INVOLVEMENT OF YOUNG EXPERTS BY EXPERIENCE IN RESEARCH

Background Document

Exploring youth involvement in research, in the context of the ambitions of the Family Faculty Utrecht

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On this background document

This research aimed to provide insights in the various options, barriers, and facilitators to involve youth (up to 25 years old) in (health) research. The study was commissioned by the Centre of Excellence for Rehabilitation Medicine and the ZonMw in preparation of the establishment of the Family Faculty Utrecht, an infrastructure to systematically involve families in all aspects and stages of research. However, during the research process valuable insights were found that we would like to share with those interested in the topic. Therefore, we have established this background document. In this document one can find more information on the project as well as on the literature study done for this report. We hope this document will provide useful insights, inspiration for (research) projects and guidance in involving youth in research. More information on the (youth) involvement in research is to be found on the website of ZonMw.

Content

About the project

Since January 2020, the Centre of Excellence for Rehabilitation Medicine, a collaboration between University Medical Centre Utrecht and Rehabilitation Centre De Hoogstraat (KCRU)[1] and ZonMw[2] have taken first steps in the realisation of an infrastructure to systematically involve families in all aspects and stages of research, inspired by the PenCRU Family Faculty in Exeter. The Family Faculty Utrecht (FFU)[3] aims to conduct relevant, high quality and feasible research of which the results are easily accessible to the target group (families of children with a disability). At the core of the FFU will be experts by experience, also referred to as people with lived experience (PWLE), who will help researchers ask the 'right' questions that are meaningful to families of children and youth with disabilities, think along in all stages and aspects of research and advise on the distribution of (new) knowledge. The yet to be established FFU facilitates the coordination of collaboration by creating modules, manuals, and network security. In the beginning, the FFU will focus on research about the parents of children with a brain-based development disability or a neuromuscular disorder. However, the goal is to broaden the target group to *young* experts by experience. KCRU has some experience with involving adolescents with cerebral palsy in research (project Participation in Perspective and development of Involvement Matrix). However, both ZonMw and KCRU realize that it takes other steps to involve young people in all aspects of research, compared to involving parents in a model of the Family Faculty. Therefore, this report aims to investigate various options, barriers, and facilitators to include youth (up to 25 years old) in research, in the context of the FFU.

About the author

Bente van Oort has been interested and active on the topic of youth engagement for years. During her bachelors in political sciences, she worked as the chair of the youth panel Care and Future Perspective where she represented the interests of young people with a chronic disorder in The Netherlands. Moreover, she did and internship at Ministry of Health Affairs, worked as student representative and contributed to the development of the first youth parliament in The Netherlands. She is currently pursuing a research master's degree in Global Health at the Vrije Universiteit in Amsterdam.

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[1] Kenniscentrum Revalidatiegeneeskunde Utrecht (KRCU).

[2] Governmental organisation promoting quality and innovation of health research.

[3] This is a working title.

Plain language summary

Engaging young people in research processes means that research and youth become equal partners in researching questions that are important for the youth involved. Involving young experts by experience in health research is good for both researchers and youth involved. It leads to more relevant findings and improves services and outcomes, but it also leads to self-empowerment of youth. The most important question is, however, *how do you organise youth engagement – in the context of family engagement – in research?* That is what this research project aimed to find out.

The process

To answer this question, I first looked at existing literature on the challenges and possibilities that are related to youth and family engagement in research. While this brought some very important insights in the helping and hindering factors, I found that the literature did not provide much knowledge on *how* to engage young people – both youth with a disability and siblings – in research. Therefore, I looked into four examples – also known as case studies - of youth engagement in research: the youth panel *Care and Future Perspective* (Amsterdam, Netherlands), the *Participation in Perspective* project (Utrecht, Netherlands), the *VIPERS project* (London, England) and the *Sibling Youth Advisory Council* (Hamilton, Canada). By investigating reports, academic articles and interviewing involved youth, I learned a lot more about how these projects can be organised and about the struggles and good ideas they came across. Also, I looked at one example in particular: *PenCRU* in Exeter, United Kingdom. They have created a '*Family Faculty'* in which parents are involved all stages of *PenCRU's* research about (parents of) children with a neurodisability. By interviewing involved researchers and family members, joining meetings of the faculty and analysing reports, ideas on how to engage families in a very structured way were presented.

