

# **Preparing Genetic Counselors for Patient Disclosure of Intimate Partner Violence: An Assessment of an Intervention Toolkit**

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## **Introduction:**

The Center for Disease Control (CDC) defines intimate partner violence (IPV) as physical, sexual, or psychological harm by a current or former partner or spouse (Breiding, Basile, Smith, Black, & Mahendra, 2015). Intimate Partner Violence (IPV) can occur among heterosexual or same-sex couples and does not require sexual intimacy. Studies conducted by the CDC in 2011 found that IPV affected approximately 29% of women and 10% of men in the U.S.

When considering the relationship between IPV disclosure to healthcare providers and the receipt of intervention, McCloskey et al. found that patients who spoke with their healthcare providers about IPV were more likely to utilize interventions such as advocacy groups, shelters and restraining orders (2006).

Additionally, the majority of victims who left abusive partners had interventions in place prior to leaving (2006). Despite the ability of healthcare providers to aid victims in leaving abusive relationships, barriers to aid remain. Some common barriers include financial dependency, lack of social or family support and desire to avoid separating children from an abusive parent (Gharaibeh & Oweis, 2009).

Resta et al. define genetic counselling is a communicative process, which aims to help individuals, couples and families understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions (Resta et al., 2006) . However, that definition is not representative of the strong psychosocial component of genetic counseling sessions. Genetic counselors often discuss sensitive topics with patients such as family dynamics, personal and family diagnoses, and access to resources.

Genetic counseling education also provides genetic counselors with psychosocial knowledge and skills. Domain two of the Accreditation Counsel for Genetic Counseling (ACGC) competencies stresses the importance for genetic counseling students to attain interpersonal, psychosocial and counseling skills within their genetic education program (2015). Some of the skills required by this domain include: employ active listening and interviewing skills to identify, assess, and empathically

respond to stated and emerging concerns; promote client-centered, informed, non-coercive and value-based decision-making; and understand how to adapt genetic counseling skills for varied service delivery models. Another role of genetic counselors is to be an advocate for their patients and communities. All of these skills are useful in working with victims of IPV.

By creating a safe place for patients, where they can feel heard, genetic counselors build rapport. Providers can dedicate anywhere from 30 minutes to one hour to a patient during a session. This may provide adequate time for patients to disclose IPV, and for genetic counselors to access hospital/department resources such as social workers and security. Furthermore, some patients may see the same genetic counselor, or the same genetic counseling department several times depending on the nature of their clinical situation. For example, a woman with an ultrasound anomaly may keep coming back for the same ultrasound. This may provide enough time and encounters between patient and counselor for the patient to gain enough trust in a counselor to disclose IPV.

To determine if patients would feel comfortable to be asked about IPV by a genetic counselor, Chen et. al surveyed 50 patients about IPV disclosure. Sixty-eight percent of patients felt comfortable having IPV asked about and 78% of patients felt comfortable having IPV addressed by a genetic counselor in a genetics session. In an unpublished follow up study, genetic counselors were asked about their feelings about IPV disclosure. With over 200 genetic counselors taking the survey, the majority of genetic counselors supported including IPV screening questions into their practice. In addition, over 1/3 of those genetic counselors who took the survey had experienced IPV disclosure during a session. Additionally, the majority of these individuals did not feel properly equipped to handle the disclosure.

Systematic reviews of UK IPV screening tools found that several short screening tools were valid and reliable for use in healthcare settings (Feder et al., 2009). The HITS (Hurts, Insults, Threatens and Screams) scale had the best predictive power (sensitivity ranged from 86% to 100%, specificity ranged from 86% to 99%), concurrent and construct validity ( $r$  ranged from 0.75 to 0.85,  $p < 0.001$ ) and reliability (Cronbach's alpha ranged from 0.61 to 0.80), with a suitable cut-off score. Similarly, a

systematic review identified 11 trials (including 13,027 participants in total) assessing the effect of universal, routine IPV screening of women in healthcare settings, without subsequent intervention beyond information giving, safety planning or referral that was offered to women immediately following suspicion (O’Doherty et al., 2014). The study found that screening increased the identification of women who had experienced IPV, but identification was still low compared with estimated prevalence rates.

There is currently a debate about whether universal or targeted screening would be more effective at helping identify victims of IPV (Valpied & Hegarty, 2015). More targeted identification strategies involve asking victims about IPV if they present with psychosocial or physical symptoms that often occur as a result of IPV, or are in a high-risk category. Psychosocial “risk factors” for asking about IPV include anxiety, depression, eating, or panic disorders, alcohol abuse, suicide ideation or attempts and self-harm. There are various situational and physical signs of abuse as well. Based on observations and questions genetic counselors ask during genetic counseling sessions, it seems they are in an excellent position to recognize these signs in a patient.

### **Approach To Adult Education**

When trying to educate an individual on a specific topic, it is imperative you understand what the demographic of the population you are trying to teach is. This will allow you to center your educational tool directly to your target audience. The theory of learning most applicable to adults is defined as andragogy. According to Dr. Cyril O. Houle, adult learners fell into three categories: goal-oriented, activity-oriented and learning-oriented (1961). Goal-oriented learners were classified as those who used education to meet well defined objectives. Li and Shieh described these goal-orientated learners’ motivations, beliefs, emotions, cognitive strategies and learning performance as having an impact on goal orientation (2016). For example, a genetic counselor who is goal orientated would take a continuing education class on variants of unknown significance (VUS) to become proficient at the analysis of a VUS. Sitthisak, Gilbert & Davis added to this by addressing how

focusing on the learner's competence level rather than focusing on gross knowledge acquisition was of greater importance (2007).

Activity-oriented adult learners were individuals who engaged in education due to the nature of the activity itself and not the defined objective of the activity. These activity-based learners do not simply learn to get results, but instead need to analyze each step in the learning process (Florian, Glahn, Drachslar & Specht, 2011). These types of learners would take the VUS class because they enjoy the experience and process. Finally, learning-oriented learners were those who simply wanted to increase their knowledge and learn, regardless of the subject. An example of a learning orientated learner would be a genetic counselor that enrolled in the VUS class because they felt it was essential to know how to analyze a VUS, along with other genetic counseling skills. Dr Kvale and others highlighted how vital it is for adults to develop their lifelong learning abilities as a means of ensuring a competitive edge in the job market (2007). It is important to understand an adult's motivations of learning in order to create an effective health education intervention that could reach all three categories of learners.

Since adult learners approach learning with different experiences, they inherently have learning backgrounds, learning styles, motivations, needs, interests and goals that are unique to themselves (Palis & Quiros, 2014). While a curriculum that is applicable to such a variety of differences among students is necessary, arguably a more important aspect for success of the intervention is to standardize limiting factors in the learning environment.

