we prepared a simplified model for prototyping and aggregating all the co-designed solutions. Conclusions: The insights shared by end users and the expertise brought by health and design specialists in a codesign process allowed a deeper understanding of the problem of psychosocial adaptation to HCR, while the adoption of agile methodologies allowed the fast-paced creation of solutions to this problem. This experience highlighted the value of interdisciplinary collaboration for the creative development of evidence-based solutions for psychosocial adaptation to HCR.

PA4-4

## ADJUSTMENT OF AYA AND CAREGIVERS OF PEDIATRIC PROBANDS TESTED FOR A GENETIC CANCER PREDISPOSITION

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**Objective:** It is unclear how adolescents and young adults (AYA), and caregivers of pediatric probands, adjust to genetic testing for cancer predisposition or how it differentially impacts