A framework for youth-friendly genetic counseling

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Abstract

Young people represent a unique cohort in the context of both healthcare and genetic risk. Genetic counselors have long recognized and documented the challenges of working with young people and their families compared with working with older adults. Challenges for health professionals include engagement with the young person, communication, developmentally appropriate psychosocial assessment, and working with the young person and their family. Likewise, young people also report experiencing challenges within the genetic counseling process. In response to these challenges, and increasing numbers of young people presenting for genetic testing, genetic counselors at the Parkville Familial Cancer Centre (Peter MacCallum Cancer Centre, Australia) formed a collaboration with the ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service. Consisting of a multidisciplinary expert panel who provide care to young people with cancer and their families, the collaboration identified the need to develop an evidence-based framework to ensure the delivery of youth-friendly care and support for young people and their families facing genetic risk. To guide this work, a working party comprising of experts in genetic counseling, adolescent and young adult (AYA) oncology, adolescent health, clinical ethics, and clinical research was established. A literature review was undertaken and based on expert and consumer input and feedback, a consensus-based framework for youth-friendly genetic counseling was developed over several stages. This paper describes the evidence base supporting the development of this framework, the process of development, and the resulting framework of youth-friendly genetic counseling.

Keywords Genetic health · Genetic counseling · Adolescent health · Youth-friendly healthcare · Models of care

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Introduction

The number of individuals seeking genetic information and genetic testing for conditions that may affect them, or a family member, is increasing (Phillips et al. 2018). When the client is a young person, the interface between processes of human development, the unique needs and experiences of young people, and genetic risk can result in challenges for both the young person and healthcare professionals providing their care.

Genetic counselors at the Parkville Familial Cancer Centre (FCC) based at Peter MacCallum Cancer Centre, Australia, identified increasing numbers of young people presenting for predictive testing for hereditary breast and ovarian cancer, Lynch syndrome, and Li-Fraumeni syndrome. This was the result of increased awareness about testing and affected parents seeking appointments for their AYA children. While being clinically competent in providing cancer genetic counseling to adults, genetic counselors reported feeling ill-equipped to provide evidence-based, developmentally appropriate care

to best support young people and their families, specifically, feeling as though they lacked the knowledge and skills to adequately manage the life stage-related complexities of AYA-hood. Alongside this, they identified practice challenges that mirrored those reflected in the literature and sought support, collaboration, joint clinical consultations, and supervision from clinicians at the ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service (ONTrac). ONTrac is made up of a multidisciplinary team of skilled healthcare professionals in the provision of best practice care for young people with cancer and their families.

As a result of the collaboration, the need for an evidence-based, developmentally appropriate approach to the care of young people with genetic risk was identified. The approach built upon processes and strengths of genetic counseling but was augmented with principles of youth-friendly care. This paper describes the evidence base and process of development for a framework for youth-friendly genetic counseling.

Definition of adolescents and young adults

The AYA period comprises a significant transitional life stage, encompassing complex heterogeneous development across physical, cognitive, psychological, emotional, social, and existential domains (Patton and Temmerman 2016). While the onset of puberty at one end and the completion of frontal lobe cognitive function and social role transitions at the other are recognized to define this period of AYA development; variation in the rate of development have resulted in reticence to define this period based on chronological age alone. The more broadly accepted definition used here to describe young people or AYAs is based on parameters of development, life stage, and social role transitions. According to this definition, successful normative development is recognized to comprise physical and cognitive maturation, identity formation, the development of peer and romantic relationships, achievement of educational and vocational goals, and the successful transition from dependence to independence (Sawyer, Azzopardi et al. 2018; Sawyer et al. 2016).

Young people and genetic counseling

A young person's experience of facing genetic risk may represent their first engagement with the health system. Consequently, their experiences may have significant implications for their current and future engagement with the health system and health management (Institute of Medicine and National Health and Research Council 2015). To facilitate positive processes that empower them in the context of their health, it is essential that their experiences are understood. Some young people at increased genetic risk report that the genetic counseling process has been supportive, an important source of information, and an important life event (Fraser et al.

2018; Godino et al. 2017; MacLeod et al. 2014; McGill et al. 2018; Vetsch et al. 2018). Conversely, others have expressed negative feelings about the experience of genetic testing, feeling poorly understood or experiencing power differentials with genetic counselors who may be perceived as “gatekeepers” for information (Mand et al. 2013; McGill et al. 2018; Vetsch et al. 2018).