It is imperative to further differentiate the types of skills being addressed through the curriculum. The British philosopher Gilbert Ryle was the first to differentiate job related skills and transversal skills (1979). In genetic counseling, an example of a job related skill would be to analyze a pedigree. A transversal skill, in contrast, would be the ability to think analytically. While ultimately these differences may seem small, it is important to ensure the most effective objectives are created during curriculum design.

## **Study Objectives:**

To address genetic counselor readiness for intimate partner violence disclosure by patients we developed a genetic counseling IPV discussion guide, drawing together a variety of IPV resources and utilizing contemporary adult learning principles to inform the design process. The purpose of this study is further refine the discussion guide with the goal of developing a tool that can be widely utilized by genetic counselors and aid in IPV screening and intervention. In this study, by analyzing and performing interviews, surveys and we will identify, create and improve interventions that genetic counselors could utilize in the event of an IPV disclosure. Additionally, to measure the effectiveness of the intervention, focus groups will be conducted with genetic counselors, program directors, and IPV advocates who have reviewed the toolkit.

## **Methods and Materials:**

### **Toolkit Design**

To help clarify the needs of genetic counselors, a survey was dispersed to genetic counselors asking whether they had experienced IPV, whether they felt prepared to handle IPV disclosure, and whether an education tool for IPV would be useful. Of the 211 respondents, approximately 1 in 3 reported IPV disclosure in at least one genetic counseling session. When referring to the counselors who did have an IPV disclosure, approximately 60% of counselors did not feel comfortable, and approximately 74% of genetic counselors who completed the survey expressed the need for an IPV intervention tool. Those interested in a tool gave their thoughts on what they'd want their tool to include, and in our attempt to address their needs the objectives for our toolkit were created.

After analyzing the results of this survey of genetic counselors, which underscored that genetic counselors felt unprepared to act after patient disclosure of IPV, we decided to create an IPV intervention toolkit. In order to create the toolkit two literature reviews were completed. The first literature review revolved around adult learning and how to present data in an effective way. We collected information regarding effective ways to distribute information to adult learners, and we ensured our toolkit revolved around the associated principles. A core piece of information found was

that for adult learners, relevance of the material made learning easier than if the information was not related (Donovan, Bransford, & Pellegrino, 1999). This information led to the creation of a visual aid in our toolkit explaining the relevance of IPV to genetic counselors.

Of equal importance, the first step in helping a victim of IPV is the ability to identify that they are a victim and act effectively. For this reason, a second review was completed to address the content to include in the toolkit. This literature review discussed health outcomes for victims of IPV in all settings, it also explored current practices concerning the proper aid to victims of intimate partner violence. The literature for this part of the project also looked for effective de-escalation techniques and guidelines for genetic counselors who may be faced with an actively violent session.

Given the wide array of learning styles we wanted to use in our tool, various methods were used to find links and create material in our toolkit. To make the visual aids in the toolkit, information from various domestic violence agency's websites, and Pubmed searches regarding IPV, and each of the main genetic counseling specialties (cancer, prenatal, and pediatric) were used. Given the CDC has done research on the topic, a link to their website regarding IPV was also included in the toolkit.

For the de-escalation techniques, an online search for de-escalation techniques was completed; we found 3 reputable sources, one was from a human services training program known as "Crisis Prevention Institute (CPI)" and had techniques written specifically for law enforcement officers. Another link was one of the only available online de-escalation self-teaching packets (BAMSI), and was chosen as an attempt to address survey respondents desire for learning through scenarios. The final link was from a workgroup from the American Association of Emergency Psychiatry and was placed in order to have a more healthcare specific resource available.

Screening tool ideas were discovered by reading research articles that discussed domestic violence/IPV screening styles and effectiveness. There are two styles, targeted and universal screening. When searching for these screening tools the goal and outcome was to have one tool (HITS) that could be used universally and quickly, and another tool (RADAR) which could be used

for a more targeted (suspected) population. Both tools were included in the toolkit bearing in mind genetic counselors would choose a style they felt was best for their practice. Appropriate follow up questions were found in a similar manner to screening tools and a link to a motivational interviewing session was included to help interested genetic counselors have a better idea of the types of questions to ask patients who disclosed or were suspected to be victims of IPV.

The toolkit itself had multiple iterations based upon the insertion of infographics which took information on the signs and symptoms of IPV (<https://www.drugs.com/cg/intimate-partner-violence.html>, 2016) and information regarding the role of IPV in patient care in a prenatal, pediatric and cancer clinical setting. These infographics were designed using Piktochart (<https://piktochart.com/>) to represent a more visual aspect to the information. These iterations culminated in the final product to provide the best version possible for the two groups to evaluate the effectiveness. Additions include two specific videos identified to be impactful in giving increased visual representation of both IPV (Domestic Violence Screening for Health Professionals, 2014) and an example of how to handle an IPV disclosure (Motivation Interviewing with Survivors of Intimate Partner Violence, 2015).

The multiple iterations of the IPV toolkit was the result of a systematic process of altering the amount, formatting, and order of the information. Only after these parameters were outlined was the specific content evaluated through discussion between the authors. The decision to create a compact toolkit led to the ultimate choice to have the toolkit not exceed two pages. This then altered the amount of content space available and refocused formatting.

The next aspect of this process was gauging what information would have the largest impact in infographic form. This transitioned into the ordering of what content would be placed where. Although partially determined by format, ultimately we determined that the logical order would be to place information to understand IPV first, followed by how to address an IPV disclosure. This was concurrent with our stated objectives and allowed for each content point to be evaluated upon the basis of being the most productive means of accomplishing our goal. As such, there is also an

understanding that as more research is conducted in this field, the information included will evolve as well. As such, while Appendix 1's version of the toolkit was evaluated to make improvements (as shown in Appendix 2), future iterations will undergo this entire process again to create the most effective IPV intervention tool possible.

### **Toolkit Evaluation**

The version of the toolkit that is being evaluated is included at the end of this paper (Appendix 1) with the final version of the toolkit below (Appendix 2). The toolkit was deemed to need assessment from both the target audience of Genetic Counselors and from experienced individuals in the domestic violence support network. The purpose of this two pronged assessment was to determine how genetic counselors view the toolkit as well as how members of the domestic violence support community feel about the presentation of IPV facts. Expedited IRB approval was obtained through Sarah Lawrence College from 25 February 2017 – 24 February 2018, under IRB # 00009775.