Based on the existing literature and the lessons learned from the case studies and the PenCRU Family Faculty, I have brought together two important findings. First, we can identify 10 important lessons learned. Secondly, we can develop six possible models of youth involvement in research. These are discussed below.

The 10 do's and don'ts in youth engagement in research

By studying the literature and the case studies, I brought together the ten most important *do's and don'ts* in the involvement of young people in research. These are discussed below.

The five most important do's:

1. ***Do ask young people directly at the start of the project when, how and why they want to be involved in the research.*** It is important to continue to ask these questions throughout the project, because all parties need to know what they can expect from one another.
2. ***Do communicate clearly.*** It is important that researchers explain their expectations, tell youth involved what is done with the young people's input and what the next steps are. Being transparent is key in every collaboration, especially in collaboration between youth and researchers.
3. ***Do provide regular check-ins***. Working together on research does not mean that youth and researchers can only talk about research: it is important that there is time for casual chats. This helps to build trust and respect between all those involved, which is very useful in the project as it makes people feel more comfortable to talk and work together.
4. ***Do make sure the youth engagement in research can be flexible*****.** Everyone who wants to be involved, needs to be able to contribute – regardless of their needs. For example, think about the accessibility of meetings and provide multiple moments and ways of giving input.

5. ***Do make sure that the organisation or research institute doing the research fully supports youth engagement in the project.*** Everyone should believe in the idea of youth involvement and know what to expect.

The five most important don'ts

1. ***Don't involve young people in the research just because it seems nice.*** Young people should be able to actually contribute and cannot be used to 'check the boxes'. Their knowledge and experience are valuable and should therefore be treated with respect.
2. ***Don't expect young people to adapt to ways of working of the researchers.*** If young people are engaged, make sure there is enough space to listen to and develop the ideas of the youth. To do so, it important to adjust to their ways of communicating and working.
3. ***Don't create (a situation of) inequality between researchers and youth.*** Youth involved should receive proportionate recognition and compensation for their work.
4. ***Don't overwhelm youth involved***. Don't surprise youth with tight deadlines, too much or too difficult information or unrealistic goals. This can be prevented by, for example, using meeting agendas or the creation of guidelines.
5. ***Don't allow for too many limitations in the project.*** For example, don't have a too strict time schedule and don't limit the number of young people.

While these *do's and don'ts* were most often mentioned in literature, reports and interviews, it is important to realise that there many more factors that influence the success of youth engagement in research. Youth engagement in research is different in every context and asks for customisation to the needs and wants of both researchers and youth involved. Therefore, the first *do* is so important: ask everyone (repeatedly) involved what is needed, wanted, and expected of the project.

Six models for youth engagement in research

When looking at the case studies, PenCRU and the literature on the topic, I found that there were six different models on *how* youth engagement in research can be organised. The models are discussed with several Dutch stakeholders with experience in youth engagement in (research) projects, to identify the chances and challenges they pose. They are discussed below.

1. ***Working with existing groups***
   Researchers can work with existing groups, like a sports team or school class, in a research project. As researchers choose the group, there is a good match between the experts by experience and the question the research wants to answer. The engagement of the group brings the researcher(s) new insights and the group many benefits. However, it also means that researchers invest a lot of time and means for only a short period of collaboration. Also, there is the risk that youth is *not* engaged in all parts of the research, especially in developing the research question.
2. ***Parents+ meetings***
   In cases like the PenCRU Family Faculty, researchers can build upon the network of parents already involved in research projects. In *Parents+ meetings*, parents and children can come together to the meetings and work together on research projects. In this way, children are engaged in the research, but also get the support and protection needed of their parents. The disadvantage of these meetings is that children might not want to talk about certain topics when their parents are present or will let their parents talk for them on their behalf.
3. ***Youth Engagement Group***
   The Youth Engagement Group is an independent group within the research institute that is engaged in every part of the research. The group develops research (questions) in collaboration with the researchers, raises awareness of the research, works with staff as partners on the research and produces brief, easily readable summaries. This ensures that youth are fully engaged

in the research, but this also asks a lot of time, energy and effort of the youth involved. This poses a risk: we don’t want to over-ask them.

