A Peer Support Program for Adolescents with Type 1 Diabetes

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Abstract

Type 1 diabetes mellitus (T1D) is a chronic condition impacting young children and subsequently follows them throughout life. The disease causes the body to lose the ability to produce insulin resulting in elevated blood sugar levels causing a cascade of detrimental complications. As children navigate through the different phases of life, especially during adolescence, the challenges of self-management of this disease can become difficult. In research, peer support programs have shown to be an effective method to approaching this challenge. This quality improvement project focused on the T1D adolescent population and created, implemented, and evaluated a peer support program, called Empower1 in the local community. Through collaboration with key stakeholders, and implementing this program for type 1 diabetic adolescents, positive social support, and disease education was promoted, based on the goal of improving health related quality of life, and theoretically leading to improved disease management. If overall improved glycemic control can be achieved, lifelong complications can be prevented. Data were collected, using the PedsQL Diabetes model 3.2 questionnaire, before and after attending the program to evaluate the participants' perceived health related quality of life and compared the two looking for patterns or changes. An increase in mean scores were demonstrated in 3 of the 5 categories, but none were statistically significant. Overall this program aimed to provide a way of building supportive relationships and friendships, along with providing diabetes education and encouragement for T1D adolescents, aiming to increase their health related quality of life.

Keywords: type 1 diabetes, peer support, health related quality of life

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Multiple health problems, acute and chronic, overwhelm the health care systems causing congestion, elevated costs, and delay, for those seeking help. These concerns can impact local, state, national, and worldwide populations, and include all age groups. Type 1 diabetes is one such concern that has an impact on all age groups, including young children through adulthood.

Type 1 diabetes mellitus (T1D) is a common chronic childhood illness [CITATION Spa15 \l 1033]. Insulin dependent type 1, or previously called juvenile diabetes, is a chronic autoimmune disease that is extremely complex and requires significant changes in a child's way of living (Barnetz & Feigin, 2012). When insulin availability falls below the body's demands, the cells are unable to take in the sugar within the blood to use it for energy [CITATION Cha11 \l 1033]. This leads to multiple complications including diabetic ketoacidosis, that causes dehydration and electrolyte imbalances, or hyperosmolar syndrome, which causes coma in adolescents, both if left untreated can lead to death [CITATION Bar12 \l 1033]. In the United States 1.25 million individuals have been diagnosed with T1D; 500,000 of them are under the age of 15, and approximately 40,000 youth are diagnosed each year [CITATION Chi14 \l 1033]. The economic burden on a person with T1D and their family on a yearly basis ranges from $3,800 to $10,000, with an average cost of $6,288 in additional medical costs per year (Tao, Pietropaolo, Atkinson, Schatz, & Taylor, 2010). If the disease is not treated properly the individual is at risk for multiple complications, raising the cost of treatment. Efforts to increase disease management adherence in this high risk group can have a positive impact on the economic burden and health related outcomes for those with T1D.

Problem Statement

Treatment for T1D is life-long, complex and demanding, requiring multiple steps. Once diagnosed, the individual must adhere to a regiment of constant monitoring of blood sugar, diet modification, administering insulin multiple times a day, and making sure they have proper emergency supplies and identification on them at all times [CITATION Bar12 \l 1033]. When the child is young, these responsibilities fall on the parents, but as the child grows older they need to take over and become responsible for their own care to prepare for the transition into adulthood (Sparapani et al., 2015). Adolescents and children with T1D lose their sense of spontaneity, having to incorporate their treatment into every hour of every day (Barnetz & Feigin, 2012). This can become increasingly more difficult as children enter the adolescent and the teen years [CITATION Bor10 \l 1033]. Many factors influence glycemic control as children age and progress through adolescence into young adulthood. Peer influence and social context can create barriers to tight control in T1D [CITATION Bor10 \l 1033]. Lacking a strong support structure including friends, peers, or mentors, can have a strong impact on the success or failure of diabetes care and self-management (Heisler, 2009). Hillard, Pu, Rausch, and Dolan (2013), reported that up to two thirds of adolescents with T1D do not meet the recommended treatment targets for glycemic control. In addition, many health disparities have been identified for this population including socioeconomic, poor social support, and a lack of ongoing disease education (Borschuk & Everhart, 2015; Borus & Laffel, 2010; Jaacks et al., 2014). Methods to combat these health disparities need to be implemented. One solution is to put peer support systems in place for T1D adolescents.

Purpose of the Project

The purpose of this quality improvement project was to implement an organized social program for adolescents with T1D, influence disease knowledge and management, create positive peer relationships, and evaluate how the program impacts their health related quality of life (HRQL). The peer group was named Empower1. Through implementation of Empower1 the gap between clinical disease management and day to day self-management can be bridged through peer support and ongoing disease education.

Clinical Question

In adolescents, age 13 to 18 with Type 1 Diabetes (T1D), does implementing a peer support program increase reported health related quality of life?

The intended outcome included an improved sense of HRQL for adolescents with T1D. HRQL is an important health outcome indicator used in clinical trials and health care to measure psychosocial outcomes (Varni, et al., 2003). Disease management for T1D includes a complex regime of controlling blood sugar levels, staying hydrated, watching diet, administering insulin, and managing symptoms in order to maintain proper metabolic control, stay healthy, and avoid future complications (Miller & DiMatteo, 2013). Lacking a strong support structure including friends, or peers, can have a strong impact on chronic disease management, making this complex treatment plan even more challenging (Heisler, 2007). In this particular age group with T1D, gaps in disease education have been found (Jaacks, et al., 2014; Markowitz & Laffel, 2012). Empower1 provided ongoing disease education and peer support during scheduled gatherings and meetings aiming to create a stronger presence of positive peer relationships and influences, and increase diabetes support, measured by an increase in reported HRQL.

Organization Assessment

The population of focus included adolescents, ages 13 to 18 with T1D, in a large Midwestern city. In order to create and implement Empower1, a program that provided effective, and educational mentoring and peer support for adolescents with T1D, the assistance of many different disciplines were required. Individuals with T1D and their families were important stakeholders in the creation, implementation, and evaluation of this program. Additional key stakeholders included the local chapter of a major charitable 501c3 organization that is dedicated to T1D. A partnership was formed with the Junior Diabetes Research Foundation’s (JDRF) Heartland Chapter. This organization offers education, support for parents of children with T1D, and conducts charity events to raise money for T1D research. By collaborating with this organization, more community members became engaged in the assessment and planning of the peer program, along with increasing access to data resources. The organization has an established network of members and community members to assist in contacting and reaching out to a large number of individuals that may benefit from a peer support program. After meeting with this organization’s outreach manager, they agreed to assist in the creation and implementation of a peer support program for teens with T1D (see Appendix A). Both the outreach manager and their planning committee were eager to begin this program. One of the organization’s current goals at that time was to increase support and educational offerings for the T1D adolescent and teen population. Their goal directly correlated with the objectives of this program.

Review of the Literature

A review of the literature was conducted and included searching specific key terms and following specific inclusion and exclusion criteria within chosen databases (see Figure 1). Key search terms included: type 1 diabetes, diabetes and adolescents for the population, and friends and peer support for intervention. Databases searched included: CINAHL, PubMed and Cochrane. CINAHL was chosen because it covers aspects of nursing and allied health with a large amount of full text material. PubMed was used due to the assumption that it would provide a large amount of material because it is the National Library of Medicine’s search interface for the MEDLINE database. Cochrane was chosen to look at their database of systematic reviews, which offers a large amount of material. Limiters used were full text and publication date between 2011 and 2016. If the study did not pertain to this project’s question then it was excluded. Inclusion criteria included studies providing high levels of evidence with a focus on peer support.