For genetic counselors to determine the efficacy of the toolkit, phone interviews were determine to be the best means to communicate the thoughts and feelings which seeing the toolkit and its resources evoked. A maximum of 45 minutes was allocated for each interview to evaluate the toolkit. The genetic counselors were from a variety of experience levels but had no formal training in IPV assessment of patients. No financial compensation to the counselors was involved.

In addition to the feedback from genetic counselors, feedback from the IPV community was obtained through phone interviews with individuals with three or more years of experience in the domestic violence support community. These phone interviews were conducted in approximately 45 minutes with the individuals asked the same questions as the genetic counselors who completed phone interviews. A total of 3 genetic counselors and 3 domestic violence advocates were interviewed for a total of an n=6.

## **Data Collection procedures**

A series of open ended questions were asked that evaluated a number of different aspects of the toolkit. First, questions regarding the layout and display of the information were asked to evaluate how well the information was presented. This included how the sentences were constructed as well as the flow of the document. The next class of questions was primarily surrounding the toolkits objectives and how well the toolkit met the overall objectives outlined. These two classifications of questions were completed with answers kept on with a digital recording to be transcribed for analysis with the full list of questions located in Appendix 3.

The transcripts of the focus group were transcribed through the transcription service Rev. The raw data was then divided into the major themes present in their responses. This includes two categories determining whether the response was positive or negative, as well as a code for each of the 6 Objectives. These major themes were then evaluated to determine the list of changes to make to the toolkit.

## **Results:**

### **Toolkit Revision:**

A total of 22 themes emerged. Table 5 shows the specific codes used as well as the frequency of each code. The first analysis of this data was to differentiate the data into two categories: Genetic Counselors (GCs) and Domestic Violence Advocates (DVA). This was done to see if there were instances where there was a difference of opinion consistent throughout these two groups. Several examples became evident in this analysis, presented in Table 1. Of these, the difference between the preference in screening tools was the most mentioned, with every individual interviewed giving an opinion and not a single individual falling out of their respective group's preference.

The very specific themes present in all individuals interviewed provided information regarding consistencies and areas for improvement in the toolkit. In this case, examples of positive reinforcement and areas of improvement are listed below in table 2. These were classified by not only the theme in which they represent, but also by the objective in which the underlying information of

the IPV toolkit was attempting to achieve. Upon review of 41 quotes, 10/41 were directly related to the toolkit as a whole, 2/41 referred to Objective 1, 8/41 referred to Objective 2, 6/41 referred to Objective 3, 7/41 referred to Objective 4, 4/41 referred to Objective 5, and 6/41 referred to Objective 6. This shows an underlying unity that all of the objectives received affirming and constructive feedback.

In this differentiation of themes, one underlying commonality presented itself by having 14 specific quotes associated with offering a recommendation. An equal number of recommendations came from GC's and Advocates with each having 7 of the possible 14. These recommendations were individually analyzed to show how specific changes to the toolkit could be a benefit in the interviewee's opinion. The summary of the findings can be found in Table 3, representing all recommendations, regardless of the practicality of the recommendation being made.

The next piece of information denoted from the qualitative data came specifically from the basis of our first objective; however, the scope of who 'awareness' was pertaining to did not stop at just genetic counselors. The full collection of this data is represented in Table 4 as the most prolific examples of awareness of all individuals who may be affected by the implementation of the IPV toolkit. Additionally in Table 5 are the tallies of each theme for the total of all 6 interviews. This qualitative data lead to the update of the IPV toolkit into version 2.0, incorporating the advice and information gleaned from the interviews both directly and indirectly. As such, Appendix 2 shows the finalized version of the toolkit with all revisions and additions.

### **Discussion:**

Substantial changes were informed by the phone interviews and the input from both Domestic Violence Advocates and Genetic Counselors was crucial for quality revisions. The inquiry of the IPV toolkit for Genetic Counselors needed to be interpreted by both the genetic counselors who would be using this, as well as Domestic Violence Advocates who were experienced in using years of training and methodologies to provide the best service to their patients as possible.

Results from the study revealed that every one of the 6 objectives in the toolkit were addressed or mentioned in interviews. The comments associated with these objectives aided in the development of themes. Among these themes was the overwhelmingly positive view on the toolkits layout, organization, and ability to effectively educate on its objectives in a way that interviewees understood and found useful.

Given the overall goal of the toolkit was to create a useful tool that could provide genetic counselors with guidelines if IPV is witnessed or disclosed during a session, the ideal theme to begin discussion is the theme of relevance (20). Quotes that elicit the general reaction of interviewees can be found below:

*“I think obviously there's a deficiency in [IPV awareness] since we don't have one [toolkit], so I think this is great that you went there and got it done.”(GC)*

*“It's all stuff that's relevant to us, and I could see how we could be prepared to use it in our sessions.” (GC)*

*“I liked all your links...they were relevant to what you were talking about, and I felt like you put them all at the appropriate spot...in the toolkit” (Advocate)*

The idea of the toolkits relevance was frequently and eagerly expressed. The theme of usefulness was also expressed fervently. Both the theme of relevance and that of usefulness could be found in all sections of the toolkit; the themes addressed and represented all toolkit objectives. Reviews of the toolkit were overwhelmingly positive with 86 positive comments and 37 comments indicating its usefulness/helpfulness. This added to an overall 123 positive comments regarding the tool vs only 33 negative comments. These numbers support the feeling that generally speaking,

genetic counselors and advocates who reviewed the toolkit thought it could be an invaluable guide. The lack of negativity regarding the toolkit further suggests the relevance of such a tool.

A potent part of the toolkit was its mode of presentation and utilization of visual aids (videos and infographics). These aids were meant to convey information, keep viewers engaged and effectively utilize space. As a result, thoughts on visual aids and toolkit organization were a large part of interviewee responses. Examples of interviewee appreciation of the visuals include:

*“And I want to say even though the subject matter isn’t pleasing, [the infographic is a] more eye-pleasing way to look at it and read it.” (Advocate)*

*“I like that [the infographic is] simplified, sort of things you may not think about like marks, and bruises, and cuts, and scars. No I think it’s a good infographic.” (GC)*

Similar to the prevalence of visual aid commentary was that regarding organization, convenience and professionalism of the toolkit. These contained 28 and 34 relevant comments respectively. It can be concluded that by including visual aids and links in a quick read tool (8 comments), the project was made suitable for genetic counselors. This conclusion is supported by the fact both IPV advocates (experts in their field), and genetic counselors agree the toolkit was efficient in its dissemination of information.