4. ***Youth Advisory Council***
   The Youth Advisory Council gives solicited and unsolicited advice about the research questions, ideas, projects and processes of a research institute. However, they are not themselves involved in all the research projects. Instead, they inform the staff on how to reach out to other youngsters or existing groups that can participate or engage in research on a more detailed level. The YAC then monitors whether the youth engaged are fully involved in all stages of the research and whether they have a structural place in the research project. A disadvantage of this approach is that researchers still have to find (more) youth to be actually part of their research.
5. ***Family+ meetings***
   Family engagement in research is not only about youth and their parents. Therefore, it important to include siblings as well. Building on the idea of the *Parents+ meetings*, researchers can ask *all* family members together to be a part of an advisory council. In this way, research projects and their results can be meaningful to the whole family. However, members of the same family may not be comfortable to share their thoughts in front of their relatives. And there may be differences in the level of involvement from different family members.
6. ***Sibling Engagement Group***
   Many sibling partners want to make sure that the sibling perspective is represented in research. In the Sibling Engagement Group, siblings can partner in research by, among other things, developing research questions, identifying creative study methods to engage with participants in studies, trying out methods, and recruiting participants through their own networks. However, like with the *Youth Engagement Group*, it is important that researchers do not over-ask the sibling partners.

Conclusion

The do’s and don’ts and the models provide inspiration for researchers about different ways youth engagement can be organised. However, it is important to remember the first *do*: ask youth regularly how, when, and why they want to be engaged.

Literature Review: Involving young people in health research

Integrated knowledge translation (IKT) is an approach to doing research with knowledge users as equal partners with researchers throughout the study (Canadian Institutes of Health Research, 2015). Family partners can be involved in different ways throughout the process of research projects. While there is increasing recognition about the value of involving patients and families in research in the field of paediatric rehabilitation, family partners in research have mainly been comprised of youth (such as those with the lived experience of a disability) and parents (such as those who have children and youth with disabilities) (Black, Strain, et al., 2018; Van Schelven, et al., 2020). There is little information about the involvement of sibling partners in research. For example, sibling partners could share useful information about their experiences with having a brother or sister with a disability. This literature review is an overview of the current literature on the possible opportunities and challenges of the involvement of young stakeholders in (health) research. Moreover, it explores the facilitating and hindering factors to young stakeholder engagement in research.

Involvement

Increasingly, children and young people are involved as partners in health-related research and directly consulted for their ideas and opinions (Kirk, 2007; Allsopet al., 2010; Clavering & McLaughlin, 2010; Domecq et al., 2014). This trend can be explained by the recognition that children have the *right* to be involved in decisions that concern them (Coad & Evans, 2008; Coad & Shaw, 2008), as well as a growing realisation that involving children and young people in research can bring mutual benefits to young people and researchers (Curtin2001; Barker & Weller 2003). The increased involvement of children and youth in research has challenged 'traditional' adult research practices in numerous ways (Wright et al., 2020). For example, evidence of the value of engaging stakeholders in producing impactful research is growing, as it informs health systems as well as health policy on improvements (Brett et al., 2014; Esmail et al., 2015; Woolf et al., 2016; Ramsden et al., 2017; Venuta & Graham, 2010).

Over the years, many authors have discussed the 'perfect' definition of the involvement, participation, or engagement of stakeholders in research. This literature review will adhere to the definition of INVOLVE[4]. INVOLVE defines *involvement* as a situation in which members of the public are actively involved in research studies (as co-applicants, advisory or steering members, joint grant holders) and inform research priorities as well as research development and conduct (Hayes et al., 2012). On the one hand, INVOLVE uses the term *engagement* to refer to members of the public only receiving and discussing research findings as knowledge users; and on the other hand, *participation* to refer to the action of taking part in a research project (research participant) (Hayes et al., 2012). This terminology helps us to get a better understanding on how and why the involvement of stakeholders is of great importance in research.

Involvement of young people with a chronic condition in research

Research shows that young people with chronic conditions suffer (social) disadvantages compared to their peers. Studies have reported that having a chronic disorder makes school performances more difficult (Lum et al., 2017), creates obstacles in achieving developmental milestones (Stam et al., 2006) and challenges different levels of social involvement (Sattoe et al., 2014; Taylor, Gibson, & Franck, 2008). Therefore, a large amount of earlier research has focused on ways to improve opportunities for these young people. Research has focused on various areas such as health care (Sattoe et al., 2015), the disability (Wintels et al., 2018), sport (Willis et al., 2017), personal development (Wintels et al., 2018) and school (Canter & Roberts, 2012).