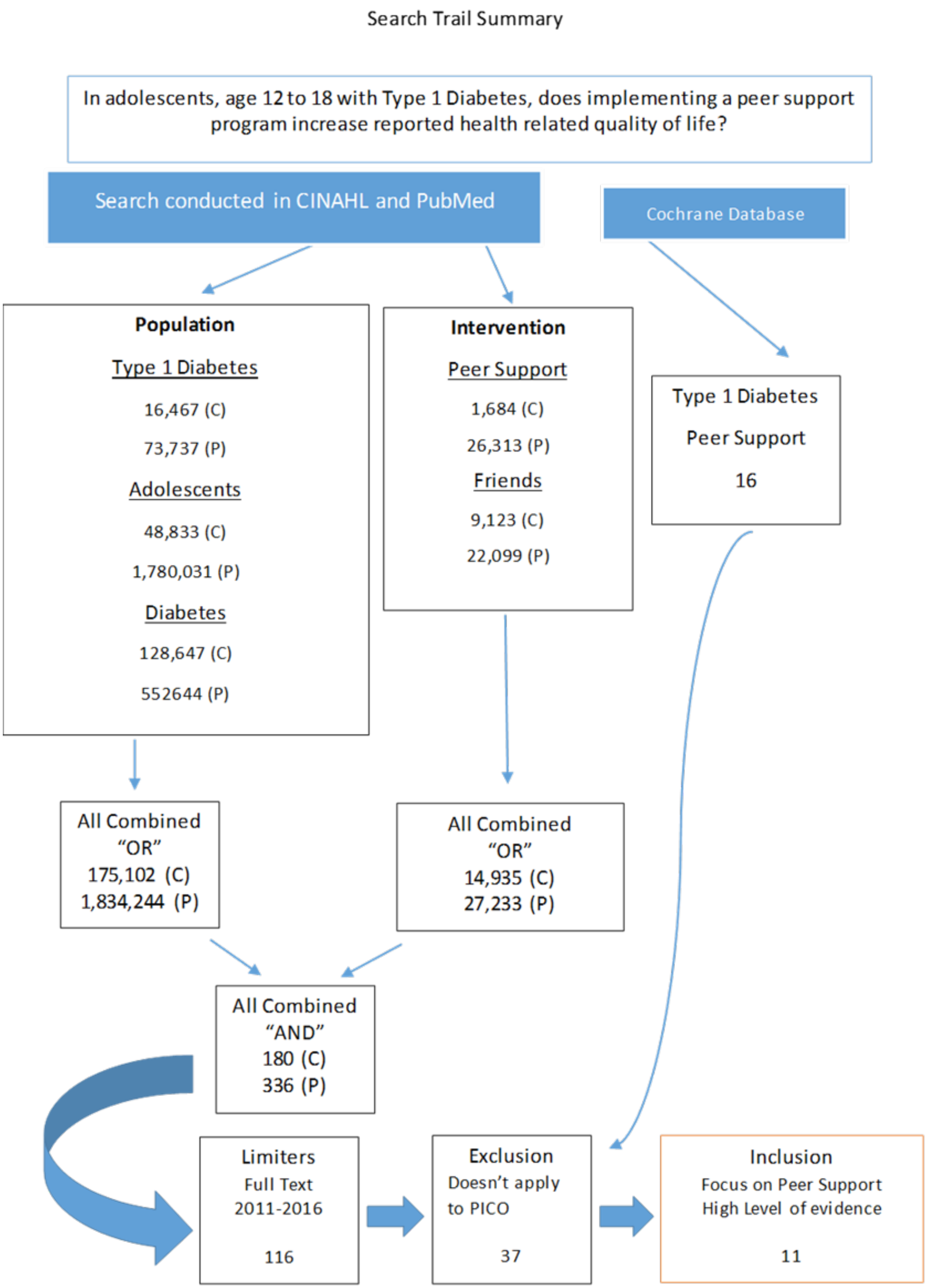


Figure 1: Literature Search Trial

Certain health disparities for this population were identified within the literature including: socioeconomic disparities, poor social support, and a lack of ongoing education (Borschuk & Everhart, 2015; Borus & Laffel, 2010; Jaacks et al., 2014). Literature has shown that during the adolescent stage of development in children with T1D, glycemic control declines (Rausch et al., 2012). A number of factors can play into poor glycemic control, some unmodifiable and some modifiable. Unmodifiable factors such as age, gender, and diabetes duration can influence treatment adherence (Borus & Laffel, 2010). For example, age of the patient at diagnosis can influence their disease management, if this is a new diagnosis they may not have mastered the skills of treating their diabetes like someone who has had it for many years. Modifiable factors include diabetes specific family conflict, family involvement, disordered eating, use of technology, and peer influence (Borus & Laffel, 2010).

Many studies have investigated different programs and strategies to transform these influential factors in order to improve treatment adherence. Studies have shown that peer support and mentors can be beneficial for youth with chronic diseases (Maslow et al., 2013). Other studies took this further and looked at the effects on the children's glycosylated hemoglobin (HgA1c) when participating in a peer mentor program. Heisler, Vijan, Makki and Piette (2010) found there was improvement, or a decrease in the HgA1c in children that participated in the peer mentor program, concluding this can be a promising method to increase self-management strategies in T1D.

Systematic reviews addressing these issues were reviewed. Heisler (2009) discussed how mobile peer support programs can be used to improve diabetes self-management and clinical outcomes, concluding that these can be beneficial, but must be well organized and include training and consistent follow up to be effective. The importance of peer relationships and strong support, at school or at social events, and in the presence of others was also identified. Peters, Nawijn, and van Kesteren (2014) identified that overall adolescents with T1D look for emotional support from friends and peers and also seek autonomy in their disease management.

Some of the articles in the review found a positive correlation between peer support and T1D disease management. For example, Fisher et al. (2012) examined peer support for self-management of diabetes in international settings through a qualitative study. This study paired up young women with T1D as designated diabetes buddies for 3 months following a 12 session curriculum. Weekly sessions were held to discuss daily life, self-management, and nutrition, in order to promote diabetes management through reciprocal support. The results showed improved assistance in daily management of diabetes, improved social and emotional support, better linkage to clinical care, and demonstrated a strong sense of ongoing support as many groups still met after the study. It was also found that peer support helped provide community resources and encouraged disease management (Fisher et al., 2012).

Palladina and Helgeson (2012) conducted a systematic review examining the relation of peer influence on diabetes outcomes for adolescents with T1D. The review found that peer support can be beneficial and social conflict leads to harmful results (Palladina & Helgeson, 2012). Palladina and Helgeson pointed out the importance and positive effects of peer relationships, especially when it involves a chronic illness requiring self-care throughout the day at school or at social events, and in the presence of others.

Another study demonstrating a positive correlation between peer support and T1D disease management was a cohort study by Markowitz and Laffel (2012). This study aimed to implement and evaluate the effectiveness of professionally led support groups, answering the question: Will these groups enhance self-motivation and facilitate peer-to-peer interactions in young adults with T1D? The findings showed a statistically significant improvement in glycemic control by a lower HgA1c and lower self-reported diabetes burden in the participants of the support groups [CITATION Mar12 \l 1033].