Both advocates and genetic counselors acknowledged that there were limitations to the toolkit, the most pronounced limitation being its inability to address legal issues. Another limitation was the lack of education genetic counselors received on the topic in school which in turn created discussion of genetic counselor indecisiveness in choosing the best follow up questions, screening tools and methods to use in their practice. Also important is the fact the toolkit’s mode of conveying information while it may work for many individuals may not work for others. Quotes that express these limitations include but are not limited to:

*“I thought it was pretty clear about wanting to develop that [toolkit] nationwide...[but] can only go so far with it because each state has their own laws, which from New York to Pennsylvania is a big difference” (Advocate).*

*“There are a couple [screening tools] to choose from so I think I’m always going to feel like ‘well which one do I use?’ And if there were just one that was tried and true for a genetic counselor or a health care provider who’s not directly in psychology then that would probably be the best.” (GC)*

*“I think that [legal issues] would be a little overwhelming for the counselors to get into with the IPV person. I think they should just be referred to their local agency that could help them with those referrals and provide them with further legal information or legal contacts so that they’re getting correct information.” (Advocate)*

While advocates conveyed their many years of experience honing their skills, approach, and understanding of IPV, genetic counselors expressed the need to build their own awareness and understanding of how best to aid victims of IPV and use the toolkit. While the toolkit is deemed useful there is also mention of the need for a standard approach to IPV created by the National Society of Genetic Counselors. Because of these feelings, a strong component of the toolkit was its ability to build awareness for genetic counselors and even advocates. Table 4 lists 18 of these comments. Furthermore, the table demonstrates how the toolkit elicits awareness that permeates all of the objectives included in its creation. A quote from that table that summarizes the effect of the toolkit overall is listed below:

*“It’s [toolkit] simple, it fits with what we know and probably knew all along, but now it confirms that we have the tools to deal with it [IPV], we just haven’t given it a name or we haven’t*

*really said, "Okay, this set of skills is only for this, only for that." I think based on what I just learned from your presentation I think I would be more comfortable assessing and then dealing with such a situation." (GC)*

Generally, the thoughts of genetic counselors and advocates were in agreement, however a very interesting finding in this study was the recognition of areas where the “experts” (IPV advocates) and genetic counselors differed in opinion. While genetic counselors voiced strong opinions on whether to change medians/modes of presentation in the toolkit advocates did not voice any (Code 12). Possible reasons for this could be the clear eagerness that advocates feel to have such a tool implemented and their understanding that there are very little products/education tools of this kind currently in existence. This eagerness and understanding may make them less inclined to change the toolkit because in their opinion its creation is already enough. This sentiment can be found throughout their interviews when they describe the toolkit overall as “incredible (interview 1), “great (interview 2)”and applicable to other professions (interview 2 & 3).

Another intriguing disagreement includes the different opinions on which screening tool is best for recognizing victims of IPV. Genetic counselors found the HITS model to be most useful whereas advocates seemed to prefer RADAR. The very likely explanation for this is the genetic counselors’ desire for a quick answer to whether their patient is a victim or not.

Despite the preference for HITS felt by genetic counselors, they did express concerns that victims of IPV may minimize their responses to the HITS model. This feeling correlates with advocates’ belief that RADAR is more effective because it allows victims who are unsure of their situation to express and recognize their situation. This suggests a toolkit that utilizes the efficiency of HITS and includes a more thorough and direct explanation of what “never, rarely, sometimes, fairly often and often” actually mean could reconcile the difference of opinions among advocates and genetic counselors and be a great addition to the toolkit.

There were approximately 43 recommendations from IPV advocates and genetic counselors. Interestingly many of the 34 negative comments in the toolkit, if not associated with legal issues, or limitations of genetic counselors, or limitations of the toolkit, were given together with recommendations. Many of the recommendations can be considered quick fixes for the toolkit. To illustrate the effect of including these recommendations in the toolkit the creation of a second version of the toolkit was made. The recommendations incorporated into version 2 of the toolkit can be found in Table 3 (14 total). The creation of this second version is to create a toolkit that is more equitable than the first.

An important piece of information for this project is that in the process of creating this toolkit a 5 genetic counselor focus group was discarded. Courtesy of this group, one of the most unexpected and significant realization during this project was that genetic counselors, while trained in psychosocial techniques, are not immune to the trauma associated with bearing witness to IPV. This focus group was deemed exceptionally biased (towards negative comments) due to the individuals interviewed having witnessed an IPV incident in their department recently. During the session it was clear that many members of the group were still processing the recent event.

Statements were made indicating their feelings of vulnerability, during the event, their lack of preparedness, and their feelings of lack of support from their institution. These feelings were so prominent during the group that the discussion was riddled with their desire to omit the event in detail, a voracity to express a need for an instant fix rather than guidelines present in the toolkit, and a sense of defensiveness. Due to the bias/disposition within this group, after much discussion, it was decided that the best course of action was to discard their testimony. Despite this discarding of their testimony, the feelings these counselors conveyed remain important. They give a clear reason for the importance of preparing genetic counselors for IPV disclosure and events.

In conclusion, while the toolkit is not perfect, it does indeed address all 6 of the desired objectives. Based on responses from interviewees it is safe to say the information provided in the toolkit is useful, relevant, and can effectively aid in the building of awareness and preparedness in

genetic counselors regarding IPV. Not only was the toolkit praised by genetic counselors but by individuals with over 10 years of experience working in the field.

Future directions for the toolkit include piloting the revised version, which may provide additional edits as well as shed light on the best way to implement such a tool. Once the tool is implemented, study of its utility within the clinical environment would be a natural next step.

The power and reason for implementation of this toolkit lies in its ability to aid genetic counselors in recognizing, and helping willing patients escape very dangerous circumstances. This toolkit acts as a first step in empowering genetic counselors and teaching them to empower victims. By empowering genetic counselors in IPV situations, giving them the tools/guidelines to act, the toolkit may be able to minimize the harm (feelings of guilt, helplessness, and anger) IPV creates in unprepared witnesses/confidants (genetic counselors). And of utmost importance, the use of this toolkit could save a life, and for that reason along with supporting results in this study it is worthy of consideration.