Moreover, to address these (social) disadvantages, there are many research projects (e.g., focused on scientific projects to create more knowledge about how young people's chances can be

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[4] INVOLVE is UK's leading public participation charity which holds the mission to put people at the heart of decision-making (INVOLVE, 2020).

improved) and implementation projects (e.g. practice-oriented projects aimed at developing tools and practical interventions) developed to improve the social position of young people with disabilities (Schelven et al., 2019). Researchers and policy makers have traditionally focused on carrying out these types of projects 'about' or 'for' young people with chronic conditions (INVOLVE, 2013). In recent years there has been growing recognition that projects must have been initiated, developed, and implemented "with" or even "by" these young people themselves. Previous research shows that young people with chronic conditions are generally able and willing to participate in projects based on different grounds (Cherrill et al., 2010; Lightfoot & Sloper, 2003). It is emphasized that these young people have the right to participate in the decision-making that concerns them. Hart (1992) defined this type of participation as "the process of sharing decisions that affect a person's life as well as life in the community where someone lives."

Opportunities and challenges in involvement of young people with a chronic disorder

Researchers emphasize the importance of involvement of stakeholders in health research, because it benefits both young people and research and implementation projects. First, involvement by young research partners with a chronic disorder contributes to their personal and social development by offering them opportunities to acquire new knowledge and skills (Bailey, Boddy, Briscoe, & Morris, 2015; Bruce & Parker, 2012; Dedding, 2009; Lightfoot & Sloper, 2003). Moreover, it helps them to develop a social network (Bailey et al., 2015; Lightfoot & Sloper, 2003) and to increase their independence, confidence, and self-esteem (Bailey et al., 2015; Bruce & Parker, 2012; Canter & Roberts, 2012).

Secondly, it is found that the results of involvement of young stakeholders are often user-friendly products, outcomes to call to action, and opportunities for empowerment and development (Powers & Tiffany, 2006; Jacquez et al., 2013; Armstrong & Manion, 2015). Moreover, the involvement of the young experts by experience goes beyond the young individual; their families gain several benefits as well. Due to the opportunities for empowerment and the increased awareness of services and support for their relatives with a disability, families experience the advantages of involvement (Bailey et al., 2015). Also, researchers report advantages from including stakeholders in their research. Various studies have shown that involvement by young people increases the relevance and quality of research (Bailey et al., 2015; Rosen-Reynoso et al., 2010). Moreover, the inclusion of stakeholders improves access to hard-to-reach youth and improved the further application of the research (Dew & Boydell, 2017; Powers & Tiffany, 2006).

However, there are also practical limitations to involving young people with chronic conditions in research projects. Some key challenges in engaging youth with disabilities (and their families) as partners in research are related to the provision of clarity about roles, power, and authority to ensure all members' contributions are equally valued. Moreover, challenges are observed in managing expectations and creating an environment of co-learning, respect, trust, shared decision-making, and reciprocity (Nguyen, Palisano and Graham, 2019). Moreover, projects in which the involvement of young people with disabilities is part of the research design, are usually less efficient because they require more time and resources from both young people and researchers than non-participatory projects (Bailey et al., 2015; Rosen-Reynoso et al., 2010; Van Staa, et al., 2010). Moreover, the contribution of young people is not always of good quality due to limited skills or knowledge that are necessary to be a suitable partner in a project (Dedding, 2009; Van Staa et al., 2010). Another challenge is to maintain the youngsters' enthusiasm during all phases of a research project (Bailey et al., 2015; Van Staa et al., 2010). The level of involvement may decrease during a project, mainly due to disappointment in the usefulness of their involvement. To meet these challenges, previous literature concludes that we must look for more effective and efficient forms of involvement (Bailey et al., 2015; Van Staa et al., 2010). In a systematic review, Bailey et al. (2015) have brought together the positive and negative consequences for both researchers and young people with a disability - when they collaborate in research.

Facilitating and hindering factors

Nguyen et al. (2019) studied stakeholder engagement in the Canadian Institutes of Health Research (CIHR). This institute is a globally recognized leader in developing initiatives as the Strategy for Patient-Oriented Research which promotes integrated knowledge translation. This is an approach in which patients, clinicians, managers, policy makers, or industry are in engaged throughout the research process as equal members with equal input and authority (CIHR, 2017a; Graham et al., 2014; Bowen & Graham, 2013). In their research, Nguyen et al. looked at facilitating and hindering factors for families and youth to participate in their researchers.

