

Involving young people in health promotion, research and policy-making: Practical Recommendations

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ABSTRACT

Youth is a dynamic and complex transition period in life where many factors jeopardize its present and future health. Youth involvement enables young people to influence processes and decisions that affect them, leading to changes in themselves and their environment (e.g. peers, services, communities and policies); this strategy could be applied to improve health and prevent diseases. Nonetheless, scientific evidence of involving youth in health-related programmes is scarce. The aim of this paper is to describe youth involvement as a health promotion strategy and to compile practical recommendations for health promoters, researchers and policy makers interested in successful involvement of young people in health-related programmes. These suggestions aim to encourage a positive working synergy between adults and youth during the development, implementation and evaluation of policies, research and/or health promotion efforts that target adolescents.

Key Words: Adolescents Health, Participation, Youth involvement, Health Promotion

BACKGROUND

Youth is one of the most dynamic and complex transition periods in life with a series of turning points that can shape identity and influence development, health and wellbeing [1]. Moreover, half of preventable premature deaths are associated with health risk behaviours developed during youth (e.g. poor dietary and physical activity patterns, alcohol abuse, drug misuse) [2]. Such behaviours can track into adulthood and contribute to the leading causes of non-communicable diseases, mortality and morbidity [3]. The prevalence of health-compromising behaviours that emerge during youth is high enough to classify them as healthcare challenges and high-priority areas for public health research, policy and practice [4, 5]. Furthermore, reducing their cumulative consequences is usually simpler and more cost-effective for societies when addressed during adolescence [5].

The terms “youth involvement” or “youth participation” are generally used interchangeably when addressing the inclusion of young people in matters that affect them, but several definitions exist to explain this concept [6-9]. For instance, the United Kingdom’s National Children's Bureau defines it as “the means by which children and adolescents influence decisions that bring about change in them, others, their services and their communities” [6].

Youth participation has become one of the axioms of effective policy and programming development [10]. However, the effectiveness of this strategy in health-related programmes has not been measured properly since many programmes are constructed using an adult lens and overlooking real-life youth’s experiences [10, 11]. Thus, a participatory strategy is gaining recognition as a viable approach not only to prevent youth health problems, but also to enhance positive development among young people [11]. Nonetheless, “there is [still] a need for better and collective understanding of what youth participation involves [and] how it can be implemented” [12], and scientific evidence base on the benefits of involving youth in health-related activities is needed [13, 14]; with efforts, underway to address this gap [15,16].

In this review, the terms youth and young people are used interchangeably to include children, adolescents and young adults from 10 to 24 years of age. In doing so, we adopted a blanket definition that incorporates a wider age group as identified by reputable stakeholder perspectives, such as that from the World Health Organization (WHO) (10-19) [17], United Nations Convention on the Rights of the Child (UNCRC) (<18), United Nations (UN) (youth 15-24; young people 10-24) [18]. Our work intends improving participation in this broader

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3 group and seeks to provide practical advice that can be tailored to the national or international
4 frameworks.
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7 The aim of this review is to reflect on the concept of youth involvement as a health
8 promotion strategy, and to provide practical recommendations for their successful
9 involvement in health-related activities drawn from a review of existing literature, reputable
10 institutional guidelines and programme toolkits that supported cases for youth involvement as
11 a health promotion strategy.
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18 *Youth Involvement*