Young people have also expressed concern about the confidentiality of their information. They have reported feeling pressure from parents to make specific decisions about genetic testing, threatening the ability of the young person with capacity, to make autonomous decisions about testing and their health (Godino et al. 2017; McGill et al. 2018; Ryan et al. 2015). Young people have also identified that the process of genetic counseling should include more thorough discussion of the implications of genetic risk and testing and the potential impacts on their lives (Fanos 1997; Fraser et al. 2018; Godino et al. 2017; Meiser and Dunn 2000; Metcalfe et al. 2011). In addition, young people have identified the importance of preparation prior to engaging in the genetic counseling process, the use of various communication methods to support information absorption, normalization of the process and their situation, being able to choose whether parents are present, being linked with appropriate supports, and having greater involvement in decision-making throughout the entire genetic counseling process (Duncan et al. 2010; Pichini et al. 2016).

Several factors have been identified that impact upon the genetic journey for young people. Some of these relate to cognitive development and how the young person understands, processes and appraises information, and comprehends short- and long-term implications of testing options and decisions; the impact of life stage-related priorities upon decision-making; verbal expressive ability; how young people identify, label, and manage emotional responses; the level of involvement of family members, partners, and peers; the presence or absence of mental ill-health, and other resilience and risk factors; the availability of practical resources; health literacy; and, their level of self-confidence in navigating the health system (Borry et al. 2009; Codori et al. 2003; Duncan and Young 2013; Malpas 2005; McConkie-Rosell and Spiridigliozzi 2004; McConkie-Rosell et al. 2008; Michie et al. 2001; Pichini et al. 2016; Williams et al. 2012). Recognition of the impact of these factors in determining how a young person responds, navigates, and manages their genetic journey illustrates that the experience for a young person facing genetic risk is vastly different to an older adult. This begins to highlight the importance of a developmentally appropriate approach to care.

Challenges for genetic counselors

Principally, due to the significant physical, cognitive, emotional, and psychosocial development of AYAs, genetic

counselors report working with this group as challenging. These challenges may also be compounded by the lack of formal theoretical and skill-based training for genetic counselors in working with this specific age group (Duncan and Young 2013). Specifically, genetic counselors report concerns relating to engaging and communicating with young people, understanding psychosocial risk and resilience, and understanding the cognitive capacity of young people in relation to decision-making; a guiding principle in genetic counseling (Duncan and Young 2013). They have also reported a conflicted sense of responsibility in balancing the needs of the young person and family members, especially when one parent may feel extremely anxious, or guilty about a genetic disorder being transmitted through their family. Challenges have also been reported when genetic testing decisions of young people and family members differ (Gaff et al. 2006). The familial nature of genetics means that genetic counselors often face managing the competing needs of multiple clients, which is especially complicated for young people whose autonomy is still emerging within the family system (Gaff et al. 2006; Peters-Brown and Fry-Mehlthreter 1996).

Youth-friendly care

Youth-friendly care has evolved from recognizing the unique experiences of AYAs facing ill health and the challenges faced by professionals in caring for them. Such care is oriented to the life stage-specific needs of young people (Ambresin et al. 2013; Farre et al. 2016; Pichini et al. 2016; Sawyer et al. 2016; Tylee et al. 2007; Vetsch et al. 2018) and recognizes that health services and healthcare professionals have a responsibility to understand and support young people's development and emerging capacity for self-management in the face of challenges to their health and well-being (Institute of Medicine and National Health and Research Council 2015; Patton et al. 2016). Several principles of youth-friendly care have been identified that support the delivery of optimum care to young people:

1. A philosophy and framework of practice that is grounded in an understanding of AYA development and the competence of young people, and supports the attainment of normative developmental milestones;
2. Engagement and a partnership approach to care;
3. Communication, confidentiality, and consent;
4. Working with a strength-based approach within resilience and risk-based frameworks; and,
5. Holistic patient-centered care (Ambresin et al. 2013; English and Ford 2007; Institute of Medicine and National Health and Research Council 2015; Patton and Temmerman 2016; Sacks and Westwood 2003; Sasse et al. 2013; Sawyer and Aroni 2005; WHO 2015).

