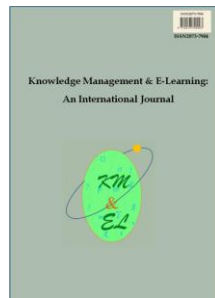


Knowledge Management & E-Learning, Vol.7, No.4. Dec 2015

Knowledge Management & E-Learning



ISSN 2073-7904

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Recommended citation:

King, C., Cianfrone, M., Korf-Uzan, K., & Madani, A. (2015). Youth engagement in eMental health literacy. *Knowledge Management & E-Learning*, 7(4), 646–657.

Youth engagement in eMental health literacy

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Abstract: There is growing recognition of the important role that eHealth Literacy strategies play in promoting mental health among youth populations. At the same time, youth engagement in mental health literacy initiatives is increasingly seen as a promising practice for improving health literacy and reducing stigma. The Health Literacy Team at BC Children's Hospital uses a variety of strategies to engage youth in the development, implementation and dissemination of eMental Health Literacy resources. This paper reviews the evidence that supports the use of eHealth strategies for youth mental health promotion; describes the methods used by the Team to meaningfully engage youth in these processes; and evaluates them against three popular frameworks for youth participation and empowerment. The findings suggest that the Team is successfully offering opportunities for independent youth involvement, positively impacting project outcomes, and fostering youth empowerment. The Team could further contribute to the positive development of youth by creating more opportunities for youth-adult collaboration on eHealth Literacy initiatives.

Keywords: eHealth; Mental health; Youth; Engagement; Literacy

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1. Introduction

At any given time, one in five Canadians will experience a mental health challenge (Kirby & Keon, 2004). Mental health challenges can often begin early in life. In British Columbia (BC), an estimated 12.6 percent, or 84,000 children and youth, experience mental health disorders that are significant enough to cause distress and impair their functioning at home, at school or in their community (Waddell, Shepherd, Schwartz, & Barican, 2014). The onset of most mental health disorders first occurs during adolescence or early adulthood (Jorm, 2011). Half of all lifetime cases begin by age 14, and three quarters have begun by age 24 (Canadian Alliance on Mental Illness and Mental Health, 2008; Kessler et al., 2005). Many mental health challenges can be addressed effectively, especially when identified early, however, the stigma associated with mental health can often preclude help-seeking and access to appropriate support.

Stigma is a central issue in the mental health field (Kranke, Floersch, Townsend, & Munson, 2010). Experiencing a mental health challenge, combined with feeling the stigma of mental illness, can be very difficult for youth. Youth are particularly impacted by stigma because of their relatively high drive to be socially accepted (Coates & Howe, 2014). Youth want to fit in, do not want to disappoint their parents, and often lack knowledge of where to access health care services and other supports (Coates & Howe, 2014).

Evidence indicates that direct contact with an individual with a mental health challenge can reduce stigma by increasing knowledge about mental illness and improving attitudes towards individuals with a mental health challenge (Heeney & Watters, 2009). Sharing personal stories has become a powerful tool in combatting mental health stigma. Youth who want to share their stories are often very passionate about mental health, and want to help other youth avoid the negative experiences and barriers that they have had to overcome. A mechanism that youth use to share their mental health story is through communications technology, such as eHealth Literacy tools and resources. The importance of engaging youth in the development and dissemination of these tools is essential to ensuring their relevance and usefulness for the target audience. The Health Literacy Team at BC Children's Hospital uses a variety of youth engagement strategies during the development, implementation and dissemination of their eMental Health Literacy resources. The Team is dedicated to improving the mental health literacy of children, youth and families across the province of British Columbia. They strive to find new ways to encourage youth participation and use technology and social media to reach youth across BC. This paper will provide a review of the evidence to support the use of eHealth strategies for mental health promotion among youth, and will present a case study of the strategies used by the Health Literacy Team at BC Children's Hospital as an

example of successful youth engagement. It will also describe a number of established youth engagement frameworks, and will use these frameworks to evaluate the Team's processes for creating eMental Health products that resonate with youth and are effective in enhancing mental health literacy in this population.