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20 Involvement is as a fundamental right for all people. For youth, this approach exists within
21 the international context of the UNCRC. Specifically, Article 12 states that young people
22 who can form their own views have a right to express them freely in all matters that affect
23 them, assigning a proper weight in accordance to their age and maturity [18]. A direct result
24 of the adoption of the UNCRC has been a change in perspective on their status in society,
25 with children and adolescents now having a say in many aspects of their lives [19, 20]. In
26 addressing health concerns for young people through the adoption of regional strategies like
27 that of the WHO European region, which explicitly seeks to “make children’s lives visible”
28 [21], and the use of adolescent-specific research like the Health Behaviour in School-
29 Children (HBSC) Study [13], policymakers, advocates and researchers can ensure that youth
30 realities are understood, appreciated and taken into account.
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39 The WHO advises that youth needs to be included as active partners in all health-related
40 activity stages, from design through to evaluation, especially for programmes affecting their
41 own health [22, 23]. This goal has been applied under strategies identified as youth
42 engagement (i.e. which identifies youth’s right to participate in decisions that impact them by
43 acknowledging the skills and strengths they add to programmes) [24, 25]; youth organising
44 (asset-based approaches, i.e. an youth development and social justice strategy that assists
45 young people in employing skills to alter power relations and create meaningful institutional
46 change in their communities) [26]; participatory action research (i.e. giving voice to youth’s
47 concerns, and launching programs and activities that meet the needs of local youth within a
48 community) [27]; youth-driven approaches or youth-adult participation (i.e. includes high-
49 quality youth- adult participation) [28]. Models and typologies of how to involve youth in
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3 participatory actions have been described [6, 11, 29, 30]. This participation has also been
4 defined as a theory named “youth empowerment” [4, 31, 32], which can be applied as a
5 framework of public healthcare systems, were adolescents, as both stakeholders and patients,
6 are catalysts in the process of creating patient-centred care [32]. All of these strategies
7 emphasise inclusion and action, offering alternative approaches based on reflection, data
8 collection, and action to improve young people’s health and reduce health inequities.
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13 *What do adult-stakeholders (e.g. health promoters, researchers, policy makers) and health*
14 *institutions gain when they embrace youth participation?*
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17 Professionals who actively listen and involve youth in programmes are more likely to
18 succeed [33] because their actions uphold youth’s rights, promote their protection and fulfil
19 the State’s legal responsibilities [34]. Evidence suggests that young people’s participation in
20 institutional and governmental decisions enhances their credibility in the eyes of society,
21 while improving public services by promoting more transparent actions and participative
22 culture [6, 35-37]. In research, youth involvement is compatible with improved quantitative
23 and qualitative methods, and is a source of innovation that may facilitate the research process
24 [13, 35, 38]. Additionally, researchers gain insight into new domains of inquiry through
25 integrating youth in data generation, analysis, interpretation and dissemination activities [12].
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33 *What do youth gain with their participation in health-related activities?*
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35 The acquisition of new skills, emotional links, knowledge, competences, self-efficacy, self-
36 esteem and confidence, which can foster young people’s autonomy and help them to
37 successfully manage the complex transition to adulthood. This reinforces their sense of
38 control and awareness of their personal, community and environmental decisions. Youth can
39 get confirmation that their views matter and this influence can affect their health [6, 11, 35,
40 39, 40]. They also learn about addressing structural constraints within institutions that are
41 supposed to serve them, as well as city or state governance affecting their life quality,
42 showing them that they have the opportunity to directly influence both methods and
43 outcomes [11, 35].
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51 *Recommendations for youth's involvement in health-related activities*
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53 By acknowledging youth’s valuable contribution to health-related activities, both adult
54 stakeholders and young people are benefited. However, if not properly done, youth
55 engagement could result in an unnecessary, burdensome, or hazardous experience for
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3 participants. Thus, a proper involvement strategy in health activities is necessary, but
4 challenging [35].

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6 A narrative review to identify specific recommendations to promote the design,
7 implementation and **evaluation** of a successful youth participation was performed based on
8 reputable institutional guidelines and programme toolkits [6, 11, 20, 29, 31, 35, 37, 40-47].
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10 These recommendations have been organised in time-stages associated to the development of
11 health-related activities or programmes (i.e. design, implementation and **evaluation**) to
12 facilitate youth involvement as a sequential process and to reiterate the importance of
13 coherent and meaningful participation throughout. A schematic overview of all
14 recommendations is presented in *Table 1*.
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20 During **all the involvement stages**, health promoters, researchers and/or policy makers must
21 consider:
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24 · *Commitment*: Adults should be willing to adapt to youth's necessities [41] and be
25 devoted to the whole process.
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28 · *Planning and schedule*: Consider sufficient time for each activity. Schedules should
29 be adapted to the youth's needs and their other commitments (i.e. school and extra-
30 curricular activities) [35].
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33 · *Be open to change*: Organisers must accept youth's perspectives and ideas and be
34 willing to adjust rules, which meet their needs [37].
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37 · *Selectiveness*: Choose the appropriate participants for partnerships. Youth vary widely
38 in their level of development and readiness to assume responsibility, and adults vary
39 widely in their degree of commitment and willingness to work with youth [13].
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42 · *Evaluation*: Participants should evaluate the process before, during and after its
43 execution. For this purpose, apply short questions with simple language, avoiding
44 abstract concepts. There are no right or wrong answers, and this message must be
45 reiterated during data collection. Also, ensure to register all kind of answers, even if
46 these are non-verbal methods of communication (e.g. drawings) [6].
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49 · *Motivation*: Ensure participant's engagement for the whole process [42].
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52 · *Sense of purpose*: Consult youth's expectations and goals in their healthy lifestyles
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- 3 · *Transparency*: All the process needs to be clear, providing straightforward data on
- 4 their right to express views freely [35].
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- 7 · *Limitations*: Participants need to understand the restrictions that affect the processes
- 8 [10].
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10 During **the design** of a youth involvement process, health promoters, researchers and/or
 11 policy makers must consider:

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- 15 · *Purpose*: Clearly state the reasons for youth involvement and the expectations of this
- 16 participation [43].
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- 19 · *Established methodology*: All the process should be evidence-based, ethical, realistic
- 20 and properly resourced [6]. There are models described for youth involvement, which
- 21 could help design a plan [6, 11, 29, 31].
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- 23
- 24 · *Theoretical framework*: Social science theories and conceptual models provide the
- 25 basis for understanding human behaviours [44]. Theoretical frameworks help monitor
- 26 both youth and adult involvement in the activities (e.g. empowerment theoretical
- 27 framework) [31].
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- 32 · *Age-appropriate activities*: Participation activities need to be meaningful to youth
- 33 according to their capabilities [20, 35]. Given the formative stage in which they live,
- 34 activities should consider the integration of learning skills in mathematics, social
- 35 studies, communications, critical thinking and problem solving [40].
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- 39 · *Working place and transportation*: Adults are responsible of creating safe
- 40 environments where youth feel welcome and therefore, willing to share their views
- 41 [11]. Identify conditions, personal risks and protective factors to create a formal or
- 42 informal place where involved youth feel safe [40]. If possible, schedule meetings in
- 43 easily accessible places, considering that youth usually do not have a personal vehicle.
- 44 Organisers should provide travel vouchers or promptly reimburse youth for
- 45 transportation costs [37].
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- 51 · *Food*: Youth rarely have the means to buy meals or dinners outside of their home.
- 52 When meetings overlap with meal times, consider providing youth with either food or
- 53 sufficient funds to pay for meals [37].
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3 · *Materials*: The cost of materials and dispensations (cameras, developing, printing, art
4 materials) must be included in project budget and covered by the responsible party.
5 For this reason, it is indispensable to have a list of materials needed for each activity
6 and participant [6].
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10 · *Institutional players*: Adults should seek to integrate institutions within the social
11 environment that influence the life of the youth that will participate (e.g. schools,
12 community centres, city councils) [11].
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- 15 · *Diversity*: Youth participation must aim to include all youth rather than only a few
16 easy to reach potential participants, regardless of their background and without
17 discrimination on any grounds -age, race, sex, language, religion, political, national,
18 ethnic or social origin, disability or other status [34]. Efforts should be made to
19 include adolescents from vulnerable backgrounds [6] (e.g. youth in public care, with
20 learning difficulties, living in low-income communities).
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- 23 · *Pressure minimisation*: Give participants some time to reflect and confirm their
24 commitment to the process [35]. Clarify that youth's involvement is a voluntary
25 participation, in which no right or wrong answers exist.
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- 28 · *Signed consent*: Information for youth and parents/legal guardians about the process
29 must be provided and it must be clearly explained, including: objectives, description
30 of the process and the roles of each participant, person or institution responsible
31 (include timescale if possible], number of expected participants and their ages,
32 facilitators, logistics and support available [35].
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- 35 · *Identify legal concerns*: Seek consent to use any material collected during activities
36 (e.g. ideas, pictures, drawings, photographs or other materials created) for reports or
37 dissemination [6]. Also, consider processing the adequate work permits or insurance
38 if youth involved is employed.
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- 41 · *Existing research and toolkits*: Identify similar youth participation models or toolkits
42 in your field. Drawing inspiration from previous successful interventions programme
43 design or research may work as a tool for questioning, understanding, and addressing
44 the issue at hand [39].
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3 During **the implementation** of a youth involvement process, health promoters, researchers
4 and/or policy makers must consider:
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7 · *Presentation and team formation:* Be sure that all participants meet each other,
8 creating a casual atmosphere. Clearly state the roles and responsibilities of everyone
9 in the process. Each participant will need to agree to the assigned roles and
10 responsibilities. [37].
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13 · *Intra-group diversity:* Recognise within the group any age, socioeconomic
14 background, race, colour, sex, language, and religion, political or ethnic origin. Some
15 of these factors may act as constraints in youth's social interaction [34].
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18 · *Barriers:* Individual and/or group health risks and stressors can be identified in
19 various domains (e.g. family, peers, school, etc.) that can have effects on the
20 individual perspectives [40]. Identify, manage and remove any stressors and/or
21 barriers wherever possible [6].
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24 · *Goals:* Set clear targets with the youth as a common agreement [35].
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27 · *Collaboration and involvement with no sole responsibility:* Aim to create a balance of
28 power between adults and youth during the research and participation process [28].
29 Remember that it is a partnership; neither the young people nor adults are necessarily
30 subordinate of the other [37]. Lack of adult involvement in youth participation may
31 obstruct rather than encourage optimal adolescent development and empowerment
32 [11].
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35 · *Brainstorming:* Create a co-learning relationship where youth and adults raise the
36 level of collective critical consciousness. Adults can be actively involved in fostering
37 conditions for youth [11], and help them to be more open to learn, engage in critical
38 dialogue and exercise creativity [10].
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41 · *Priorities:* Establish priorities for the process, generating theories of causality,
42 solutions and change [39].
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45 · *Latest trends:* Youth culture evolves so rapidly that by the time older age groups
46 begin to understand it, youth have already adopted a new trend. To create an empathic
47 interaction with youth, be sure that participating adults are updated on the latest
48 tendencies and youth's preferences [45].
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- 3 · *Decision in peers' representation*: Let participants select among themselves those that
- 4 will represent them [35].
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- 7 · *Everyday language*: The participatory process should include a language with which
- 8 youth are familiar. Avoid labels or nicknaming among youth without their approval
- 9 [43].
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- 12 · *Communication*: Nowadays, youth communicate to a larger extent via social media
- 13 applications and services. As such, it should be considered as a practical tool in youth
- 14 involvement. Social media allows interaction outside the confines of physical
- 15 proximity, which could benefit the involvement procedure beyond face-to-face
- 16 interactions [46].
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- 19 · *Creativity*: Allow youth to express themselves in a way that others may appreciate
- 20 what they hear. Be sure to encourage creativity during the process [47].
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25 During **the evaluation** of a youth involvement process, health promoters, researchers and/or
26 policy makers must consider:

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- 29 · *Incentive or rewarding participation*: This does not necessarily mean an economic or
- 30 tangible reward. Ensure participation ends in a meaningful way, e.g. evaluate
- 31 satisfaction, pride or incentives [11].
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- 35 · *Acknowledging*: Recognise all the participants' contributions in the process, both
- 36 youth and adults [10, 34].
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- 39 · *Confidentiality*: Youth participants should afford the same degree of protection
- 40 regarding confidentiality, anonymity and data protection as adult participants [6].
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- 43 · *Communication*: Support youth's share their experiences, which can have a powerful
- 44 impact on audiences of all ages [35].
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- 47 · *Resolutions*: Identify power differentials between participants. Move toward change
- 48 strategies on these levels that mediate power by improving conditions for youth,
- 49 ensuring that the results from this collaboration are translated into actions. In addition,
- 50 findings should be accessible to the general audience to raise awareness [6, 29].
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54 **DISCUSSION**

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3 Youth involvement in health-related programmes can make a difference in programme
4 success [10, 37, 48]. There is evidence to suggest that participatory approaches to health add
5 value to programmes [10, 33]. In many ways, however, it is as much about changing cultures
6 [24] as it is about changing processes. For this reason, youth involvement as a health
7 promotion strategy has the potential to promote health by satisfying youth's developmental
8 needs in a positive manner [11]. Youth involvement is not a traditional risk-factor based
9 public health approach; it provides a new focus on the assets that youth inherently possess,
10 adopts them while also eliciting changes in youth themselves. However, the best frameworks
11 may include elements of both approaches (public health and youth development) working
12 together [48-50].
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20 Some successful health-related programmes have reported the use of youth involvement as a
21 fundamental strategy (**Table 2**) [24, 48, 51-53]. For instance, the Spanish participation at the
22 European Youth Tackling Obesity (EYTO) project, (implemented as a randomised controlled
23 trial) significantly increased daily fruit consumption and daily physical activity practice in
24 adolescent' participants. This positive result is attributable to the youth being involved at the
25 design and implementation stages of the activities [48, 51-53]. In the referenced examples,
26 youth involvement supported the creation of a collective critical consciousness [11], not only
27 by creating a work synergy with adults, but also raising awareness among peers and their
28 communities. However, youth participation can pose a challenge to health promoters,
29 researchers and policy makers as they balance the importance of involving end-users to
30 increase uptake of effective interventions, programmes and policies [47] and the feasibility of
31 those approaches in light of resource limitations or knowledge constraints that may dissuade
32 them from engaging. Essentially, the main challenge is how to effectively involve youth to
33 create a working synergy that improves policies and programmes worldwide. For this reason,
34 and for a proper evaluation of this strategy, health programmes that include youth should put
35 this strategy into practice.
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46 The youth involvement recommendations in this manuscript are not checklists to follow, but
47 aim to facilitate a process that reflects a true partnership between youth and adults in a
48 professional setting, integrating the perspectives and skills of youth with the experience of
49 adults [10]. These recommendations stem from evidence of what works and may be useful
50 along health promotion efforts and future youth research. The practical suggestions seek to
51 contribute towards the development of evidence-base on health promotion, research and
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3 policy-making and practice around youth participation while also reducing the gap between
4 stakeholder intent and understanding of youth participation in health-related activities.
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6 7 **CONCLUSION**