## **Tables**

### **Table 1**

Topic	GC's	Domestic Violence Advocate
Changing the median/mode of presentation	Change median to be more friendly to learning	No mention
Screening tools	Preferred HITS model	Preferred RADAR model
Abbreviations	Understood all	Did not understand medical terminology (addressed in table 3)
Customize to GCs	Feel toolkit should be more customized to GCs in certain sections	Believe the toolkit could be useful for professions other than genetic counselors (other health providers and even for training lawyers/prosecutors)

**Table 2**

Theme (Code)	Objective	Example	Interpretation for Toolkit
Legal Issues (14)	3	I thought it was pretty clear about wanting to develop that [toolkit] nationwide...[but]can only go so far with it because each state has their own laws, which from New York to Pennsylvania is a big difference (Advocate).	Include national intimate partner violence hotline
	4,5	“[If] someone reports it, is this one of those situations where you would maybe have to break confidentiality if you thought someone's life was in danger? Like a child abuse situation (GC).	Identified need for more information. Possible addition to toolkit in future iterations.
	6	The person who called for help, the IPV person [Victim] who called for help, once the police arrive, and they're dealing with the batterer, the IPV person [Victim] will then turn around and start abusing the help that has come to them because they don't really want the aggressor to be arrested at that point. (Advocate)	Add note that victims of IPV may not be receptive to intervention
Relevant (20)	1	“It's all stuff that's relevant to us, and I could see how we could be prepared to use it in our sessions.” (GC)	Applicable to Genetic Counseling Practice
	2	“I liked all your links...they were relevant to what	Identified layout

		you were talking about, and I felt like you put them all at the appropriate spot...in the toolkit” (Advocate)	of additional resources was appropriately placed.
	3	“...It's just a few relatively simple and direct questions. And what they have found through research is that if a woman is asked directly, in private, she will usually answer honestly.” (Advocate)	Reinforced efficacy of screening tools provided.
	6	“ I thought [the actively violent section] was good. I thought it was very good to include it, because, you know, a lot of times people don't think about that - particularly, I would think, in the field of genetic counseling. (Advocate)	Confirm utility of resources for GCs that prepare them for an actively violent session
	ALL	“I think obviously there's a deficiency in [IPV awareness] since we don't have one [toolkit], so I think this is great that you went there and got it done.”(GC)	Attests to the need for IPV toolkit/guidelines
Median/ Mode of Presentation (12)	6	“..I'd be so curious and interested to see the actual tips and the de-escalation workshop, and things like that.”(GC)	Addition of a video showing de-escalation techniques
	ALL	“..It would be nice if it was actually like an interactive module. Not interactive, but maybe like slides.” (GC)	Future work in IPV should be interactive
		“I would like to have all the links at the top, because once you see it you know the links are there and then each time you have to go through the whole document to find [them].” (GC)	Consider separate links page
Limitations- GC practice (16)	2	“What I liked of it[visual aid] is the physical and the emotional...I kind of never really thought about or knew about the emotional components... But I'm wondering, is there any other piece of the pie? Is there a social component..And they [Video explaining IPV] mentioned the substance abuse, is that in there...”(GC)	Create visual (or give information) regarding social signs and implications of IPV
	3	“There are a couple [screening tools] to choose from so I think I'm always going to feel like ‘well which one do I use?’ And if there were just one that was tried and true for a genetic counselor or a health care provider who's not directly in psychology then that would probably be the best.”	Addresses potential for indecisiveness due to lack of GC specific tool

		(GC)	
		“... I think that a layperson... or somebody who is studying to be a genetic counselor and doesn't know anything about IPV would be shocked [at the prevalence].” (Advocate)	Recognition that GCs may not be taught about IPV
		“I think it's [routine screening] easier depending...in a pediatric setting, it's a little tougher because maybe patient's parents may not want to fill it out in front of their kids, especially older kids, or their partners that they're with. It's much easier to implement in offices where I think the partner that's being abused goes individually.” (GC)	Recognizes that screening tools may not be safe or answered accurately if a victim is not alone when answering
	4	I think that [legal issues] would be a little overwhelming for the counselors to get into with the IPV person. I think they should just be referred to their local agency that could help them with those referrals and provide them with further legal information or legal contacts so that they're getting correct information. (Advocate)	Confirms legal concerns should not be addressed by GCs
		“...I feel embarrassing, but my knowledge is very rudimentary on this [follow up questions after IPV disclosure] topic.”(GC)	Validates usefulness of providing a list of follow up questions in the toolkit
	5	“...Yeah, I probably would not have known, off the top of my head, what other resources to go to. I think I'm a little complacent in the fact that I fall back on the institutions, and just the directory within to know what to do.”(GC)	Affirms GC lack of knowledge regarding IPV resources outside of their institution
	6	I don't know if it would be normal for a genetic counselor to discuss with a patient and their partner...if they were together, if they would choose to want to discuss IPV at that time.” (Advocate)	Include wording in safety section of toolkit that discussing IPV with partner present may not be safe
Customize/ Specific to Genetic Counseling	3	“And then the screening...Since there's a lack of one for genetic counselors. Because ideally it would be one that's just kind of ...” (GC 1) “Customized for us, yeah.” (GC 2 completes sentence).	Discusses desire for screening tools customized for GCs

(15)			
	5	<p>“...It depends on where they're [GCs] working, what institution they're in, and what resources are local. So, I think it's [section stating identify the proper resources in your individual institution] a good reminder to them, you know, If you're starting out working in this institution, why don't you see if you can find these things out first in case nobody in your institution has already talked to you about these things?”(Advocate)</p>	<p>Acknowledges that toolkit resource section cannot be one-size-fits-all</p>
	ALL	<p>“ I wish that something like this could be taught to the medical community, not just the genetic counselors, just to bring awareness to the doctors, the nurses” (Advocate).</p>	<p>Mentions generalizability of toolkit, does NOT believe it should be limited to GCs only</p>
<p>“maybe the NSGC can come up with some kind of a policy regarding how to deal with abusive relationship in a counseling session” (GC)</p>		<p>Examines the possibility of NSGC creating policy for GCs to follow in regards to IPV disclosure</p>	
Limitation of Toolkit (17)	ALL	<p>“That's [question of what is the best medium to learn] tricky to answer for me, because I find that might change with each person. I personally like bullets...Somebody else might really like the - you know... good videos.”(Advocate)</p>	<p>Acknowledges different learning styles and that the toolkit cannot address them all</p>
	6	<p>“I think it's always helpful for the person to know that they can't fix everybody, number one. And number two, they have to have awareness of their own safety when in the situation.And, I always told people, always figure your way out of wherever you're at. ” (Advocate)</p>	<p>Explains that the toolkit alone may not be sufficient to explain the best way to handle an actively violent session</p>
	4	<p>“And then I'm thinking also what would I do with that answer [Response to follow up questions] if a patient said "yesterday" or the patient said "five years ago"? What does that mean? What do I do with that information? So why am I asking this question? To see if there's a long-term abuse or short-term abuse, and if that's what I'm going after maybe that's what I need to ask. (GC)</p>	<p>Criticizes follow up questions as potentially leading to answers the toolkit does not have the space to provide responses to directly</p>