2. Literature review

2.1. Addressing youth mental health literacy

Health literacy is a key factor in health promotion and the adoption of health-promoting behaviours. Health literacy is an asset that can be built over a lifetime as "a means to enabling individuals to exert greater control over their health and the range of personal, social and environmental determinants of health" (Nutbeam, 2008). Health literacy skills allow individuals to access, understand and use information to promote their health (Nutbeam, 2008). Massey, Prelip, Calimlim, Quiter and Glik (2012) offer an expanded definition of health literacy for adolescents that includes the ability to navigate the health system, understand rights and responsibilities, know about preventative care, seek information, and understand patient-provider relationships. In addition, youth health literacy includes general literacy, media literacy and computer literacy – all of which are necessary for youth to interpret health information delivered through a variety of different media channels (Manganello, 2008).

Supporting mental health literacy is particularly important because some of the initial signs of a mental health challenge may not be apparent to anyone except for the person who is experiencing them. Mental health literacy refers to the knowledge, beliefs, and abilities that support the prevention, recognition, and or management of mental health and substance use challenges (Rootman, 2007). The burden of mental disorders among youth, compounded with low mental health literacy within this population (Kelly, Jorm, & Wright, 2007), suggests that improving mental health literacy in youth and young adults should be a priority when designing health interventions. A high degree of mental health literacy at the population level makes early identification and appropriate intervention for mental health and substance use challenges more likely.

Youth are an important target group for mental health literacy initiatives because they generally have lower utilization of health services and their understanding of their role in improving or maintaining their mental health tends to be lower than in the adult population (Massey et al., 2012). In addition, they are at a crucial stage of development in terms of physical, emotional and cognitive changes as they are developing more autonomy and forming behaviour patterns (Manganello, 2008; Wong, Zimmerman, & Parker, 2010). However, the field of mental health literacy is relatively new, and has not been extensively studied to date. Best practices in mental health literacy, including what is most effective for youth and young adult populations, are, for the most part, new and emerging. Although there is currently very little evidence on the effectiveness mental health literacy program components (Kelly, Jorm, & Wright, 2007), the use of youth engagement is beginning to emerge as a promising practice.

2.2. The value of youth engagement

The value of youth engagement is well-documented in the literature. Evidence supports a social inclusion approach where all members of society are valued in a more collaborative, inclusive approach to complex issues such as (mental) health and well-

being (Head, 2011). Youth have the right to participate in decisions that are relevant to their lives and should be viewed as assets rather than burdens (Checkoway & Gutierrez, 2006). In addition, the inclusion of engaged youth as valued team members in mental health initiatives is fundamental to the development of effective and relevant mental health information, resources and tools (Coates & Howe, 2014). Youth are often underutilized, and should be part of the planning, delivery and evaluation of youth-focused initiatives to ensure that their needs and perspectives are understood and addressed. It is important to recognize and honour the expertise that comes from simply being a young person (Checkoway, 2011).

When youth are engaged, they develop an increased sense of belonging, feel valued, and are connected to positive role models; this can support the prevention of, and recovery from, mental health challenges (Wong, Zimmerman, & Parker, 2010; Coates & Howe, 2014). In addition, youth participation and engagement has been shown to enhance mental health literacy (Coates & Howe, 2014; Edwards, Wood, Myfanwy, & Edwards, 2012).

2.3. Theories of youth participation and engagement

Participation and engagement can take many forms. Hart's (1997) "ladder" of participation illustrates a stepwise progression of participation that ranges from non-participation (e.g. manipulation) to full participation (e.g. child-initiated, shared decisions with adults) in the context of youth and adult interactions. Shier's (2001) Pathways of Participation is a complement to Hart's model, but focuses solely on participation types and offers key questions to determine the current level of participation. Both of these models are adult-centric and make the assumption that the highest rung of the ladder is the most desirable. Treseder (1997) offers a more flexible approach, where there are multiple equal forms of participation. This model acknowledges that in some cases, entirely youth-driven initiatives may be inappropriate. Evidence shows that outcomes may be less positive without adult involvement, as this places too much burden on youth who frequently have less experience and fewer resources at their disposal (Wong, Zimmerman, & Parker, 2010). The TYPE Pyramid offers a framework that features intergenerational partnerships and depicts the optimal types of participation for youth empowerment. The framework moves from symbolic participation (where youth have voice, but little power) to pluralistic or shared control, to independent participation (where adults give up power for youth to gain power). This model is distinct because it is based on an empowerment framework and appreciates the involvement of both youth and adults, where adults serve as resources rather than experts. It encourages adults to provide guidance and social support while creating an environment where youth can feel safe and welcome to share their opinions (Wong, Zimmerman, & Parker, 2010). Intergenerational partnerships come in different forms. For example, youth leaders can be a bridge between generations by supporting ideas and recruiting additional youth participants. Adults, in turn, can share their experience and knowledge around lessons learned (Wong, Zimmerman, & Parker, 2010).