The increasing awareness of the importance of developmentally appropriate models of care, the long-standing establishment of adolescent health as a subspecialty, and the recognition of the right of young people to be adequately supported to participate in all decisions about their life have led to many health services and subspecialty fields formally adopting the principles of youth-friendly care (Ambresin et al. 2013; Fraser et al. 2018; Godino et al. 2017; Institute of Medicine and National Health and Research Council 2015; McGill et al. 2018; Patton et al. 2016; Tylee et al. 2007; Vetsch et al. 2018; WHO 2015, 2017). To date, however, youth-friendly genetic counseling approaches have been slow to advance.

Methods

The process of framework development involved a modified co-design process conducted over 8 stages, within an 18-month period. This work was led by a project officer appointed with the support of a Peter MacCallum Cancer Centre Foundation grant. The procedure and the associated time frames are illustrated in Fig. 1 and described below.

Stage 1

An expert reference group was formed, comprising of individuals with theoretical and clinical expertise in adolescent medicine and psychosocial care, AYA oncology, genetics, genetic counseling, clinical ethics, and research. The expert reference group defined the scope and parameters for the work. There was consensus by all members that the framework needed to be evidence-based, founded in the tenets of both adolescent health and genetic counseling, and address understanding from the literature in a tripartite way: (1) the experience and needs of young people and their families engaged in the predictive testing process; (2) practice challenges in work with young people and families; and (3) principles of youth-friendly care. The expert reference group agreed that the purpose of the framework was neither to advocate for young people, or their parents, seeking genetic testing nor to facilitate clinical decision-making regarding testing, options, and outcomes. There was also agreement that the framework would be developed for typically developing AYAs and would need to be adapted when working with a young person who has developmental and cognitive disability (Finucane 1998). The primary purpose was to develop a framework that could guide typically developing young people, their families, and the healthcare professionals working with them, through the genetics process.

Fig. 1 Framework development process

Stage 2

A mapping exercise was undertaken utilizing the expert reference group's collective experience. The following domains were examined and their experiential responses delineated:

1. Aims of genetic counseling
2. Process of genetic counseling
3. Differences in genetic counseling processes with AYA clients
4. Concerns of genetic counselors in relation to this work
5. Knowledge about the experience of young people as clients
6. Aims of adolescent healthcare
7. Principles of youth-friendly care

Stage 3

In alignment with the mapping exercise, an extensive literature review was conducted specifically examining the domains described above.

Stage 4

Following the completion of the mapping work and the literature review, the reference group began delineating a draft framework for youth-friendly genetic counseling. This initially comprised a tabulated framework that described the genetic counseling process and associated youth-friendly practice points. This version of the framework then underwent review over two stages.

Stage 5

Review and evaluation of the draft framework by the reference group and a broader collective of professional experts from genetic counseling and adolescent health were undertaken. The feedback highlighted that the framework was well-aligned with the genetic counseling process, although there needed to be greater flexibility built in to account for practice variations across services to ensure broad applicability and uptake. Additionally, while youth-friendly practice points had been identified in the initial framework, to fit within the genetic counseling process, more specific information was required about youth-friendly practices to support professionals in understanding and implementing practice change. The addition of a table of practice points was added to the framework.

Stage 6

The framework was reviewed and evaluated by a group of consumer experts comprising young people aged 15–25 years from the Victorian Youth Cancer Action Board. The feedback highlighted that the practice points needed to be less theoretical and more practically relevant to healthcare professionals to ensure alignment with the actual needs and specific experiences of young people. An example related to the importance of setting appropriate appointment times with young people to fit around other life commitments (e.g., school, study, and work) and ensuring that appointment times were not too early in the day. Another example included the

importance of considering a youth-friendly environment and what this meant in practical terms in relation to resourcing such spaces for young people. Based on this collective feedback, the framework was amended.

Stage 7

The framework was finalized.

Stage 8

Endorsement for the framework was sought and provided by the Human Genetics Society of Australasia (HGSA), the peak body for genetic health professionals in Australasia.

Stage 9

Currently, we are piloting the education module with Australian genetic counselors through workshops to evaluate its applicability and practicality within the context of their work with young people. Focus groups will be undertaken following the workshops and results presented in a future manuscript.

Results

The framework

The framework of youth-friendly genetic counseling holds the young person at the core. It builds upon the existing client-centered approach used in genetic counseling, the strengths of the genetic counseling process, and augments it with principles of youth-friendly care. The framework delineates specific practice points to ensure the delivery of developmentally tailored care throughout the genetic counseling process, from the time of referral to closure.