To evaluate if there is an interest in participating in a peer group, a study, conducted by Lu et al.(2015), aimed to identify attitudes and topics relevant to peer mentoring as an adherence-promoting intervention for adolescents and young adults with T1D. The results of the study found that the majority of the adolescents and young adults indicated interest in peer mentoring as a potential intervention to improve glycemic control (Lu et al., 2015). Results also showed that peer mentoring is instrumental in overcoming the social barriers to diabetes control (Lu et al., 2015). This study supports the idea that this quality improvement project could be beneficial for the target population.

This review was limited to a small portion of articles, indicating the need for more research in this area. Strengths of the review include providing a better insight to perceptions, feelings, and fears of adolescents with T1D. The literature review assisted in identifying the needs of T1D adolescents including the need for more support, nurturing, and education in self-management of their diabetes. (see Appendix B)

Theoretical Framework

This project was based on the social ecological model, a behavioral change theory, which focuses on developing programs that influence behavior through social environments (see Figure 2). Behavioral change theories in health care are centered around disease management, prevention, and health education (Cherrington et al., 2012). These theories were created using several theoretical perspectives and research disciplines including: psychology, anthropology, sociology, nursing, economics, epidemiology, statistics, and marketing (Butts & Rich, 2011). This quality improvement project was primarily based on the social ecological model.

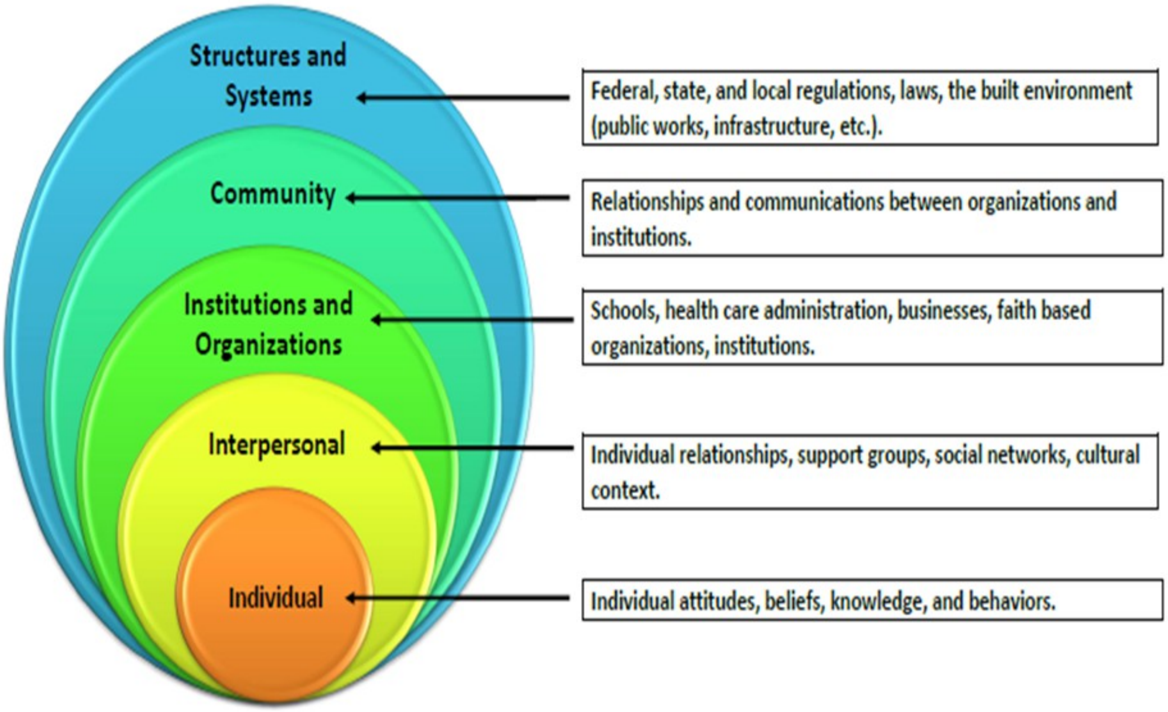


Figure 2: The Social Ecological Model (CDC, 2013).

The social ecological model is a theory which can be applied in both clinical settings and non-clinical settings. The social ecological model emphasizes that behavior is molded by many influences, and behaviors both shape and are shaped by their social environments (Butts & Rich, 2011). The model breaks down the different social influences on health into multiple levels. By addressing the different levels of influence from both a micro and macro stance, health promotion, prevention, and disease management can be impacted (Centers of Disease Control & Prevention [CDC], 2013). This quality improvement project focused on the interpersonal level and how interventions directed towards the interpersonal level can influence a population of adolescents with T1D. Success for the peer support program would be demonstrated by a positive impact on the T1D population. Then the other levels of the social ecological model may also be impacted with growth of the program. Examples include impacting schools, organizations, and communities through this peer support program. Non-acute, or community settings are becoming more popular for the implementation of health management, prevention, and education programs, similar to the design of this program (Cherrington et al., 2012). By applying the Social Ecological Model to this quality improvement project, the peer interventions utilized in the program focused on education, social support, self-efficacy, and empowerment within a social setting (Simoni, Franks, Lehavot, & Yard, 2011). The Social Ecological Model aligns well with this project in the sense that it allows the program objectives to be met by shaping behavior through social influences.

Methodology

Design

The project design was a descriptive quality improvement project, to promote and improve peer support in T1D adolescents. To meet the project objectives organized social activities and formal education opportunities were provided for this target population on a monthly basis.

Setting

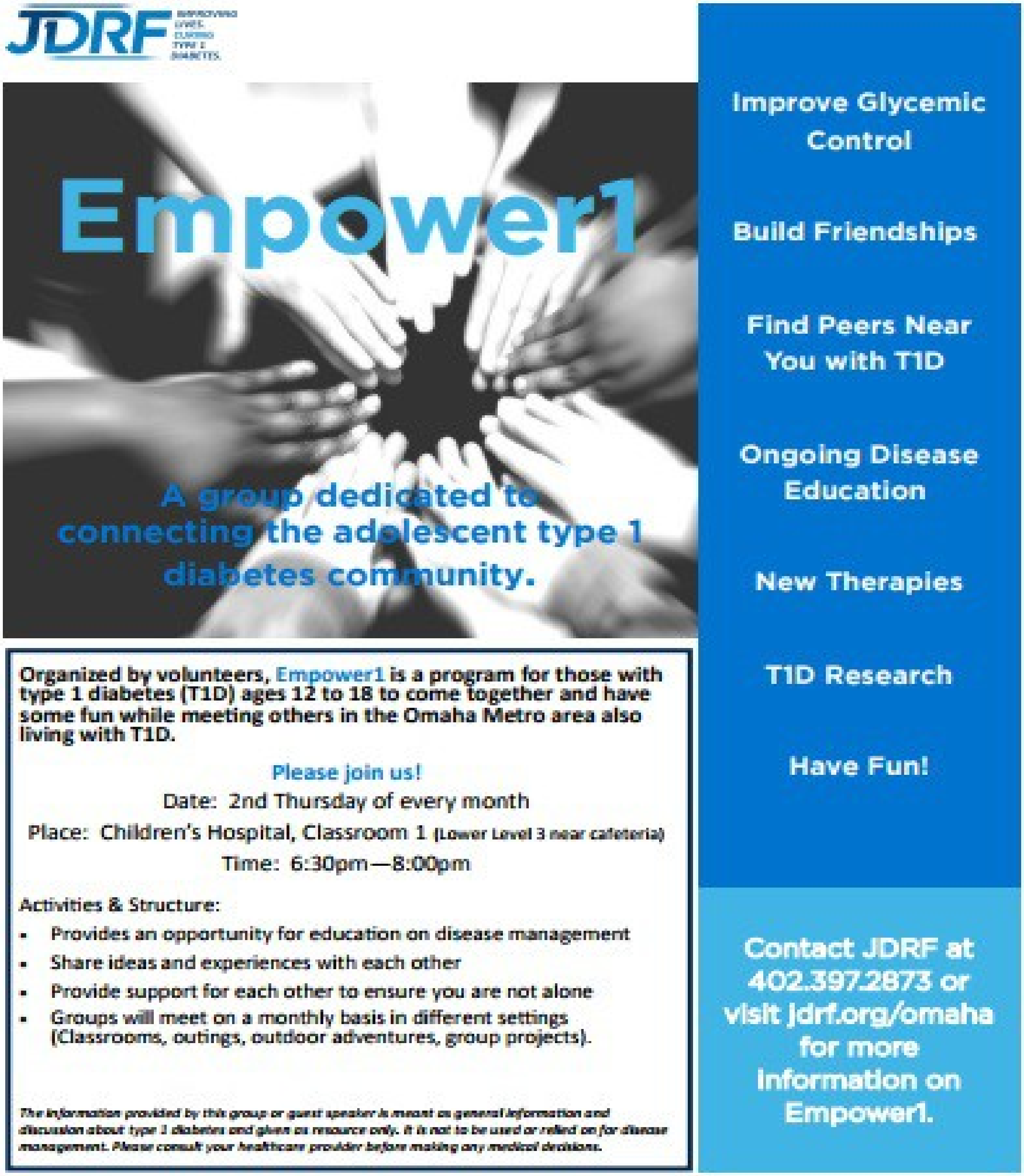
This project aimed to allow participants to build relationships with others their own age who also have T1D. They were given the opportunities to take part in group activities as well as gain formal education on T1D and its management. The group activities allowed time for participants to get to know each other and possibly build friendships with others that also have T1D.