Youth that choose to participate in these types of youth-adult partnerships are often not representative of the general population. More active participation is associated with higher income, education, and socioeconomic status (Checkoway, 2011). Participation can also be influenced by culture, age, gender, religion, family and media (Checkoway, 2011). Advancements in technology and telecommunications have resulted in decreased active community participation by youth (Checkoway, 2011). Other barriers to participation include 1) youth not viewing themselves as change-makers; 2)

“Adulthood”: adults viewing youth through a deficit lens, and youth internalizing this view by questioning their own legitimacy and limitations (Checkoway, 2011); and 3) adults being cautious about the risks and responsibilities of engaging with youth under the age of 18 (Head, 2011). Although formal research on successful youth engagement practices is limited, other new and promising practices are emerging, including: avoiding tokenism; setting expectations that are realistic and that allow for flexibility within the youth’s commitment; acknowledging the diversity of youth and their experiences; recognizing possible risks and responsibilities for youth under 18; promoting the benefits of youth participation to adults; ensuring there are enough resources to support youth participation; respecting the needs and interests of youth participants; creating a welcoming environment by respecting and encouraging youth; enabling youth by facilitating, mentoring, teaching and providing feedback; and allowing for more time and flexibility to work with youth (Cargo, Grams, Ottoson, Ward, & Green, 2003; James, 2007).

Successful youth engagement requires first being aware of the youth’s desire to be involved, gathering the required resources, and incorporating new processes that are truly embedded into a standard of practice (Head, 2011). This shift should reflect a participatory approach rather than a top-down approach, as research indicates that if members of the target audience for a particular communication strategy are involved in design and dissemination, better outcomes are achieved (Neuhauser & Kreps, 2003). Active citizen participation is recognized as a key approach to health promotion based on the principle of empowerment. Participation builds on strengths and creates ownership to support long-term change; citizens become agents of their own change and contributors to broader community change (Wong, Zimmerman, & Parker, 2010). In this way, youth can impact population-level outcomes by influencing resource allocation, program implementation and priority-setting (Checkoway, 2011). Active participation can impact individual personal and social development (improved knowledge, practical skills, confidence and critical thinking), organizational development (resources are more accessible, increased credibility and sustainability), as well as the broader community and society (Checkoway, 2011; Checkoway & Gutierrez, 2006; James, 2007; Coates & Howe, 2014).

3. Case study: Youth engagement in eHealth literacy initiatives at BC Children’s Hospital

3.1. The health literacy team at BC Children’s Hospital

The Mental Health Literacy Team at BC Children’s Hospital develops and disseminates a range of easy to use, evidence-based and relevant information, resources and tools. The Team aims to enhance the mental health literacy of children, youth and families across BC through a number of initiatives, including eHealth initiatives, which are disseminated across a range of settings and channels. These initiatives include: Youth and Young Adult Mental Health Literacy Initiatives; Mental Health Literacy School-Based Initiatives; Disordered Eating and Eating Disorders Mental Health Literacy Initiatives; and Cross-Cultural Mental Health Literacy Initiatives. In addition, the Health Literacy Team raises public awareness about mental health and encourages early symptom recognition and intervention through: interactive websites for children and families (keltymentalhealth.ca) and youth (mindcheck.ca); outreach to youth through social media channels (e.g. Facebook, YouTube, Twitter, Instagram); the development of online tools and web applications; and educational webinars open to participants from across BC.