The framework comprises two visual resources. The first describes the linear process for youth-friendly genetic counseling (Fig. 2). To align with the standard genetic counseling process, the framework is illustrated within three phases of the counseling process: the beginning, middle, and end. While some of the youth-friendly care practice points are foundational and applicable to all three phases, the expert reference group determined that to make the framework clear for practitioners new to this area, it was important to clearly align these practices within the context of each phase, even if this created repetition.

The practice points required to support the implementation of youth-friendly care throughout the genetic counseling

Fig. 2 Youth-friendly genetic counseling process

Table 1 Principles of youth-friendly genetic counseling and associated practice points

Principles of youth-friendly care	Practice points
<p>Developmentally founded practice</p> <p>A philosophy and framework of practice grounded in an understanding of AYA development. Care that supports the best health outcomes and the attainment of normative developmental milestones and recognizes the right and emerging capacity of young people to be involved and make decisions about their life and care.</p>	<ul style="list-style-type: none"> ▪ Acknowledge AYA as a distinct client group accessing genetic health services ▪ Understand that the dynamic stages of AYA development, rather than chronological age are used to determine most developmentally appropriate approach to the provision of clinical care^a ▪ Know how to assess for developmental stage^a ▪ Adopt an individualized, holistic clinical approach that looks beyond the physical/genetic aspects of a young person and integrates the biological, psychological, social, and vocational aspects of development and supports the attainment of normal developmental milestones^a ▪ Adopt multidisciplinary, interdisciplinary, and interorganizational, collaborative approaches to care. ▪ Advocate for young people accessing health services, their strengths and unique needs^a <p>e.g., Patton et al. (2016), Sawyer et al. (2016), and WHO (2017)</p>
<p>Youth-friendly engagement^a</p> <p>A partnership approach to care that recognizes the dual expertise of the young person and the professional and supports meaningful, developmentally appropriate, consistent engagement to foster a trusting and effective client-counselor relationship.</p>	<p>During consultations:</p> <ul style="list-style-type: none"> ▪ Greet young person first as you meet them and their family or social supports. Speak to the young person directly^a ▪ Negotiate the relationship and expectations of engagement with the young person and family members at the outset ▪ Explain that it is usual practice to have time alone in the consultation with the young person to provide them with the opportunity to talk independently and identify their specific concerns or needs. This is also the purposes of conducting a thorough psychosocial assessment. Offer this time alone as part of the consultation^a ▪ Consider engaging different clinicians when working with young people and family members. If possible, allocate one clinician to the young person and one to family members (e.g., parents) to avoid confusion and foster trust between the young person and professional^a ▪ Routinely schedule longer appointment times for young people and their family to allow adequate time for communication, psychosocial assessments, information provision, and decision making processes^a ▪ Be sensitive to and respect cultural norms when seeing young people from CALD or other cultural backgrounds, e.g., Ambresin et al. (2013), Pichini et al. (2016), and Sawyer and Aroni (2005) ▪ Engage with the young person as the client, opposed to the referrer or parent from the time of referral throughout the genetic counseling process^a ▪ At the time of referral, contact the young person directly and provide information about the service to them.^a Negotiate a time for the initial consultation and address any questions
<p>Youth-friendly communication</p> <p>Developmentally appropriate, tailored communication that supports informed decision-making and promotes ongoing engagement.</p>	<ul style="list-style-type: none"> ▪ Be clear, direct, and honest in your communication ▪ Use plain language, avoid technical terminology and jargon ▪ Maximize the use of open-ended questions ▪ Try to avoid mimicking or speaking like the young person as it can be seen as insincere and young people value the professionalism and of their healthcare team^a ▪ Allow the young person time to respond and try not to answer for them or assume ▪ Pay attention to non-verbal as well as verbal cues ▪ Be empathetic, respectful and non-judgmental, particularly when discussing sensitive issues <p>e.g., Pichini et al. (2016), Sacks and Westwood (2003), and Sawyer and Aroni (2005)</p>
<p>Developmentally appropriate information and education</p> <p>Developmentally appropriate, tailored information and education that utilizes multiple formats to ensure clarity about information and supports the engagement of young people in decision-making.</p>	<ul style="list-style-type: none"> ▪ Be aware of varying literacy levels among young people and adjust the information provided appropriately. Do not assume that the client is literate ▪ Ensure written information is developmentally appropriate. Provide complex information in different ways such as such as written, verbal, diagram, pictures, and where appropriate, use evidence-based internet sites^a ▪ Understand that the young person may not have engaged with the health system before.^a Provide information about the health system, genetic health processes, and roles of all involved^a