In order to do make this program a success a partnership needed to be formed with an organization within this T1D population. A local non-profit organization that focuses on T1D, the JDRF's Heartland Chapter agreed to collaborate and helped gain access to this population. Written support from the local T1D organization stating their willingness to participate and take an active role in this project was obtained (see Appendix A).

The peer support program, Empower 1, consisted of monthly meetings, outings, adventures, group projects, and ongoing education offerings for adolescents with T1D. The first three meetings were held at a designated meeting place, which the partnering T1D organization had set up at the local Children's Hospital. The fourth session was held at a local amusement center where the teens participated in group activities including mini golf and laser maze games. Each session included both formal education along with team building activities and allotted time for open discussion among the group.

Sample

The population of focus included male and female adolescents, ages 13 to 18 with T1D in the Omaha area. Age of diagnosis and level of disease management were not contributing factors for participation. Exclusion criteria included adolescents who are unable to obtain permission from their parent(s) or legal guardian to complete the questionnaire. A signed parental consent form (see Appendix C) had to be submitted before the adolescent could complete and submit the questionnaire. Participants were recruited through online advertisement on the collaborating non-profit organization's website and through email invitations from the JDRF. The local chapter of the JDRF utilized their member email list to distribute electronic invitations to attend the Empower1 program on a monthly basis (see Figure 3).



JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES.

Empower1

A group dedicated to connecting the adolescent type 1 diabetes community.

Improve Glycemic Control

Build Friendships

Find Peers Near You with T1D

Ongoing Disease Education

New Therapies

T1D Research

Have Fun!

Organized by volunteers, Empower1 is a program for those with type 1 diabetes (T1D) ages 12 to 18 to come together and have some fun while meeting others in the Omaha Metro area also living with T1D.

Please join us!

Date: 2nd Thursday of every month

Place: Children's Hospital, Classroom 1 (Lower Level 3 near cafeteria)

Time: 6:30pm—8:00pm

Activities & Structure:

- Provides an opportunity for education on disease management
- Share ideas and experiences with each other
- Provide support for each other to ensure you are not alone
- Groups will meet on a monthly basis in different settings (Classrooms, outings, outdoor adventures, group projects).

The information provided by this group or guest speaker is meant as general information and discussion about type 1 diabetes and given as resource only. It is not to be used or relied on for disease management. Please consult your healthcare provider before making any medical decisions.

Contact JDRF at 402.397.2873 or visit jdrf.org/omaha for more information on Empower1.

Figure 3: Empower1 Invitation

Instrumentation

This quality improvement project collected and analyzed data by utilizing a pre and post questionnaire. The Pediatric Quality of Life Inventory (PedsQL) for diabetes measurement module 3.2 was used (see Appendix D). The PedsQL module 3.2 is specifically designed to measure HRQL and support for children with diabetes (Varni et al., 2003). The PedsQL module includes five dimensions: diabetes, treatment I, treatment II, worry, and communication. Previous studies have been conducted to evaluate, and have established the validity and reliability of this tool (Varni et al., 2003). The reliability standard of the PedsQL questionnaire for diabetes exceeds the standard of 0.70 in the diabetes and communication sections. Validity of the PedsQL tool demonstrated medium to large interrelations between HRQL scores of healthy children and children with T1D (Varni et al., 2003). Permission to use this tool was granted by Mapi Research Trust (see Appendix D.3).

Procedures and Data Collection

Each month one meeting was offered, starting in January of 2017, and included both formal meetings with education provided, and a fun team building activities. The timeline for implementation and data collection of this project ran from January 2017 to April 2017, with data collected during this time.

Areas of focus for education included: how to deal with the changes of being teenagers with T1D, how to overcome obstacles and challenges, and also tips and secrets of keeping T1D under tight control while still being a normal teenager. Additional areas of discussion included going off to college, the transition to self-management of their diabetes once they move out, and sharing personal experiences of the challenges of diabetes. An outline for the educational topics is provided (see Appendix E). Education was provided and conducted by licensed health care providers and representatives through the JDRF. Competence of these individuals and their ability to provide accurate and effective teaching were evaluated by the program directors, including the primary investigator and the collaborating organization’s outreach manager, through discussion and reviewing the material that was covered before that specific teaching session.

Data were collected through the self-administered questionnaire distributed to participants during the peer support sessions. The pre questionnaire was handed out and collected at the beginning of the participant’s first session attended. The post questionnaire was handed out and collected at the end of the third session, with one questionnaire per participant. At the fourth session, the post questionnaire was offered again for any participants who did not attend the third session and had not yet filled out a post questionnaire. Only participants that had attended a minimum of two sessions were allowed to complete the post questionnaire. This questionnaire took approximately fifteen minutes or less to complete. An organization representative and the primary investigator collected the questionnaires. The primary investigator and organization representative were present at the peer group meetings. The primary investigator collected, reviewed, and analyzed the data collected from the pre and post questionnaires. Each pre and post PedsQL questionnaire were identical, and the responses were not altered. All completed questionnaires from participants who completed a pre questionnaire and had attended two or more meetings were analyzed.

Rigor and validity were utilized to guard against bias and control confounding variables in the collection and analysis of the data. Threats to validity were be addressed by using a homogeneous sample. Rigor were demonstrated through complete documentation of changes and decision making processes, along with full disclosure of data, decision justification, and methodology of the project.