They found that it is of great importance to *ask* youth and families directly when, how, and why they would like to be engaged in research, which is an essential goal among research teams to better understand and accommodate for their needs. Parents argued that while participating in monthly meetings was feasible and important, it was challenging to fit this into their busy schedules. Therefore, a contributing facilitating factor for families to engage in research was to provide regular face-to-face or online meetings. In these meetings, one would not only discuss the research, but also provide check-ins for team members to build trust and mutual respect and facilitate open communication. This enabled transparency of different perspectives, tasks, and expectations (Flicker, 2008).

According to Sinclair (2004), the practical limitations of involvement can be overcome by introducing forms of participation that are "embedded in organizations and part of the mainstream, rather than an isolated or marginalized activity." Almost all ongoing studies describe a form of participation in which young people with chronic disorders are only involved in one (part of the) project (Bruce & Parker, 2012; Dedding, 2009; Rosen-Reynoso et al., 2010; Van Staa et al., 2010). However, following Sinclair's argument, it is necessary to go beyond this isolated form of participation, and to work towards a structural and embedded form of involvement. For example, by offering young people a meaningful position within an organization or allowing them to participate in multiple projects and activities for a longer period. This would increase the effectiveness of involvement, because it sustains and facilitates dialogue between young people and professionals. Moreover, this ensures that the "consultation fatigue" phenomenon due to separate and unrelated participation activities will not likely occur (Sinclair, 2004).

Another important consideration with research that engages stakeholders is the extensive time and financial investment of families. This is often either understated or underestimated (Flicker, 2008; Suleiman et al., 2006). For that reason, Flicker (2008) emphasises the need for clear communication of the heavy time commitment and costs to all partners involved in the beginning of the research project. Suleiman et al. (2006, p. 142) adds that in overcoming this challenge “youth and their adult allies also need to create a realistic timeline to ensure that youth have sufficient time to understand the context of their work and execute their recommended strategies for action.” Moreover, research found that in order to save costs and pay attention to time management, the research must include clear and explicit communication of all tasks and activities to balance the needs of youth and families and the needs of the research project management; careful planning; institutional support; and setting realistic timelines and goals for the partnership (Powers & Tiffany, 2006; Forsythe et al., 2014, 2016; Johnson et al., 2016).

Lastly, Nguyen et al. (2019) calls to ensure accessibility and providing necessary accommodations is to secure access to equal opportunities and contributions. The authors encourage researchers to ensure that youth’s needs (for example, aid, supports and adaptations for those with hearing impairments) are accommodated and that all activities and events related to the research are accessible (for example accessible transportation, buildings, and meeting spaces). This needs to be done prior to the engagement in research (Nguyen et al., 2019).

These findings are supported by other researchers. Issues identified as barriers to change included adult attitudes and intransigence, lack of training for key adults, lack of clarity leading to tokenism, the nature of organizations (i.e., their formality, complexity, bureaucracy and internal politics) and the short-term nature of much funding. The evidence suggests that good practice includes a listening culture among staff, clarity, flexibility, adequate resources, skills development and training for staff and participating children and young people, inclusion of marginalized groups, feedback, and evaluation (Cavet and Sloper, 2004).

Forms of involvement

An important way to counter challenges and hindering factors is to choose a proper design of stakeholder engagement. Ramsden et al. (2017a, p. 2) argue the following: "… patients/individuals and/or communities should be seen as being involved in research in the following ways: (i) all aspects of designing the proposal including the development of meaningful questions; (ii) co-production of the processes to be used during and throughout the project; (iii) named as investigators and/or members of the leadership team; (iv) engaged in the analysis and interpretation of findings/results, dissemination of findings/results through presentations; and (v) being co-authors." As mentioned above, it is of great importance to create clarity on the roles, contributions, and expectations in research partnerships and to manage the power differentials among team members (Flicker, 2008). In this way, people feel included and can add value to the work in their own suitable way. Suleiman et al. (2006) argue that shared decision-making power is to be clearly communicated and transparent to all partners from the onset of the research partnership. With the choice for a particular research design, a framework for stakeholder engagement is already set out. In the following section of variation of forms of participation are described.