Table 1 (continued)

Principles of youth-friendly care	Practice points
Consent Consents the young person to engagement in their care.	<ul style="list-style-type: none"> ▪ Provide information about self-management strategies for young people to empower them in the management of their health and care^a <p>Adjust information and the approach to education as the young person develops and their needs change. e.g., Godino et al. (2017) and McGill et al. (2018)</p> <ul style="list-style-type: none"> ▪ Discuss consent at the outset with the young person and their identified supports. Re-visit as new decisions arise^a ▪ Formal written consent to engagement in care may also be considered and assist with empowerment and engagement, e.g., Ambresin et al. (2013) and Sawyer and Aroni (2005)
Confidentiality Ensures that the young person understands the limits of confidentiality and maintains confidentiality to foster trust, communication, and engagement.	<ul style="list-style-type: none"> ▪ Explain confidentiality at the outset and the limits to confidentiality to the young person and their family to minimize uncertainty and foster trust ▪ Explain it may be necessary to share some information with other professionals in order to provide the best possible treatment. Stress that you will seek their permission first in this case ▪ Ensure the young person's understanding of the limits of confidentiality ▪ Be aware of your professional and legal obligations with respect to maintaining confidentiality and promoting privacy^a <p>e.g., Ambresin et al. (2013), English and Ford (2007), Sasse et al. (2013), and Sawyer et al. (2013)</p>
Capacity Understands cognitive capacity and the capacity of each young person to make informed decisions about care.	<ul style="list-style-type: none"> ▪ Understand the criteria for ensuring that someone has capacity to make decisions ▪ If in doubt about capacity, discuss with a professional trained in youth-friendly care and/or refer for a formal assessment of capacity by a cognitive psychologist or psychiatrist <p>e.g., Ryan et al. (2015)</p>
AYA psychosocial assessment Provides care that considers the importance of, and supports the young person across all physical and psychosocial domains with the routine use of a developmentally appropriate bio-psychosocial assessment framework that utilizes a strength-based, resilience, and risk approach.	<ul style="list-style-type: none"> ▪ Conduct developmentally appropriate psychosocial assessments throughout the process of genetic testing. The HEEADSSS assessment provides a systematic approach to developing rapport with the young person and performing a holistic, biopsychosocial resilience and risk assessment across the domains of home, education, employment, activities, drugs and alcohol, sexuality, suicide, and mental health^a ▪ For young people with complex, co-morbid problem health concerns, a multidisciplinary approach to care may be required. Care planning may include referral to allied health professionals or specialist services and engaging the young person's supports, acknowledging the changing roles of parents and genetic health professionals during adolescent development ▪ It can be helpful to develop a referral directory to appropriate local, community, and private health relevant healthcare providers to support care planning <p>e.g., Callard et al. (2012) and Sacks and Westwood (2003)</p>
The environment An appropriate environment that considers developmental needs and preferences makes young people feel welcome and supports good engagement.	<ul style="list-style-type: none"> ▪ Create a relaxed and welcoming environment for young people, e.g., have adolescent-specific posters, pamphlets, and reading material available. Display information about the service confidentiality policy in the waiting room ▪ Offer youth only clinic times (i.e., setting aside a particular time or afternoon specifically for young people)^a ▪ Adopt flexible administrative and appointment booking procedures for young people (early appointments are often not preferred or appropriate etc.)^a <p>e.g., Ambresin et al. (2013) and Tylee et al. (2007)</p>
Self-care Working with young people can present different practice challenges. Self-care is essential	<ul style="list-style-type: none"> ▪ Undertake education and training in youth-friendly care as part of professional development to support you in the provision of care to young people ▪ Be aware of the complexities and challenges that may arise in work with young people ▪ Engage in regular professional supervision ▪ Identify supports for you within the workplace ▪ Collaborate with youth-specific services for support in care planning ▪ Identify supports outside of the workplace to promote self-care <p>e.g., Tercyak (2010)</p>