	5	“No, I think it's [ hard. I think the piece of information I want is like, "Okay, what does my institution have in place?" But that's so specific to each place I don't think you can do that". (GC)	Affirms keeping the “identify resources within your institution” section cannot be customized
Missing Information (23)	2,4	“If that's supposed to be all-encompassing of signs and symptoms, are [financial and substance abuse] lacking?” (GC)	Included Financial and substance abuse in followup questions
	ALL	“I did notice there were a couple links I couldn't get to.” (Advocate)	Ensure url links are up to date.
Visual Aids (22)	1	“I just go back to the word impactful, because they're all really important. And I think they will all be enlightening for a genetic counselor to read.” (Advocate)	Ensures information is appropriate from a domestic violence advocate's viewpoint.
	2	“And I want to say even though the subject matter isn't pleasing, [the infographic is a] more eye-pleasing way to look at it and read it.” (Advocate)	Confirms utility of Infographic.
		“Only because after I read the information I don't have to reread the paragraph. I can see the highlighted points are bulleted.” (Advocate)	Confirms utility of Infographic.
		“I like that [the infographic is] simplified, sort of things you may not think about like marks, and bruises, and cuts, and scars. No I think it's a good infographic.” (GC)	Confirms information is relevant to GC's.

		<p>“...it breaks things down, and it’s easy for [GC’s] to have somewhere close by that they can refer to it.” (Advocate)</p>	<p>Confirms utility of infographic.</p>
		<p>‘I feel like its eye-catching.’ (Advocate)</p>	<p>Confirms visual appeal of infographic</p>
		<p>“I also liked that you have male and female” (GC’s)</p>	<p>Showed that inclusive of all situations.</p>
	4	<p>“...other than the video, the long video, I think all of the information that’s here is very useful.” (Advocate)</p>	<p>Replace long MI video with shorter video clip.</p>
Quick Read (21)	4	<p>“Sometime,s a simple question... will open up such a dialog between the IPV person and the advocate or screener or the professional person so that they are able to disclose more...” (Advocate)</p>	<p>Simplicity of follow questions has a profound impact.</p>
	ALL	<p>“I think it was good, you know, easy to read. It provides a lot of information. I like the layout.” (Advocate)</p>	<p>Showed layout was beneficial to efficacy of toolkit.</p>
		<p>“It’s simple, it fits with what we know and probably knew all along, but now confirms that we have the tools to deal with [IPV].” (GC)</p>	<p>Confirmed IPV is not out of our scope of practice.</p>
		<p>“What I really like about it is that it was relatively brief. So, for me that means that people will be more inclined to read it, to actually look at it.” (Advocate)</p>	<p>Usefulness in its compact design.</p>

**Table 3: Recommendations**

Objective	Example	Interpretation for Toolkit
1	<p>“To be honest, [the picture of children] kind of confused me. I was like, ‘Oh over a person. Oh one in’, and then I had to count the people.” (GC)</p>	<p>Remove picture of children representing 1 in 4 and replace with text.</p>
	<p>“I’d like to know what articles [the statistics of IPV] came from and if there’s more in that article I could learn.” (GC)</p>	<p>Add in DOI reference number for cited information.</p>
2	<p>“...I would say maybe, of genetic counselors and IPV, maybe like some family history information might be a good idea...you know like learned behavior. You know maybe something kind of just how somebody who grew up in a home with domestic violence, may become a perpetrator. (Advocate)</p>	<p>Include mention of utility of family history information in signs and symptoms.</p>
	<p>“I guess the people, the two people could be interchanged, in terms of you have emotional on one side, but it looks like the guy is in physical pain. Then you have physical on the other side, but she looks like she’s a little depressed.” (GC)</p>	<p>Change infographic to better reflect text below it.</p>
3	<p>“...after saying RADAR, you go ahead to spell out what RADAR is. You’ve capitalized the routine... I think maybe bold the letters that the acronym stands for...[like when] we write for syndromes like CHARGE and VATER...” (GC)</p>	<p>Bold first letter of each acronym</p>
	<p>“...when you say to talk about IPV with patients, you don’t have in [the toolkit] a bullet about routinely screening females.” (Advocate)</p>	<p>Add in sentence regarding routine screening</p>
	<p>“[The screening tools] you know it might be good to use in combination with the other model.” (Advocate)</p>	<p>Create GC specific screening tool in future.</p>
	<p>“I think maybe just [add in] sort of an introductory...some sort of wording just saying that HITS and RADAR are two tools you can use.” (GC)</p>	<p>Add in sentence explaining HITS and RADAR</p>
4	<p>“I think the specific language is a very high-level language...I think I would use simpler terms.” (GC)</p>	<p>Simplify language in the toolkit’s in future iterations</p>
	<p>“...describe the correlation between alcohol and abuse, but not the cause, because it’s not causative, alcohol, and that’s often misunderstood concept...” (Advocate)</p>	<p>Add in alcohol into follow up questions</p>

5	“...determine if your institution have social workers or other services present.” (Advocate)	Specifically mention identifying social workers in institution resources section.
6	“I think labeling that as sort of a last step, as motivational interviewing, just kind of classifying it. Makes it easier for people, for it to stick in their head...” (GC)	Relabel and distinguish motivational interviewing
All	In regards to ‘termination of pregnancy, “Oh, okay. Okay. That was just a term I wasn’t familiar with.” (Advocate)	Remove all acronyms that are not explicitly explained.

**Table 4: Examples of New Awareness built Through IPV toolkit.**

Objective	Example
1	“Because when you talk those numbers, you realize, ‘wow, this not just a rare or occasional occurrence.’” (Advocate)
	“You know, whether its breast cancer or some type of disease, it could be too late because they’re not caring for themselves that they’re worried about the violence in their [home].” (Advocate)
	“Again, making you feel like, "Okay, we really need to ask about this stuff and recognize it when it's in front of us", because there really could be actual clinical sequelae ...that come out of it.”(GC)
	“Let's look at that again [Genetic Counselors and IPV visual aid]. Oh, yeah. I kind of found this ... I don't want to say eye-opening, because it's not like I live in my head under a rock about these things, but ...”(GC)
	What got me when I first opened it the other day was how it was interwoven into our skills. Where it's like, "Oh, wait a minute. Yeah, we could totally be asking about this. And, yes, these are areas that come up in our sessions." It just felt like it had a lot of the stuff that we as counselors are trained on embedded in it already.(GC)
2	“I didn't know that [purple ribbon/color signifies IPV awareness]...Hey we learned something else”(GC1)
	“That's why they're [people in diagram] wearing purple... Got it”(GC2)
	“Coming into this I felt like, "Okay, domestic violence, you look for bruises." But now I know that's not it. That's not everything.” (GC)
3	“[Victims] maybe thought that they were alone in that situation, and I think by them having access to this information helps them learn that they’re not alone and that there is