A collaborative and co-design approach as suggested by Kohler et al. (2017) and Morris et al. (2011) may help to establish meaningful youth involvement in research as it recognizes stakeholders as partners who bring complementary expertise to the research. Another way to encourage research teams to determine and clearly communicate the level of stakeholder engagement is to adhere to the INVOLVE document (Bartlett et al. 2017; Hayes et al., 2012). In this document the level of stakeholder engagement in research ranges from the role of a consultant (requesting review and taking feedback into consideration) to collaborator (mutual appreciation of unique knowledge, skills, and experience of each member). This will be discussed in more detail later in this report.

Moreover, there are different frameworks developed on how to offer a structural method to involve stakeholders in research. First of all, Graham et al. (2006) developed the Knowledge to Action (KTA) process. This is a conceptual framework for knowledge translation, in which stakeholders can engage in two phases: (1) knowledge creation and (2) action. The KTA approach is useful in promoting stakeholder engagement or partnership by involving stakeholders in the knowledge creation process, so the research relevance is ensured.

Another framework is the Steps Model as proposed by Adams et al. (2017). This model focuses on stakeholder engagement by providing a comprehensive five step process for developing partnerships with stakeholders. The steps are based on trust, mutually beneficial outcomes, and metrics to assess the impact. The Steps Model can also be used to conduct inter-professional healthcare research. This idea was proposed by Soever et al. (2014) and Légaré et al. (2011) to integrate and acknowledge the unique contributions of the individual team members.

The Learning Health Care System (LHCS) has the goal to promote engagement and collaboration among patients, communities, and clinicians in research (Smith et al., 2013; Morain et al., 2017; Faden et al., 2013). To improve the quality and delivery of healthcare services, the LHCS integrates patient engagement and research, as well as clinical operations and infrastructure. This collaboration improves care and creates new knowledge (Moore et al., 2017).

The synthesized framework is developed by Shippee et al. (2015) and is helpful in enhancing partnerships and team interactions. The authors identified four key components that facilitate stakeholder engagement: reciprocal relationships, patient and service user initiation, co-learning, and re-assessment and feedback. Moreover, in this framework the various stages and phases within the research process are identified to see where stakeholders can be engaged. The authors differentiate the following phases: preparatory (agenda setting and funding), execution (study design and procedures, study recruitment, data collection, data analysis), and translational (dissemination, implementation, evaluation) (Shippee et al., 2015).

The consolidated framework for implementation research (CFIR) is best used if the goal of the research partnership is to implement knowledge (Damschroder et al., 2009; Damschroder & Lowery, 2013; Graham & Logan, 2004; Rycroft-Malone et al., 2002; Rycroft-Malone et al., 2016). CFIR facilitates the application of evidence into practice, similar to the action phase of KTA.

Another framework used in to involve patients and families in the development of interventions and policies to improve health outcomes is the multidimensional framework. The framework proposed by Carman et al. (2013) includes three critical aspects of engagement. First, there is a continuum of engagement activities that range from consultation to shared leadership. Secondly, the different levels of engagement are included in the organizational design, governance and in policy making. Lastly, attention is given to the multiple factors influencing patients' willingness and ability to engage (Carman et al., 2013). Important in this framework are the varying levels of engagement. A stakeholder could provide feedback on research outcomes, while another stakeholder engages as co-investigator. This framework is also used in the Canadian Institutes of Health Research citizen's engagement (in research) framework. Their framework includes five levels of public engagement: (1) inform and educate; (2) gather information; (3) discuss; (4) engage; and (5) partner (CIHR, 2018).

Sheridan et al. (2017) released the 'PCORI engagement rubric'. This is a practical tool that describes how and when engagement can occur during clinical research, but also provide key considerations for engagement to researchers, patients, and other stakeholders. The rubric uses a patient-centred approach and focusses on the 'foundational engagement principles': trust, honesty, transparency, co-learning, reciprocal relationships, partnership, and respect (Sheridan et al., 2017; Frank et al., 2015). An important consideration emphasized in the rubric is financial compensation for patients and stakeholders. Sheridan et al. (2017) suggests that "compensation demonstrates recognition of the value, worth, fairness of treatment with others involved in the research project, and contributes to all members of the research team being valued as contributors to the research project" (PCORI, 2016, p. 1). Other important considerations the authors mention are: defining roles, power, and authority for patients and stakeholders and the provision of bi-directional training for engagement (Sheridan et al., 2017).