Through these resources and services, the Team aims to help break down stigma and negative stereotypes about mental illness, replacing them with innovative and empowering approaches to achieving mental health and well-being. The Health Literacy Team engages youth in the development of eHealth literacy resources at a variety of levels. Over the past several years, the Team has developed a suite of mental health and substance use resources and tools for youth including:

- ***mindcheck.ca*** - an interactive youth and young adult website that allows youth to check how they are feeling and quickly connect to mental health resources and support. Support includes education, self-care tools, website links and assistance in connecting to local professional resources. *mindcheck.ca* also utilizes social media channels, including Facebook, Twitter, YouTube and Instagram.
- ***Dealing with Depression (dwdonline.ca)*** - an interactive tool for teens ages 13-17 experiencing low mood and depression. This resource helps youth understand, learn and apply specific antidepressant skills. The resource features radio theatre stories to illustrate the key concepts and opportunities for practice and monitoring progress.
- ***Stop Wondering, Start Knowing: A Mental Health Video Resource for Schools*** - a resource for use in high schools in BC to spark dialogue and increase awareness about mental health. The resource features videos of youth with lived experience and a facilitator guide to provide teachers with instructions for leading discussions and activities. The guide also includes background information about mental health challenges and links to additional resources.
- ***MindShift App*** - a free, easy-to use mobile app to help young people cope with feelings of anxiety. *MindShift* is designed to help youth learn how to relax, develop more helpful ways of thinking, and identify active steps that will help them take charge of their anxiety.
- ***Stresslr*** - an interactive, mobile web app designed to help enhance the ability of children ages 9-11 to learn about stress, understand how they react to stress, and to develop healthy strategies to deal with stress in their everyday lives.
- ***Breathr*** - a new mindfulness app for youth that is currently in development. *Breathr* introduces users to information about the brain science of mindfulness, and uses interactivity to encourage engagement with simple mindfulness practices that are easy to access and integrate into day-to-day life.

In developing the eHealth Literacy resources described above, the Health Literacy team ensures the quality of each initiative in a number of ways, including reviewing current evidence and existing resources; engaging interdisciplinary stakeholder groups (including experts and mental health professionals); and ensuring that content is reviewed by a plain language specialist. In addition, the Health Literacy Team has engaged youth in a variety of ways. The Team's involvement of youth in their initiatives can be evaluated by comparing the activities to three of the models for youth participation and empowerment: Hart's (1997) Ladder, Treseder's (1997) Degrees of Participation and the TYPE Pyramid (Wong, Zimmerman, & Parker, 2010). The Health Literacy Team strives to avoid any activities that would operate on the third level of "tokenism" (or below) on Hart's ladder of participation.

3.2. Symbolic empowerment methods

As part of the development of the Health Literacy Team's eHealth tools, youth are often consulted through surveys, focus group sessions, and on an individual basis to provide input and feedback at different stages throughout a project's development. In these cases, youth are consulted and informed, (level five on Hart's ladder) or assigned but informed (Treseder, 1997). They are informed and aware of the process, and their ideas are taken seriously; however, the project is led by adults and the final decisions are made by the adult project leads. This relationship is reflective of *the symbolic empowerment* framework of the TYPE pyramid model.

For example, during a recent round of revisions to the *mindcheck.ca* website, a group of youth were recruited from an existing youth mental health engagement program. Each participant was assigned a specific section of the site to review and present their feedback during a focus group session. Suggestions were incorporated into updates to the website. A similar process was undertaken during the initial planning stages for the *Dealing with Depression* online resource, where high school-age youth participated in a focus group session to share their ideas about revisions to the content, look and feel, and format of the new resource. In addition, when developing *Stresslr*, a group of youth aged nine to eleven was recruited via social media and provided input on the stressors in their lives, how they react to stress, the coping mechanisms they have used, and what type of tool would be helpful for them to learn and manage stressful situations. In each of these instances, the Health Literacy Team relied on the expertise and lived experience of the youth to help shape the final product and to ensure that it would be relevant and practical for the intended audience.