	- there's help and that they're going through something that's very real." (Advocate)
	"So, like I said, they didn't realize they were in a situation because they weren't being physically hurt, so they thought that it wasn't a violent situation that they were [in]." (Advocate)
4	"All the stats and how to ask those direct questions once you've uncovered something. I found that six minute video very helpful." (GC)
5	"I think it's a good reminder just to validate that [The ability to speak to colleagues about their thoughts on how to handle a disclosure] ... Because I'm someone that needs that[validation]. Like, "Okay, good, I did what I was supposed to do." (GC)
	"Ya I probably wouldn't have known, off the top of my head, what other resources to go to. I think I'm a little complacent in the fact that I fall back on the institutions, and just the directory within to know what to do." (GC)
6	"...to see it [de-escalation techniques] listed and to read through it it's like, "Oh, yeah. Okay." And you feel like, "Oh, duh. Yes, of course. That makes total sense." But then it's like, "Wait, is that really going to work?" Okay, if that's how law-enforcement is trained then hopefully there's something to it."(GC)
	"I feel like your safety should always come first. So that's something to keep in mind." (Advocate)
	I feel like they [de-escalation techniques] were very ... Like stuff I've heard before, and just need a refresher.(GC)
ALL	"It's simple, it fits with what we know and probably knew all along, but now it confirms that we have the tools to deal with it, we just haven't given it a name or we haven't really said, "Okay, this set of skills is only for this, only for that." I think based on what I just learned from your presentation I think I would be more comfortable assessing and then dealing with such a situation." (GC)
	"In fact, it made me think back on whether or not there were signs that with patient disclosures that I missed. Just things, you know, made me think about any possible ways I could have addressed those better." (GC)
	"...this really made me think back on patient disclosures that I may have missed." (GC)

**Table 5: Raw Code Data**

<b><u>Code/Meaning</u></b>	<b><u>Code Tally</u></b>	<b><u>Code</u></b>	<b><u>Code Tally</u></b>
1/Positive	86	12/ Change median or mode of presentation	6
2/ Negative	33	14/ Legal Issues	7
3/ Objective 1	13	15/ Customize, Specify for GCs	10
4/ Objective 2	17	16/ Limitations Based on genetic Counselor Practice	29
5/Objective 3	20	17/ Limitations Of Toolkit	18
6/ Objective 4	15	19/Awareness	36
7/ Objective 5	14	20/ Relevant	16
8/ Objective 6	12	21/ Quick Read	8
9/ Helpful, really helpful, useful	37	22/ Visual Aids	28
10/ Flow, Organized	15	23/ Missing Info	21
11/ Convenience, Centralized, Professionalism	19	24/ Recommendations	43

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## **Intimate Partner Violence (IPV) Discussion Guide for Genetic Counselors**

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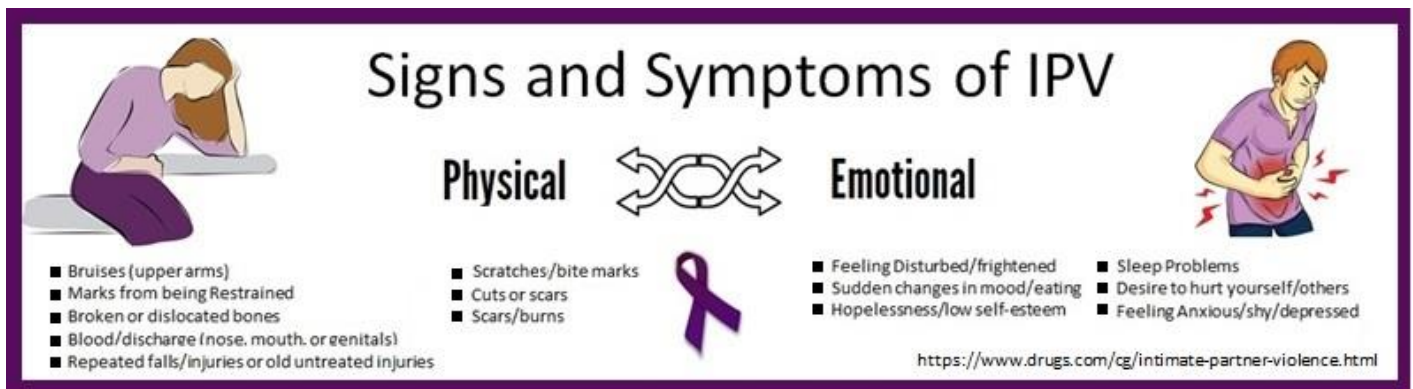
### **Why Genetic Counselors?**

- ACGC lists one of the core competencies for Genetic Counselors to become proficient in Interpersonal, psychosocial and counseling skills within their genetic education program
- Genetic Counselors build rapport by creating a safe place which can provide adequate time and comfort for a patient to disclose IPV. This can happen in all specialties of Genetic Counseling and positively impact a patient's health outcomes.

### **When To Talk About IPV With A Patient**

- If your patient asks or expresses concern about IPV
- If the IPV is disclosed during a conversation or session with your patient
- If a patient manifests signs and symptoms of IPV

People of all ages, genders, economic statuses, ethnicities, and sexual orientations can be victims of IPV



### **Suggestions For Screening And Discussion With Your Patients**

**HITS:** HITS stands for Hurt, Insult, Threaten and Scream. The tool includes four questions that professionals can administer verbally or via questionnaire to assess risk for Intimate Partner Violence (IPV).

#### **HITS Screening Tool**

**RADAR:** Radar stands for Routinely Screen Female Patients, Ask Direct Questions, Document Your Findings, Assess Patient Safety, And Review Options & Referrals. RADAR is a New York State domestic violence screening and intervention guide.

#### **RADAR screening and intervention**

Video Example: [Domestic Violence Screening for Health Professionals](#)

### **Identifying The Proper Resources Within Your Individual Institution**

- Speak with Colleagues about if/how they've handled IPV disclosure in the past
- Identify if your institution has a specific policy in place for IPV disclosure and what the policy entails
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## Appropriate Follow Up Questions After IPV Is Disclosed

AMA Journal of Ethics [Moser, 2014] published interview questions healthcare professionals can ask patients to determine whether IPV is a concern. By obtaining a history and creating a safe space for dialogue, no judgment is placed on the patient or their partner; they are obtaining history and creating the basis to problem solve. These questions can be followed by “How can I help? What are you hoping I will do?”. By clarifying the patient’s goals, you can engage and empower them.