Data Analysis

Data were analyzed using descriptive and inferential statistics. The PedsQL scoring instruction guide provided with the tool was used to analyze the questionnaire data (see Appendix D.2). Each of the 5 dimensions were scored and reported separately as individual dimensions, and a total score including all 5 dimensions was also calculated and reported. The PedsQL tool utilizes a 5-point Likert scale. Results are not weighted, but scores were transformed linearly on a scale of 0 to 100. The 5 dimension means were calculated by dividing the sum of the transformed scores over the number of items answered for each dimension. The total mean score of the 5 dimensions was calculated by dividing the sum of all of the items over the number of items answered on all of the scales. Analysis included measuring the central tendency through the median of each of the questionnaire responses. The total mean scores from the pre and post PedsQL questionnaires were compared using a paired *t* test. A paired *t* test was utilized due to the assumption that the two results are not independent of each other and are connected. Data analysis was completed with the help of a statistician and reviewed by content experts to ensure quality, trustworthiness, and integrity in this project.

Results

During the first 4 sessions of Empower1 12-22 adolescents with T1D were in attendance. The sample size for completion of both the PedsQL pre and post questionnaire was N=7; results discussed reflect the N=7 sample.

An increase in the post survey mean results in 3 of the 5 dimensions was demonstrated. (see Table 1) The My Diabetes dimension pre mean was 910.71 and the post mean score was

942.86. The Treatment dimensions both showed an increase in mean scores: Treatment 1 had a pre mean of 407.14 with a post mean of 428.57, and Treatment 2 had a pre mean of 528.57 and a post mean of 550.00. The increase in the mean scores indicates an improvement in these areas after attending 2 to 4 peer support sessions. The Worry and Communication dimensions did not show an increase in mean scores. (see Figure 4) The Worry and Communication dimensions had a slight decrease in the post score. The Worry pre score was 214.29 and the post was 203.57. The Communication dimension had a pre mean score of 339.29 and a post mean score of 321.43. None of the dimensions showed a significant change in the scores, this may be due to the small sample size. (see Table 2)

Table 1

Pre and Post PedsQL questionnaire results

	n	Mean	Stan.Dev	Min	Max
My Diabetes Pre	7	910.71	207.59	675	1175
My Diabetes Post	7	942.86	180.11	700	1150
Treatment I Pre	7	407.14	98.65	250	500
Treatment I Post	7	428.57	63.62	325	500
Treatment 2 Pre	7	528.57	65.23	425	600
Treatment 2 Post	7	550	70.71	425	600
Worry Pre	7	214.29	69.00	125	300
Worry Post	7	203.57	33.62	150	250
Communication Pre	7	339.29	60.99	275	400
Communication Post	7	321.43	75.59	175	400

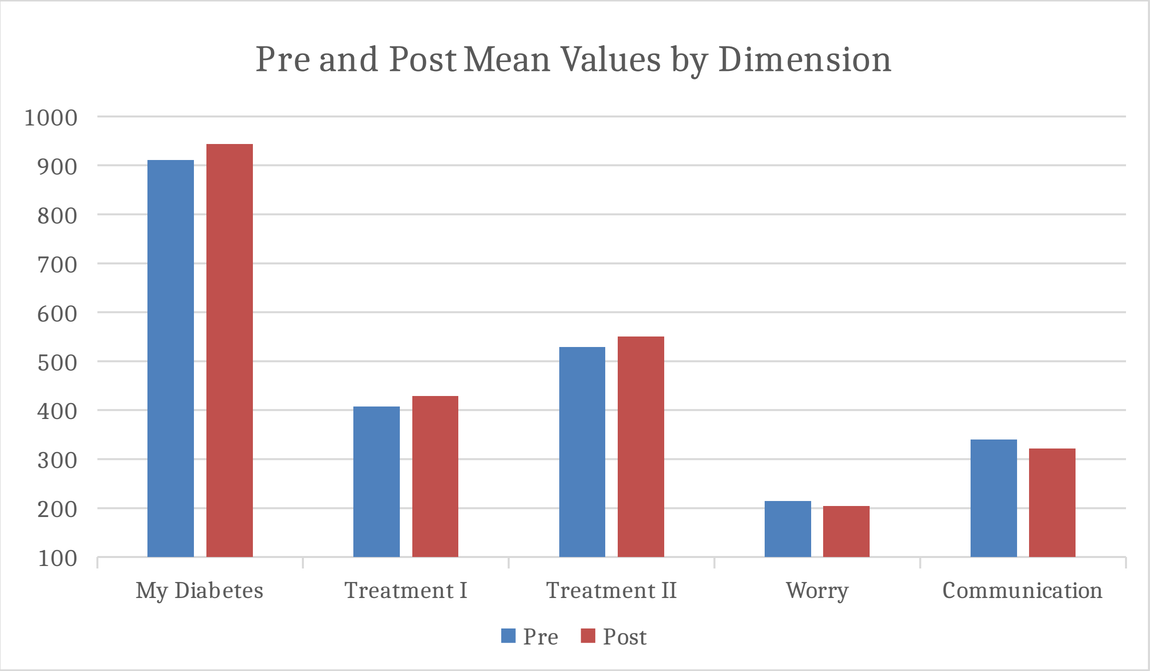


Figure 4: PedsQL pre and post questionnaire mean values

Table 2

Paired t-test Data

	My Diabetes	Treatment I	Treatment II	Worry	Communication
t	0.49	0.44	0.54	0.36	0.48
p-value	0.63	0.67	0.60	0.72	0.64

Note: Paired t-test was used to test if a difference exists between the pre and post questionnaire data results. Statistical significance = $p < .05$.

Ethical

Data were collected through a validated pre and post questionnaire, the PedsQL Diabetes Module 3.2 and was recorded and reviewed by the researcher and a member of the T1D organization. No personal identifying information was collected on the questionnaire or reported in the dissemination of the quality improvement project results. The data collected were entered into a password protected personal computer. Data stored on the personal computer have no personal information or identifying markers or codes that would link the data to the participants. The paper questionnaires collected from participants will be kept for a minimum of 5 years in a locked file cabinet that only the primary investigator has access to. After the minimum of 5 years the paper form of the questionnaires will be destroyed.

During the entire process accurate, confidential, and ongoing record keeping was conducted to maintain the integrity of all data collected. Minimal risks were identified for those participating in this project. Risks included discussing personal T1D disease management on a voluntary basis; however, there was no requirement to discuss if any individual did not feel comfortable.

This project included working with minors and required parental/guardian consent to be given for each participant. The parental consent (see Appendix C) explained the project objectives, described how the study would be carried out, and the data to be collected. The language was formatted in an easy to understand presentation, and the parents were presented a copy of the consent form in its entirety if they desired one. The primary investigator’s contact information was presented with the consent, inviting parents to contact the primary investigator with any questions or concerns. Informed consent was distributed to the parents at the first session and collected in person or by mail.

No conflict of interest was identified with this quality improvement project. Unbiased objectivity was maintained during this study. The primary investigator is not employed by, or received any compensation from the nonprofit organization by partnering with them to implement this program. This quality improvement project was implemented following approval from the Nebraska Methodist College Institutional Review Board (IRB).

Significance and Implications

As the review of literature had indicated, multiple health disparities exist for the T1D community, and even more challenges can arise during the adolescent years. Research has shown a decline in disease management in this specific age group along with a lack of peer support (Hillard et al., 2013 & Palladina & Helgeson, 2012).

By creating positive peer relationships through this program, the participants will be a source of encouragement and positive influence for each other and offer ongoing support for the years to come. Intended outcomes of this quality improvement project were to create an improved sense of HRQL for adolescents with T1D, closing the gaps in disease education that have been found for this particular age group, and to create a stronger presence of positive peer relationships, influences, and diabetes support. This concept of peer support can be utilized by nursing and health care providers as a core component of disease management and prevention of long term complications for T1D. As health care systems recognize the impact social and peer support has on this population, then Empower1 can become a liaison or bridge, closing the gap between scheduled appointments or clinical care, and everyday disease management [CITATION Pee14 \l 1033].