^a Denotes that this element of youth-friendly care may be challenging for a practitioner who is new to working with young people

process are delineated in Table 1. These practice points cover the following domains:

1. Developmentally founded practice
2. Youth-friendly engagement
3. Youth-friendly communication
4. Developmentally appropriate information
5. Considerations of consent, confidentiality, and capacity
6. AYA psychosocial assessment
7. The environment and self-care for healthcare professionals

Together, these domains comprise what is recognized to be youth-friendly care, aimed at comprehensively supporting the developmental and health outcomes for young people. In addition, practicing in a way that recognizes both the developmental needs and capabilities of young people. For example, addressing and greeting the young person as the client, rather than the parent; using modes of communication preferred by the young person; utilizing developmentally appropriate psychosocial assessment frameworks that assess all appropriate domains of resilience and risk; understanding the importance of assessing cognitive capacity; explaining and reinforcing confidentiality; facilitating time alone during a consultation with a young person; and, understanding when and how to appropriately refer for additional support. Some of these practices are consistent in the approach taken in genetic counseling with all client groups. However, others are novel and specific to the developmental stage of the AYA cohort.

Discussion

Genetic counselors are primarily trained and proficient in adult-based counseling theories and techniques. The life stage of clients and the impact of development on the genetic counseling process had limited consideration. The impact of facing genetic risk on the development of young people has also received little attention. Given longstanding documentation of the challenges faced by genetic counselors in providing care to young people, and the increasing number of young people presenting for genetic testing, the need for a developmentally-specific approach to genetic counseling is evident. This framework delineates the founding principles of youth-friendly genetic counseling. The framework provides practice points enabling genetic counselors to reflect on current practice and identify areas that may be amended, including practical strategies to achieve practice change.

Although the impetus for developing the framework arose in a cancer genetic counseling setting, specifically young people seeking predictive genetic testing, it has been developed using principles of youth-friendly care and is broadly applicable and can be used by all genetic health professionals working with AYA clients. The recommendations presented within

this framework reflect ideal practice. Adopting and embedding many of these practice points requires additional information, learning, practical application, and practice. Additionally, some may not be achievable within particular work environments and may require modification in specific contexts. Furthermore, the specific practices recommended here necessitate assessment of cognitive capacity and may not be appropriate for those young people with cognitive impairment (Ryan et al. 2015). It is also recognized that some of these practice changes may be challenging for the clinician who is new to working with young people (Vetsch et al. 2018). To achieve embedded, sustainable practice change, education for health care providers, including genetic counselors, is required across multiple levels, including education for those in genetic counseling training programs as well as practicing clinicians. This education must be more than theoretical and allow for practice of the skills required to embed youth-friendly care in work with young people. Education must address skills including communication strategies, maintaining confidentiality, understanding capacity and consent, psychosocial assessment, provision of holistic care, and developmental-specific counseling techniques.

To accompany the framework presented here, an education module has also been developed. The focus of the education module is to cement the additional skills necessary for the provision of youth-friendly care. This includes a workshop structure, facilitation guide, and resources for practitioners. It is intended that this can be used as professional development for already qualified and experienced practitioners and is currently undergoing evaluation. While education is the cornerstone to enable practice change, ongoing support and training are also essential for genetic counselors working with AYAs, as stipulated in the National Society of Genetic Counselors Code of Ethics:

1. Continue their education and training to keep abreast of relevant guidelines, regulations, position statements, and standards of genetic counseling practice.
2. Work within their scope of professional practice and recognize the limits of their own knowledge, expertise, and competence (National Society of Genetic Counselors 2018).

Conclusion

The challenges faced by genetic counselors in the provision of quality, evidence-based care to young people have been well-documented. The question of how genetic counselors can provide such care has been considered for many years, demonstrating an awareness and desire by genetic counselors to

change practice and provide youth-friendly care (Callard et al. 2012; Gaff et al. 2006; Peters-Brown and Fry-Mehlretter 1996; Tercyak 2010; Tse et al. 2013). However, an evidenced-based framework of youth-friendly genetic counseling has been lacking. This article presents the first theoretical and skill-based framework of youth-friendly genetic counseling developed by experts in medical and psychosocial aspects of adolescent health, AYA oncology, genetic counseling, clinical ethics, and research. It is hoped that this provides a practicable approach to improving care and outcomes for young people facing genetic risk and the experience of clinicians providing their care.

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