In a number of cases, the Health Literacy Team has had the opportunity to make youth voice a central component of a project by featuring personal stories and experiences as part of the final product. As part of the launch of the *mindcheck.ca* website, the Health Literacy Team leveraged social media channels and endorsement from a popular local sports team to encourage youth from across BC to upload a video pledging to support a friend or family member who may be struggling with their mental health. Over 220 video pledges were uploaded to *mindcheck.ca*'s "In One Voice" campaign page, and these were shared widely with other youth via social media. By using social marketing strategies to create engagement and dialogue both on *mindcheck.ca* and on social media channels, the Team was able to significantly raise awareness and use of the website among the target audience within a very short period of time. A province-wide evaluation of the campaign demonstrated that in the short-term, health literacy goals of the campaign were achieved, and that after being exposed to the campaign, nearly 25% of youth had talked about it with someone else (Livingston, Tugwell, Korf-Uzan, Cianfrone, & Coniglio, 2013). At one year follow-up, there was some evidence to suggest that the campaign may have contributed to small but significant changes in personal stigma and social distance (Livingston, Tugwell, Korf-Uzan, Cianfrone, & Coniglio, 2014).

Another example of a project which had youth voice as a central component is the *Stop Wondering, Start Knowing* school resource, which features stories told by real BC youth who experienced significant challenges to their mental health and were willing to share their experience to help others recognize the signs of a mental health challenge and connect to supports. The inclusion of candid interviews with youth with lived experience ensured that the tone, language, and design of the resource would resonate with the high school audience that it is intended to reach. In each of these projects a *symbolic*

empowerment structure was utilized, where youth were invited to lend their voice to the initiative, but adults maintained control over decision-making.

3.3. Pluralistic empowerment methods

In addition to seeking one-time involvement by youth at a particular stage in the project timeline, other initiatives have allowed for more sustained involvement of youth throughout the planning and development process. In many cases, youth sit on the advisory committees for projects that are directly relevant to their personal experiences. These projects are adult-initiated, but allow for shared decision-making with the youth, in alignment with the sixth level of Hart's (1997) ladder of participation, or the "adult initiated, shared decisions with children" category on Treseder's (1997) model.

For example, youth with lived experience with depression and anxiety were included as part of the ongoing project advisory committees for the *Dealing with Depression* online resource, *MindShift App* and *Breathr* app. In this way, youth were directly involved from the inception of the project to the creation of content. They participated in a series of planning meetings to help provide direction and make shared decisions regarding design and interactive components of the tools. By inviting youth to become members of the project team, the Health Literacy Team is able to draw on their knowledge and experience to significantly contribute to the direction of the project, and ensure that the final product is the right fit for the intended audience. According to the TYPE pyramid (2010), this relationship would be considered pluralistic, and creates an environment where youth actively participate, and youth and adults share in the decision-making process. One youth advisory committee member expressed his appreciation for being engaged at this level: "*As a youth, I'm incredibly grateful for the opportunity to contribute my experiences and ideas on projects like Breathr. With the projects being youth-focused, I feel like I can be a part of the change I've always wanted to see. Not only that, but by giving me such a role, I can see how much the project team cares about getting youth involved. It's been incredibly empowering!*"

3.4. Independent empowerment

Finally, the Health Literacy Team also facilitates youth engagement strategies in which youth have an active participant role, and adults allow for youth to have most of the control. This is the highest level of participation identified on Hart's (1997) ladder. The Health Literacy Team employs a number of youth as paid members of the project team. At this level of involvement, youth not only have a voice, but also have a direct role in initiation, planning, decision-making, and project coordination, thus equating to the autonomous category on the TYPE pyramid. Over the past two years, the Team's Youth Coordinator has gradually taken on greater levels of responsibility within the e-mental health portfolio of the Health Literacy Team, and now plays a lead role in several youth-based initiatives. In addition, the Team's youth peer support workers are solely responsible for managing and evaluating all of the *mindcheck.ca* social media channels, which reach thousands of individuals across BC each week. Through these same social media channels, the Health Literacy Team reaches out to youth to promote a variety of other events, programs and initiatives throughout the year, including quarterly "tweet chats" on Twitter, a provincial youth mental health ambassador program, and an annual anti-stigma youth summit. The effects of youth engagement via the *mindcheck.ca* social media channels are lasting and far-reaching, having resulted in many youth from across the province gaining the knowledge, skills and confidence to share their stories, reach out

for support when needed, and support others. As one youth participant stated, *“I just want you to know what you’re doing is truly inspiring and so appreciated. It’s really nice knowing there are people out there that have gone through what we’re going through and are willing to help us. It gives me hope that it’s possible to get better. So thank you.”*

