A Measure of Informed Decision-Making in Prenatal Genetic Screening: Instrument Development

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**Introduction:** Informed decision-making (IDM) is having adequate knowledge when making decisions about some aspect of one’s health. Deciding whether or not to receive PGS requires a thorough consideration of medical harm versus benefit, personal beliefs and values, familial input, and societal norms and pressures (Henneman et al., 2008). Unfortunately, many PGS decisions are made based solely on the gist of information health care professionals provide (Reyna, 2008). In other words, expectant couples often are not informed about all aspects of the PGS process and are only provided with information they themselves or the health care professional deem important. The purpose of this research presentation is to discuss the development of a valid and reliable measure of informed decision making in prenatal genetic screening (IDM-PGS).

**Method(s):** A thorough review of the literature unveiled key points of consideration for ensuring IDM during prenatal genetic screening (PGS). These key points were used as domains under which items were developed. After development of these items, the researcher gathered a group of peers to discuss the face validity of each item. In the next phase, the content validity index of the instrument will be measured by sending the instrument to five content experts. Finally, the instrument will be piloted with a representative sample for construct validity and reliability.

**Results:** This research is part of dissertation work and though it is still in process, it will be completed within a required time frame. Preliminary findings show strong face validity of the items in the instrument.

**Discussion & Conclusions:** There is a lack of extant quantitative research related to IDM-PGS. This lack of literature in combination with the highly controversial nature of this topic highlights the need for more extensive quantitative research. The administration of the developed instrument will allow for generalizability of results. Once generalized to the population, current gaps and deficiencies in IDM-PGS will be seen. These results will promote the advent of interventions. Clinical decision pathways assisting expectant couples making PGS decisions and improved instructional information for the health care provider will, ideally, improve an expectant couples IDM-PGS.