- When did your partner start discounting your feelings?
  - Was there an event that precipitated your partner becoming more aggressive (use patient’s own word) with you?
  - Does anything make it better or worse?
  - Are there money problems? Does your partner have any medical or psychiatric problems?
- Motivational Interviewing Video Examples: [Motivational interviewing: An advocate](#)

## The Actively Violent Session

Surveys found evidence of counselors and other healthcare professionals witnessing IPV when working with patients. Below are the recommendations for getting to safety and/or de-escalating a situation

- **Your safety is priority. If you feel threatened by a patient or a patient’s partner, remove yourself from the room and return with security/colleagues for support**
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# Genetic Counselors and IPV

 Prenatal 	<ul style="list-style-type: none"> <li>• Pregnant women reporting higher severity of IPV have a greater likelihood of delivering an SGA and LBW neonate</li> <li>• Pregnant victims of IPV were found to have a 2.1-fold increased risk for pre-term birth. Specifically, emotional abuse without violence is associated with a 1.6-fold increased risk whereas emotional and physical abuse is associated with a 4.7-fold increased risk.</li> <li>• Meta-analysis of lifetime prevalence of IPV among TOP-seeking populations was found to be 24.9%</li> </ul>
 Cancer 	<ul style="list-style-type: none"> <li>• Victims of physical or sexual abuse by a partner are 87% less likely to be up to date with pap smear screening and 84% less likely to be up to date with mammograms</li> <li>• A common theme among patients who had breast cancer was the belief that stress from their relationship with an abusive partner caused the cancer</li> <li>• IPV has a negative influence on cancer-related well-being factors including a cancer patient’s ability to report anxiety or depression</li> </ul>
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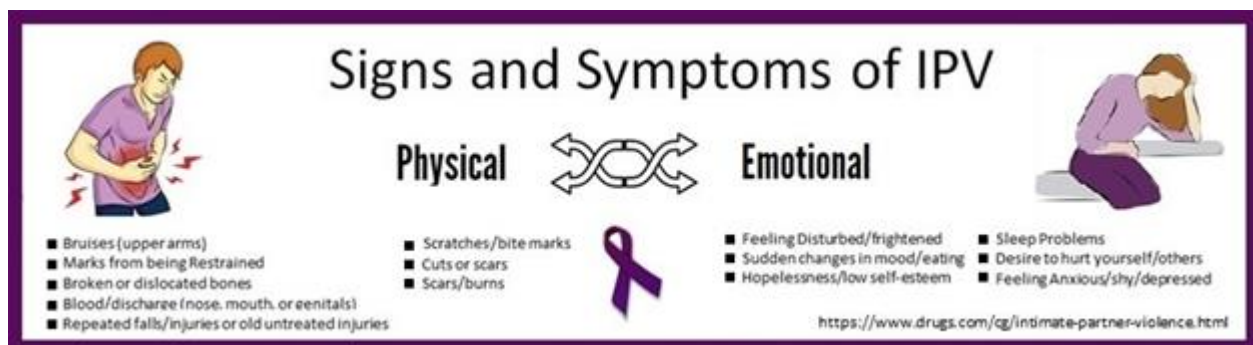
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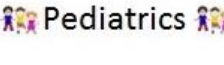
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### **Appendix 3: Interview Questions**

#### GENERAL QUESTIONS BASED ON TOOLKIT DESIGN

- What are your initial thoughts on the layout of the toolkit?
- Is there anything that seems distracting or irrelevant?
- How would you improve it? Any recommended additions or removal of items?
- What did you like about the toolkit layout?
- Did you feel the intervention met its goals?
- In what ways did it fail?
- In what ways did it excel?
- Was the toolkit easy to understand?
- Were there any sentences that were grammatically incorrect or too complex to understand?
- Were there any statements that were too vague?
- Did reading anything make you feel personally uncomfortable or offended?
- Did the toolkit have appropriate word choice?
- What improvements would you suggest?
- Did you find the images or infographics useful, appropriate, and well placed?
- Given the goals and objectives outlined, do you feel this is an appropriate toolkit?

#### **INTERVIEW QUESTIONS BASED ON OBJECTIVES**

*Building awareness (Objective 1):* A Summary of another researcher's preliminary findings for a survey which assessed how often genetic counselors encountered IPV disclosure will be part of the toolkit (verbal permission already received).

1. After reading the summary of results, what were your thoughts on the number of counselors overall who reported having experienced IPV disclosure or activity in their session?
2. Do you feel that the survey adequately represents genetic counselors' desires and/or need to be trained in IPV? Why or why not?
3. Did you learn anything new/interesting from the toolkit about IPV
4. Which information medium was most useful? Ie. essays, vs. videos vs. infographic
5. How can this section of the toolkit be improved?

*Recognizing signs and symptoms (objective 2)*

1. What were your thoughts on the "recognizing signs and symptoms" section of the toolkit
2. What was the most useful and least useful aspects of the toolkit for recognizing signs and symptoms?
3. How could this section of the toolkit be improved?

*Screening tools (Objective 3)*

1. Do you perceive the screening tools provided in the toolkit as being useful in the future?
2. If you could add or change anything in the screening tools would you? If so what would you change?
3. Do you feel you could use these screening tools in your practice?
4. Does your institution have its own screening tool for IPV? If so, which screening method do you prefer?

*List of Follow up questions (Objective 4)*

1. What were your thoughts on the follow up questions for IPV patients?
2. Did you have previous knowledge of the forms of questioning presented?
3. Do you think this form of questioning will be useful?

*Identify the proper resources based on your institution (Objective 5)*

1. Did you have previous knowledge of how to find answers/resources through your institution? / How would you have addressed IPV disclosure prior to the toolkit infographic?
2. Do you believe you will use the flowchart in the event of IPV disclosure?
3. How could this section of the toolkit be improved?

*Equip genetic counselors with basic principles of preparation for actively violent sessions (Objective 6)*

1. What were your thoughts on the safety tips/strategies provided in the toolkit?
2. Prior to viewing the toolkit, would you have utilized the skills mentioned?

3. In what way do you feel the safety plan could be improved?

General question: Overall, do you believe this toolkit could be useful to genetic counselors?

**DOMESTIC VIOLENCE ADVOCATE SPECIFIC QUESTIONS (PHONE INTERVIEW)**

How many years of experience do you have working with victims of domestic violence?

Do you feel this toolkit, if used by genetic counselors, could be useful for victims of IPV?

Given your experience, what additional information do you feel could be added to the toolkit?