Lastly, Hamilton et al. (2018) developed a patient-driven and empirically based conceptual framework named the PIER framework. The framework brings together eight interconnected themes to explain meaningful engagement: team interaction, procedural requirements, convenience, research environment, contributions, support, feeling valued, and benefit. The PIER framework patient perspectives with current evidence (for example guidelines, recommendations, frameworks, and models) (Kirwan et al., 2017; Howe et al., 2017; Shippee et al., 2015; de Wit et al., 2017).

The frameworks above describe important themes to consider when choosing a form of stakeholder involvement in (health) research: engagement in the knowledge creation process, integration and acknowledgement of the unique contributions of the individual team members, facilitation of reciprocal relationships, patient and service user initiations, co-learning, and re-assessment and feedback, the provision of an overview of the different phases of the research (and how stakeholders can be involved), the creation of a continuum of engagement activities, the necessity of feedback on research process and outcomes and (financial) compensation for patients and stakeholders. These frameworks and their underlying themes can be combined depending on the teams' research needs and goals (Nguyen et al., 2019).

Conclusion

Involvement of young people with a disability brings a lot of possible opportunities into the research. Based on the systematic review by Bailey et al. (2015) and the more recent papers (between 2015-2020) included, the following table provides an overview of opportunities and challenges in involving young people with a disability in research.

Table 1. Overview of opportunities and challenges in involving young people with a disability in research

Possible opportunities for young people	**Possible opportunities for research(ers)**
• Increased trust • Increased self-confidence • Newly gained skills and experiences • More responsibility and independence • Ability to get in touch with peers • Increased knowledge and options for making choices • Ability to become increasingly empowered • Positive change in expectations • Possibility to express frustrations and valuations • Awareness of their opinions and ideas being respected and valued • Awareness of their ability to make a difference • Awareness of their ability to help other young people with their efforts • Creation of more user-friendly products • Higher likelihood of outcomes to call to action • Increased positive outcomes for their families: o Opportunities for empowerment for their relatives o Increased awareness of services and support for their youth	• Improved applicability and quality of research • Better prioritisation of research questions that are important for the target group (young people) • More age-dependent and accessible ways of recruitment and advertising material • Better accessibility of research protocols and interventions • More credibility and interest in the research • Positive contribution to data collection, especially during interviews • A unique perspective for data analysis, in particular on data found by young people themselves • Successful contribution to interview transcript coding • Improved access to hard-to-reach youth • Improved further use(applicability) of the research
Possible challenges for young people	**Possible challenges for research(ers)**
• Learning about other people's experiences (with e.g., the same disease) can cause anxiety and stress • Increased awareness of differences between how young people see themselves and how others see them • Perceptions of tokenism, which may result in disillusion and reduced benefits • Inability to maintain confidentiality in meetings • Possibility of young people initially feeling intimidated by the unknown people and the (working) environment • Possibility of losing confidence or interest if young people are confronted with challenges that they cannot handle	• Need for more resources, staff skills and training to facilitate engagement • Longer duration of research process • Difficulty of providing clarity about roles, power, and authority to ensure all member's contributions are equally valued • Long duration of creating and difficulty of maintaining an environment of co-learning, respect, trust, shared decision making and reciprocity • Risk of the contribution of young people not always being of good quality due to limited skills or knowledge

Based on the existing literature one can identify many factors that influence the success of youth involvement in research. These facilitating and hindering factors are brought together on the following page.

Table 2. Overview of facilitating and hindering factors in involvement of young experts by experience in research

Facilitating factors (do…)	**Hindering factors (don't…)**
• Ask youth and families directly when, how, and why they would like to be engaged • Provide regular face-to-face or online meetings • Provide check-ins for team members to build trust and mutual respect and facilitate open communication • Communicate clearly in the beginning of the research about the heavy time commitment and costs to all partners involved • Communicate clearly and explicitly about all tasks and activities • Plan carefully • Provide institutional support • Set realistic goals for the partnership • Ensure accessibility • Provide necessary accommodations • Embed involvement of young people in organizations and ensure it to be part of the mainstream	• Communicate poorly between team members • Leave out time/space for (informal) check-ins • Communicate unclearly on time commitment and costs • Communicate unclearly on division, moments and creation of tasks and activities • Neglect planning • Leave out institutional support • Set unrealistic goals for partnerships • Provide inaccessible locations and activities • Neglect the qualified provision of necessary accommodations. • Allow consultation fatigue

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