

Additional File 1:

Survey Items

Attitudes Toward Preimplantation Genetic Testing and Quality of Life among Individuals with Hereditary Diffuse Gastric Cancer Syndrome

Ibrahim H. Shah, BA

Erin E. Salo-Mullen, MS, MPH, CGC

Kimberly A. Amoroso, MS, CGC

David Kelsen, MD

Zsafia K. Stadler, MD

Jada G. Hamilton, PhD, MPH

Corresponding author: Jada G. Hamilton, Memorial Sloan Kettering Cancer Center, 641 Lexington Avenue, 7th floor, New York, NY 10022. Phone: 646-888-0049, Fax: 212-888-2584, Email: hamiltoj@mskcc.org.

DEMOGRAPHIC INFORMATION:

What is your gender?

- ☐ Male
- ☐ Female

What is your current age? _____

What do you consider to be your race/ethnicity?

- ☐ Caucasian
- ☐ Asian
- ☐ Black or African
- ☐ Hispanic
- ☐ Other: _____

What is your current relationship status?

- ☐ Single
- ☐ Married / Life Partner
- ☐ Separated / Divorced
- ☐ Widow / Widower
- ☐ Other: _____

Please describe your highest level of education:

- ☐ Did not complete high school
- ☐ High school graduate
- ☐ Attended some college, but did not graduate
- ☐ College graduate
- ☐ Post-graduate

Please describe your current household income:

- ☐ Less than \$50,000 per year
- ☐ Between \$50,000-100,000 per year
- ☐ Between \$100,000-200,000 per year
- ☐ More than \$200,000 per year

Which, if any, of the following religions do you identify with as being a member?

- ☐ Buddhist
- ☐ Catholic
- ☐ Eastern Orthodox
- ☐ Hindu
- ☐ Jewish – Ashkenazi
- ☐ Jewish – Sephardic
- ☐ Jewish (other)
- ☐ Latter Day Saints or Mormon
- ☐ Muslim
- ☐ Protestant
- ☐ Seventh Day Adventist
- ☐ None
- ☐ Other: _____

Please rate the impact that religion has on your overall decision-making:

- ☐ Not at all
- ☐ Somewhat
- ☐ Moderately strong
- ☐ Very strong

PERSONAL & FAMILY HISTORY INFORMATION:

Personal Cancer History:

Have you been diagnosed with cancer?:

- ☐ Yes
- ☐ No

If yes, what type of cancer were you diagnosed with and how old were you at diagnosis?

Type #1: _____ Age at #1 diagnosis: _____

Type #2: _____ Age at #2 diagnosis: _____

Type #3: _____ Age at #3 diagnosis: _____

In what year did you have *CDH1* genetic testing? _____

Have you undergone total gastrectomy?

- ☐ Yes, I have undergone a prophylactic total gastrectomy.
- ☐ Yes, I have undergone total gastrectomy that was initially thought to be prophylactic, but gastric cancer cells were found upon surgical pathology review.
- ☐ Yes, I have undergone a total gastrectomy because of a previously identified gastric cancer.
- ☐ No, I have not undergone total gastrectomy.

If yes, how old were you when you underwent total gastrectomy? _____

Family Cancer History:

How many (if any) of your first-degree relatives (parents, siblings, children) have been diagnosed with a HDGS-associated cancer (i.e. diffuse gastric cancer or lobular breast cancer)?

0 1 2 3 4 5 6 7 8 9 10 11+

If you have had first-degree relatives who have been diagnosed with HDGC-associated cancers, hold old were these family member when they were diagnosed with their (first) cancer?

Family Member #1: _____ Family Member #2: _____

Family Member #3: _____ Family Member #4: _____

Family Member #5: _____ Family Member #6: _____

Family Member #7: _____ Family Member #8: _____

Family Member #9: _____ Family Member #10: _____

Family Member #11: _____ Family Member #12: _____

How many (if any) of your first-degree relatives (parents, siblings, children) have died from a HDGC-associated cancer (i.e. diffuse gastric cancer or lobular breast cancer)?

0 1 2 3 4 5 6 7 8 9 10 11+

If you have had first-degree relatives who have died from a HDGC-associated cancer, how old were these family members when they have died from their cancers(s)?

Family Member #1: _____	Family Member #2: _____
Family Member #3: _____	Family Member #4: _____
Family Member #5: _____	Family Member #6: _____
Family Member #7: _____	Family Member #8: _____
Family Member #9: _____	Family Member #10: _____
Family Member #11: _____	Family Member #12: _____

Personal Reproductive History:

Do you have biological children (conceived using your and your partner's egg and sperm)?

- ☐ Yes
- ☐ No

If yes, what are the ages of the children?

Child #1: _____	Child #2: _____	Child #3: _____
Child #4: _____	Child #5: _____	Child #6: _____

Do you know your biological children's *CDH1* mutation status (i.e. positive or negative for the familial *CDH1* mutation)?