The results of Empower1, a quality improvement project, did not show a significant improvement in health related quality of life for the adolescents with T1D. The results did show an increase in the mean scores in 3 of the 5 dimensions: My Diabetes, Treatment I, and Treatment II. The My Diabetes dimension of the PedsQL Diabetes Module focuses on the physical effects of diabetes and the problems the disease may cause. It could be speculated this increase, or improvement in mean scores for this dimension are a result of increased encouragement and disease management education received from attending Empower1. The Treatment I dimension involves the physical and emotional aspects of diabetes and its treatment. The increase in mean scores in this dimension may be related to peer and emotional support gained from attending the peer support group sessions. The Treatment II dimension addressed the difficulty of disease management in T1D and also demonstrated an increase in post mean scores indicating an increased HRQL in this area. During each Empower1 session time was devoted to diabetes specific education and opportunities for health-promoting peer education between group participants. This education, peer teaching, and support may have led to the increase in mean scores in the Treatment II dimension.

Two dimensions did not demonstrate an increase in mean post scores, the Worry and Communication dimensions. The Worry dimension focuses on the adverse effects of T1D, many of which are difficult to control. Adolescents with T1D are often not mature enough to understand the short and long term effects of this disease leading to the potential of them worrying about the adverse effects. Even with ongoing peer support and increased education it can be difficult to decrease these fears or worry. The Communication dimension addresses communication between the adolescent with T1D and physicians and nurses, or the ability to explain T1D to others. Empower1 did not address these specific issues, concluding this is why no increase in mean scores were seen for this dimension.

Discussion

The results of this quality improvement project do indicate there is potential to have a positive impact on HRQL for adolescents with T1D showing a need for more projects like this one to explore the benefits of peer support for adolescents with T1D in the future. Future studies could include measuring HRQL after attending a peer support group for a much longer time period and could include a larger number of participants. Another option is to look at glycemic control and analyze if providing organized peer support and ongoing education for this age group would result in improved disease management and blood glucose control.

To ensure the program will continue on beyond a few sessions, the program must be able support the specific needs of the participants. Program participants will be involved in the decision making process and planning for future sessions, education topics, and team building activities. Proposed locations for future team building will include amusement parks, meeting at a local state park for a campfire and dinner, or going to a movie together. Formal education can continue to be built into the scheduled sessions, along with fun team building activities. If this program is effective, sustainable, and possesses scalability on a local setting, then it has the potential to spread to a regional and national level, continuing to grow for several years. Empower 1, a peer support program, offers ongoing social and emotional support, assistance in daily disease management, and provides a link to clinical and community resources [CITATION Pee14 \l 1033].

In summary, T1D requires complex self-management that often shows a decline during the adolescent years. Through identification of the present health disparities for the T1D community a proposed solution was identified. The solution was to create and implement a peer support program, Empower1, for T1D adolescents. By collaborating with the local non-profit T1D focused organization and including key stakeholders such as T1D adolescents, young adults, and their families, the implementation and evaluation of a peer support program has become a reality. Although the sample size for the data collected during this project was small, it does show signs of being beneficial for those that attended and has paved the way for future improvement in peer support for adolescents with T1D. This project provided positive social support, and disease education, structured around the goal of improving health related quality of life, and could possibly lead to improved disease management. If overall improved glycemic control can be achieved within this target population through peer support, lifelong complications can be prevented.

The quality improvement project, Empower1, aimed to provide a way of building supportive relationships and friendships, along with providing education and encouragement for T1D adolescents, through social interactions with their peers. Empower1 aims to instill reassurance in these individuals that they are not alone, that this is not something that should inhibit them from pursuing their dreams or slow them down, and T1D is manageable.

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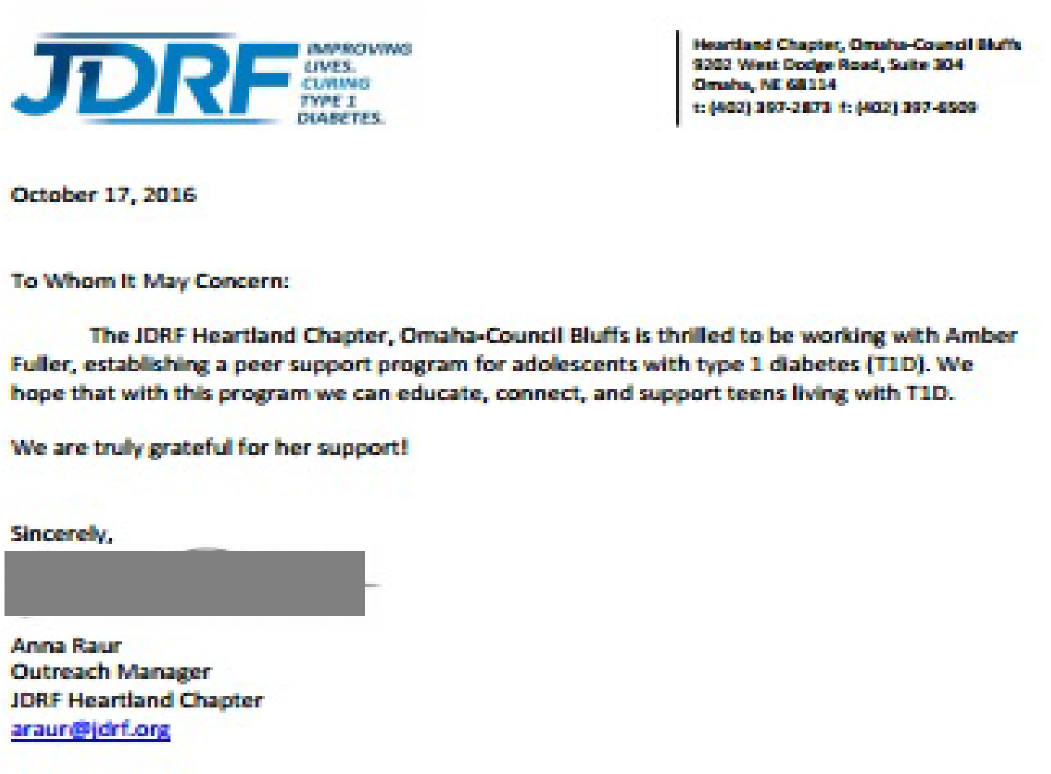
Appendix A: Letter from JDRF



JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES.

Heartland Chapter, Omaha-Council Bluffs
9202 West Dodge Road, Suite 304
Omaha, NE 68114
t: (402) 397-2873 f: (402) 397-6509

October 17, 2016

To Whom It May Concern:

The JDRF Heartland Chapter, Omaha-Council Bluffs is thrilled to be working with Amber Fuller, establishing a peer support program for adolescents with type 1 diabetes (T1D). We hope that with this program we can educate, connect, and support teens living with T1D.

We are truly grateful for her support!