One of the key benefits of having youth-led projects is that youth involvement naturally fosters connections to other young people. Because of these relationships, more youth are then likely to become engaged in the project, to feel comfortable speaking up, and to confidently share their perspective, all of which contribute to a much richer and more diverse process overall. For example, one youth described their experience working with the Health Literacy Team as empowering: *“My involvement in the development and review of e-mental health initiatives as a youth has been nothing short of empowering. It’s incredible how eager people are to hear the youth perspective and I believe it’s leading to more products that are not only designed FOR youth, but designed... BY them as well.”*

At project completion, youth often play a key role in dissemination and communication strategies. When youth can speak knowledgeably to their peers about a resource that they helped develop, while using a language and tone that is familiar and comfortable for them, it is possible to generate genuine interest, and to reach a much broader audience than would otherwise be possible.

4. Discussion

Youth prefer media that are interactive, customizable and available in multiple formats, thus allowing for easy access, greater variety, and rapid dissemination of information (Skopelja, Whipple, & Richwine, 2008). Organizations with a mandate for health promotion among youth should take advantage of these features and provide information in the language and media that youth prefer and find most appealing. Wong, Zimmerman & Parker’s (2010) TYPE Pyramid provides a framework for understanding the balance between youth participation and adult involvement to foster a pluralistic relationship where there is shared control and co-ownership. When this model for youth engagement is applied to the eMental Health Literacy projects at BC Children’s Hospital, we see that the majority of activities involve a symbolic relationship (youth voice; adult control) or an independent relationship (youth participation; mostly youth control). While these relationships improve project outcomes, the process of youth and adults working together can provide optimal conditions for positive youth development (Wong, Zimmerman, & Parker, 2010). Moving forward, the Health Literacy Team should consider making a greater effort to operate at the pluralistic level of shared control, where youth have an active role and share in the decision-making process with adults.

Meaningful, pluralistic engagement of youth in the development of eHealth Literacy initiatives requires a commitment on the behalf of the organization to bring youth into the core planning team, and a recognition that youth have the innate knowledge and skills to contribute meaningfully to the development of resources for other youth. When youth involvement is only a peripheral, tokenistic component of the planning process, the impact of youth voice is substantially reduced. The greatest benefits are seen when youth play an ongoing and significant role in the entire project lifecycle, are supported by adults, and have shared control over decision-making.

5. Lessons learned

Many lessons have been learned throughout the course of this work, and the Health Literacy Team continues to seek opportunities to authentically bring youth voice into the program. The youth who come forward to engage in this work are generally not representative of the broader youth population, and there is room for increasing representation of youth from different cultural, linguistic and socioeconomic backgrounds to better meet the needs of more diverse populations. Given the diversity of the youth population of BC, this is a priority area moving forward. Similarly, the youth who engage in this work are less likely to be from rural or remote geographic areas, and therefore may not be able to speak directly to the unique challenges that these communities face. eHealth strategies offer an important mechanism for reaching across geographic regions, and therefore a greater effort should be made to engage youth from these population groups in the development of projects and initiatives. Social media strategies offer one of the best means of creating these connections, and the potential for using these tools should be explored more comprehensively.

6. Conclusion

The evidence to support the use of eHealth strategies to improve the health of youth is abundant; however, the importance of authentically and strategically engaging youth in the development of these tools and resources cannot be understated. By creating meaningful opportunities for youth to be involved in the planning, implementation and dissemination of eMental Health Literacy tools, the Health Literacy Team at BC Children's Hospital helps to ensure that the final products reach and address the needs of the intended youth audience. Youth engaged on the Team's projects are highly computer and social media literate. For this reason, they serve as the best means of communicating with their peers and spreading the word about new resources and educational materials developed by the Health Literacy Team. Empowering young people who have personal experience with mental health challenges to play a critical role in the development of these resources fosters their personal development and self-esteem. Over the past few years, the sharing of personal stories of recovery from real youth has inspired many more young people to open up about their own struggles, creating a ripple effect in the community and encouraging others to speak out and seek support. By continuing to promote the importance of the youth voice, providing shared control over youth-focused initiatives, and striving to achieve meaningful youth engagement, the impact of the Health Literacy Team's eHealth initiatives on youth wellness can continue to create healthier communities across the province.

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