- ☐ Yes, I know all of my biological children's mutation statuses.
- ☐ I know some of my children's mutation statuses.
- ☐ No, I do not know any of my biological children's mutation statuses.
- ☐ Other: _____

Have you or your partner experienced 2 or more pregnancy losses (i.e. miscarriages)?

- ☐ Yes
- ☐ No

Have you or your partner been diagnosed with infertility?

- ☐ Yes
- ☐ No

Have you or your partner used donor gametes?

- ☐ Yes
- ☐ No

If yes, did you use donor gametes to eliminate the risk of a *CDH1* mutation in your children?

- ☐ Yes
- ☐ No

Have you or your partner used in-vitro fertilization (IVF)?

- ☐ Yes
- ☐ No

Have you or your partner used pre-implantation genetic diagnosis (PGD)?

- ☐ Yes
- ☐ No

Do you have adopted children?

- ☐ Yes
- ☐ No

If yes, did you adopt to eliminate the risk of a *CDH1* mutation in your children?

- ☐ Yes
- ☐ No

ATTITUDE TOWARD PRE-IMPLANTATION GENETIC DIAGNOSIS (PGD):

Do you want to have (more) biological children now or in the future?

- ☐ Yes
- ☐ No

Had you heard about pre-implantation genetic diagnosis prior to participating in this survey?

- ☐ Yes
- ☐ No

If yes, from whom or where did you hear about pre-implantation genetic diagnosis (PGD)?

- ☐ Physician
- ☐ Genetic counselor
- ☐ Family member
- ☐ Friend
- ☐ Internet or newspaper
- ☐ Other: _____

Do you believe it is an acceptable practice for healthcare providers to inform individuals who have *CDH1* gene mutations about the availability of PGD?

- ☐ Yes
- ☐ No

If no, please describe the reason for your opposition: _____

Have you previously considered using pre-implantation genetic diagnosis (PGD)?

- ☐ Yes
- ☐ No

If yes, did you meet with a reproductive endocrinologist to discuss PGD?

- ☐ Yes
- ☐ No

Please indicate your level of interest in learning more about PGD:

- ☐ Not interested
- ☐ Uncertain
- ☐ Somewhat interested
- ☐ Very interested

In general, do you believe that pre-implantation genetic diagnosis (PGD) is acceptable for conditions that occur during childhood?

- ☐ Yes
- ☐ No

Do you believe that pre-implantation genetic diagnosis (PGD) is acceptable for families with *CDH1* gene mutations?

- ☐ Yes
- ☐ No

If you want to have (more) *biological* children in the future, please rate the likelihood of you using PGD for the *CDH1* gene mutation in the future:

- ☐ Definitely not
- ☐ Probably not
- ☐ Do not know
- ☐ Probably
- ☐ Definitely

If you answered 'definitely not' or 'probably not,' please explain the reason for your opposition:

If you have already completed your family, would you have considered using PGD for the *CDH1* gene mutation if this technology had been available when you were having children?

- ☐ Definitely not
- ☐ Probably not
- ☐ Do not know
- ☐ Probably
- ☐ Definitely

If you answered 'definitely not' or 'probably not,' please explain the reason for your opposition:

Have any of your family members (other than your partner) previously used reproductive technologies?

- ☐ Yes
- ☐ No

If yes, which technology was used? (Circle all that apply)

- ☐ Donor Gametes
- ☐ In-vitro Fertilization (IVF)
- ☐ Pre-implantation Genetic Diagnosis (PGD)

After completing this survey, will you discuss the availability of the PGD with a family member who has a risk to have a child with the *CDH1* gene mutation?

- ☐ Definitely not
- ☐ Probably not
- ☐ Do not know
- ☐ Probably
- ☐ Definitely
- ☐ Not applicable—nobody appropriate in my family

If you have any, what is your main concern or worry about PGD? _____

If you believe there are any, what is the main benefit of PGD? _____

IMPACT OF HEREDITARY DIFFUSE GASTRIC CANCER (HDGC) SYNDROME ON LIFE:

How often do you worry about your chances of developing gastric and/or breast cancer (again)?

- ☐ Not at all/Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Almost all the time

On a scale of 1 to 10 (1=not severe, 10=most severe), please rate how severely HDGC syndrome has affected your overall health and well-being:

0 1 2 3 4 5 6 7 8 9 10

Do you experience guilt related to HDGC syndrome affecting your family members?

- ☐ Yes
- ☐ No

How satisfied are you with your quality of life?

- ☐ Uncertain
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

Has having HDGC syndrome caused you to alter important life decisions?

- ☐ Uncertain
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

If you would like to tell us more about how HDGC syndrome has caused you to alter important life decisions, please do so here: _____

Has having HDGC syndrome affected your current or future reproductive decisions?

- ☐ Uncertain
- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

If you would like to tell us more about how HDGC syndrome has affected your current or future reproductive decisions, please do so here: _____