Sincerely,

[redacted]

Anna Raur
Outreach Manager
JDRF Heartland Chapter
araur@jdrf.org

Appendix B: Literature Review Matrix

Article Citation **Level of Evidence** **PICOT Question**	**Purpose of Research** **Design Used**	**Measurement Tools / Inclusion criteria for systematic reviews**	**Sample and Size**	**Results of Research**	**Comments / Recommendations**
Citation: Borschuk, A. P., & Everhart, R. S. (2015). Health disparities among youth with type 1 diabetes: A systematic review of the current literature. *Families*, *Systems & Health*, 33(3), 297-313 **Level of Evidence:** Systematic Review **PICOT Question:** What are the differences in health and psychosocial outcomes in T1D.	**Purpose**: A systematic review to examine the differences in health and psychosocial outcomes in type 1 diabetes, to evaluate the health disparities that exist for T1D youth. Electronic databases were searched for articles that fit specific criteria. **Design**: Systematic Review of qualitative and quantitative data	Criteria for selection of articles: 1. Type 1 diabetes cases only, 2. Child or adolescents only, 3. Health or psychosocial outcomes grouped by race/ethnicity, 4. Peer-reviewed, 5. English language, 6. Published in an academic journal.	30 articles 27 articles reporting findings in health outcomes 3 articles reporting findings in psychosocial outcomes	Findings indicate there are significant disparities in health and psychosocial outcomes based on race/ethnicity and socioeconomic status in youth with T1D.	Not very detailed in specific findings, good overall review of results and themes found within the articles. Good review for understanding health disparities in this specific population.
Citation: Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current opinion in pediatrics*,	**Purpose:** A systematic review to examine the different interventions and their efficacy in improving glycemic control in adolescents	Criteria for article selection: 1.Include obstacles teens face in regard to adherence behaviors 2.Invterventions trialed to	52 Articles Studies included participants ages 11-25	1.Themes identified in barriers to adolescent adherence include peer influence, affect, disordered eating. 2.Successful	Good overall review of barriers and inventions to overcome the identified barriers. Utilizing different types of support can help increase

22(4), 405-411. **Level Of Evidence**: Systematic Review **PICOT Question**: What are the most effective interventions to overcome barriers to good glycemic control in T1D adolescents?	with T1D. **Design:** Systematic Review of qualitative and quantitative data	help teens negotiate their diabetic regimens		interventions include persistence, expanding the number of teen supports (parental, peer, professional) and ongoing psychoeducational tolls to motivate behavior change and increase adherence	glycemic control and disease treatment adherence
Citation: Heisler, M. (2009). Different models to mobilize peer support to improve diabetes self-management and clinical outcomes. *Family Practice*, 1-10. **Level of Evidence:** Background paper and discussion **PICOT Question:** What are the different approaches to mobilize peer support for diabetes self-management and are they effective?	**Purpose:** To provide an overview of the different approaches to mobilize peer support for diabetes self-management support and to discuss the evidence on the effectiveness of these interventions and models. To discuss the directions of future research in this area.	Reviewed multiple types of peer support intervention studies including random controlled studies and cohort studies.	Reviewed multiple peer support programs including: face-to-face group self-management, peer coaches and mentors, peer community health worker programs, telephone based programs, and web and e-mail support programs.	Identified the theme that there is a lack of sufficient support for those with diabetes and low-cost, easily accessible peer support programs demonstrate they are beneficial in supplementing clinical treatment for diabetes.	Recommendations were provided on how to structure a successful peer support program and discussed the need for future research in this area.
Citation: Fisher, E. B., Boothroyd,	To evaluate the four key	Conducted internationall	Mentee and	Qualitative results	Continued contact

R. I., Coufal, M., Baumann, L. C., Mbanya, J. C., Rotheram-Borus, M. J., . . . Tanasugarn, C. (2012). Peer support for self-management of diabetes improved outcomes in international settings. *Health Affairs*, 31(1), 130-139. **Level of Evidence:** Cohort Study **PICOT Question:** Does implementing diabetes buddies providing ongoing support for diabetes improve disease management?	functions of peer support for diabetes management **Design:** Qualitative Study	y, diabetes buddies were designated to promote diabetes management through reciprocal support. Women were designated buddies for 3 months following a 12 session curriculum. Weekly sessions were held to discuss daily life, self-management, and nutrition.	Mentor: Had to attend training program, and continue with the program for 12 weeks, young women, 22 women completed the program	showed improved assistance in daily management of diabetes, improved social and emotional support, better linkage to clinical care and that there was a sense of ongoing support as many groups still met after the study	through texting and meetings with their buddy encouraged disease management. It was also found that peer support helped provide community resources. The support helped encourage regular clinical care and provided ongoing support that continued after the 12 week sessions were complete. It was even found that the groups expanded their numbers and continued weekly meetings.
Citation: Heisler, M., Vijan, S., Makki, F., & Piette, J. (2010, October). Diabetes control with reciprocal peer support versus nurse care management. *Annals of Internal Medicine*, 153(8), 507-515 **Level of Evidence**: 2 Randomized Control Trial **PICOT Question:** Does peer-support used as a supplement	**Purpose:** To compare reciprocal peer-supported (RPS) program with nurse care management (NCM). Design: Randomized Controlled Trial	HgA1c levels were obtained through laboratory results, medical records were also used to gather other data and demographics.	244 total RPS: 125 NCM: 119 All participants were male veterans	Findings: 89% of the participants completed the study and 95% complete the survey assessment at 6 months The RPS group had a mean decrease of 0.88% in their HbA1c and the NCM group	Reciprocal peer support shows promise as a method for improving diabetes care. Health benefits were seen in both groups with a higher amount in the RPS group. The RPS group also reported greater diabetes-specific social support.

to nurse-led group sessions improve glycemic control in T1D patients?				had a 0.07% decrease. Between the groups difference was 0.81%; $P < 0.001$	Shows that peer support can offered increased health benefits.
Citation: Lu, Y., Pyatak, E. A., Peters, A. L., Wood, J. R., Kipke, M., Cohen, M., & Sequeira, P. A. (2015). Pateint perspective on peer mentoring: type 1 diabetes management in adolescents and young adults. *The Diabetes Educator*, 41(1), 59-68. doi:10.1177/0145721714559133 **Level of Evidence:** 3: Cohort Study **PICOT Question:** In adolescents and young adults, is there an interest in peer mentoring as an adherence-promoting intervention?	**Purpose:** To identify attitudes and topics relevant to peer mentoring as an adherence-promoting intervention for adolescents and young adults with T1D. **Design:** Data collected from self-administered surveys from 2 diabetes clinics.	Surveys were completed on a computer during their appointment while waiting to be seen. Thematic coding was conducted on qualitative data. 2 investigators reviewed the patient responses and generated a list of themes, 2 research assistants also assigned themes for each question and then were all compared and matched by another researcher. Frequency tabulations were performed on the various themes to	Self-administered survey to look patient attitudes and perspective on peer mentoring. 54 adolescent mentees, and 46 mentors	Findings: A majority of the adolescents and young adults indicated interest in peer mentoring as a potential intervention to improve glycemic control. Results also showed that peer mentoring would also be helpful in overcoming the social barriers to diabetes control.	A need for peer mentoring does exist and it has a potential to help improve glycemic control and disease management adherence. This study is useful in the sense that aligns with the idea of my capstone project of a peer support program for adolescents with T1D and does a need or desire for this type of support exist.