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9 Youth involvement in health-related activities needs to be a carefully planned process that, at
10 every stage, encourages synergy between youth and relevant adult stakeholders such as health
11 promoters, researchers or policy makers. Thoughtfully implementing youth participation as a
12 health promotion strategy will help all involved stakeholders achieve health and well-being
13 goals. This synergy should catalyse joint efforts aimed at the improvement of young people's
14 health. This synergy should catalyse joint efforts aimed at the improvement of young people's
15 health.
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For Review Only

Table 1: Schematic overview of youth involvements practical recommendations for health promoters, researchers and/or policy makers

During the design of a youth involvement process	During the implementation of a youth involvement process	During the completion of a youth involvement process
Define the purpose of youths' participation	Introduce all the participants and make them feel part of a team	Incentive
Use an established and reliable methodology	Identify intra-group diversity	Acknowledge youth's and adult participation
Base the participation on a theoretical framework	Recognise possible stressors and barriers	Assure confidentiality
Choose age-appropriate activities	Set goals	Share experiences
Select a suitable working place and transportation	Remember that youth should collaborate, be involved, but not be solely responsible	Make public resolutions of the process
Provide food if necessary	Think with young people	
Make materials available	Consider youth's participation priorities	
Include institutional players	Identify youth's latest trends	
Contemplate diversity	Let young people decide in case of peers' representation	
Minimize pressure	Use everyday language	
Collect signed consent by young people and parents/legal guardians	Embrace communication through youth's usual networks (e.g. social media) as much as young people want	
Identify and address any legal concerns	Persuade youth's creativity	
Use of existing research, work and toolkits		
During all the youth involvement stages		
Guarantee the determination and serious adult commitment Plan and schedule Be open to change Select appropriate participants for partnerships Evaluate the process Motivate Consult young people about their sense of purpose and future Make sure the process's transparency Participants need to understand limitations and restrictions		

Summary of considerations based on reputable international institutional guidelines and programme toolkits for an adequate youth involvement.

Table 2. Examples of youth involvement as a health promotion strategy

Project Name	Country	Description	Web site
The Students Commission	Canada	Founded in 1991 to help young people put their ideas for improving themselves, their communities and their world into action. In 2000, it became the lead of The Centre of Excellence for Youth Engagement, which networks academics, youth organizations and young people together to provide research and training to improve youth programs and youth engagement in Canada. The Commission works with the Health Behaviour in School-aged Children (HBSC), a WHO Collaborative Study, in Canada team to develop and carry out their youth participation efforts. For an example of their work [10]	www.studentsmission.ca/
The Dream Teens Project	Portugal	In 2013 was launched in Portugal to give voice to young people in matters that affect them. Participants (under-18) were actively involved in the elaboration of research instruments and group debates on issues such as mental health, sexuality, substance consumption, self-harm, interpersonal violence, academic success and expectations, family support, social support networks, leisure, among others. Young people have identified emerging problems, gaps and solution trajectories [51]	www.dreamteens-en.aventurasocial.com/
The European Youth Tackling Obesity (EYTO) Project	United Kingdom, Portugal, Czech Republic, Spain	In 2014 was launched to create a multicentre project. Five selected adolescents (in each country) were tasked with designing and implementing youth-led social marketing approach to promote healthy eating and physical activity and to stem the rise in obesity amongst young people aged between 13 and 18 years old living in low socioeconomic areas [47,50].	http://www.eyto.org.uk/