		identify themes. Demographics and diabetes adherence of each patient was also collected and analyzed.			
Citation: Maslow, G., Adams, C., Willis, M., Neukirch, J., Herts, K., Froehlich, W., . . . Rickerby, M. (2013). An evaluation of a positive youth development program for adolescents with chronic illness. *Journal of Adolescent Health*, 52, 179-185. **Level of Evidence:** Cohort Study **PICOT Question:** Does group mentoring have an impact on adolescents with chronic illnesses?	**Purpose:** To examine the outcomes of a group mentoring program called The Adolescent Leadership Council (TALC) bringing together high school students and college mentors all with chronic illness. **Design:** Qualitative analysis	Pre and post surveys were conducted to evaluate transitions readiness and loneliness along with educational, vocational, and health care related outcomes. TALC uses positive youth development approach, emphasizing strong relationships between youth and adults while learning important life skills and to take a leadership role.	22 high school students participated, all had a chronic illness, age 13-19, able to participate in group discussions. Mentors were recruited from Brown University, had a chronic illness, and had to complete a 2 hour group training.	Qualitative analysis of survey results showed participants felt the program promoted their developmental of general life and chronic illness management skills. Loneliness report decreased from 46 to 38.5 (p<0.001) Health care self-advocacy increased 3.8 to 4.2 (p<0.001)	The TALC program applies positive youth development principles and has shown to support positive educational, vocational an health care outcomes for youth with chronic illness
Citation: Markowitz, J. T., & B, L. L. (2012, April). Education and psychological transitions in care:	**Purpose:** This study aims to implement and evaluate the effectiveness of	Participants were solicited through fliers to attend support	15 young adults Inclusion: ages 18-30 with T1D	Findings: Participants showed an improvement in glycemic	Recommendations: Professional led support groups are beneficial for young adults

support group for young adults with type 1 diabetes. *Diabetic Medicine*, 29(4), 522-525. doi:10.1111/j.1464-5491.2011.03537.x **Level of Evidence: 3** Cohort Study **PICOT question:** Do professionally led support groups enhance self-motivation and facilitate peer-to-peer interactions in young adults with T1D?	a professionally led support groups. Will these groups enhance self-motivation and facilitate peer-to-peer interactions in young adults with T1D? Pre and post test design	groups, data were collected before during and after the program. Survey: Problem Areas in Diabetes and Self-Care Inventory Glycemic control was measured by HgA1c values	Recruited by fliers	control by a lower HgA1c and lower self-reported diabetes burden. HgA1c showed improvement P=0.10 so results were statistically significant.	with T1D. Sample size was small and participation was solicited. Useful in the sense that positive results were found in those that participated in the peer support group.
Citation: Palladina, D. K., & Helgeson, V. S. (2012). Friends or foe? A review of peer influence on self-care and glycemic control in adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 37(5), 591-603. **Level of Evidence:** 1 Systematic Review **Question:** What relation does peer influence have on diabetes outcomes in adolescents with T1D?	**Purpose:** To examine the relation of peer influence on diabetes outcomes for adolescents with T1D. **Design:** Systematic review: PsychInfo and Medline databases and personal archives were used to find studies that met their criteria.	Criteria for articles to be included: the majority of the sample had to include youth with T1D. Data were summarized and compared in provided tables. Studies were reviewed and analyzed. Quantitative articles included studies linked to glycemic control and peer relationships. Qualitative articles included	24 Articles were included.	Findings: The results found that peer support can be beneficial and social conflict leads to harmful results. It was pointed out the importance of peer relationships, especially when a chronic illness involves self-care throughout the day at school or at social events and	Peer support is helpful for those with T1D. Sample size of only 24, still helps support my capstone in regards to the benefits of peer support in T1D and the harmful effects that social conflict can have on disease management.

		ways peers effect self-care.		in the presence of others. Some of the articles in this review did find a positive correlation between peer support and T1D disease management.	
Citation: Peters, L. W., Nawijn, L., & van Kesteren, N. M. (2014, January). How adolescents with diabetes experience social support from friends: Two qualitative studies. *Scientifica*, 2014, 1-8. doi:10.1155/2014/415849 **Level of Evidence**: Qualitative Study **PICOT Question**: In adolescents with type 1 diabetes, does social support have a positive influence on their self-management?	**Purpose**: To investigate social support from the perspective of the adolescents with diabetes. Main objective to explore the experiences, expectations and attitudes of adolescents with T1D and their friends with respect to social support in coping with diabetes. Online discussions and in home interviews were used. A meta-analysis of two studies was discussed.	Participant's perspectives were coded and grouped into themes by a cyclical process of reflections, observation, and analysis. Study 1: all forum entries were exported to a file and analyzed using content analysis. Study 2: Interviews were transcribed verbatim and analyzed with Kwalitan version 5.09 using content analysis.	Study 1: 28 participants, online forum Study 2: 11 pairs of adolescents with T1D and their best friend. Interviews were conducted in the participants homes	Study 1: all participants felt social support had a positive impact on them, but to what extent differed between participants. Mostly they wanted to be treated as normal. Study 2: participants did not feel limited by their diabetes. The best friends revealed they would be willing to offer more support for their friend with T1D. Both studies	During diabetes education, the importance of social support should be discussed. Overall the adolescents with T1D look for emotional support from friends and seek autonomy in their disease management. Supports idea of peer support program for capstone project

				showed adolescents with T1D mostly need emotional support from friends.	
Citation: Rausch, J. R., Hood, K. K., Delamater, A., Pendley, J., Rohan, J., Reeves, G., . . . Drotar, D. (2012). Changes in treatment adherence and glycemic control during the transition to adolescence in type 1 diabetes. *Diabetes Care*, 35, 1219-1224. **Level of Evidence:** 2 year longitudinal multisite cohort study **PICOT Question:** Is the changes in glycemic control during the transition to adolescence in T1D unidirectional or bidirectional?	To examine the unidirectional and bidirectional models change and how each effects adherence and glycemic control in adolescents with T1D	Over a 2 year period HgA1c was measured at 6 month intervals over the 2 years Frequency of blood glucose monitoring and the results was tracked via participants' meters or a log book over the 2 years. The results were analyzed using multiple regression analysis.	225 participants Ages 9-11 (at start of study) Male and female Had T1D for 1 year or more at the beginning of the study	The findings documented a significant decrease in glycemic control over the 2 year period. A decrease in blood glucose monitoring frequency also declined.	The results from this study showed a decline in glycemic control in participants before entering and during the early stages of adolescent. By targeting this age group early on to encourage and increase blood glucose monitoring frequency this may have a positive impact on future glycemic control.

Appendix C: Consent Form

Empower 1:

A peer support program for adolescents with Type 1 Diabetes

NEBRASKA
METHODIST
COLLEGE
THE JOSIE HARPER CAMPUS

720 N 87th St, Omaha, NE 68114

Informed Parental Consent

Informed consent for ______________________________ is provided by ________________________ (parent or legal guardian) to participate in this quality improvement study: Empower 1.

Primary Investigator: Amber Fuller

Organization: Nebraska Methodist College

Partnership with JDRF for this project

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you agree that your child may participate)

You will be given a copy of the full Informed Consent Form

Please feel free to contact Amber Fuller at amber.fuller2@methodistcollege.edu or 402-980-2217 with any questions or concerns.

Part 1: Information Sheet

Introduction:

I am Amber Fuller, a graduate student at Nebraska Methodist College. I am conducting a quality improvement project involving adolescents with Type 1 Diabetes (T1D). This project is looking at how attending an organized peer support program for adolescents with T1D impacts their perceptions on quality of life with diabetes. I am looking for adolescents, ages 13 to 18 with T1D who will be willing to participate in this study.

Study Purpose:

The purpose of this project is to implement an organized social program for adolescents with T1D. This program will allow them to come together and build relationships, encourage health-promotion, offer T1D education, and evaluate if the program can ultimately shape their health and lifestyle behaviors in a positive manner to improve their disease management and increase their reported health related quality of life through social influences.

Procedures:

The project will be conducted by providing a pre and post questionnaire for the participants to fill out. (Parents or guardians may request a copy of the questionnaire that will be used). Once permission is granted by parent or guardian then the participants can attend the scheduled meetings or gatherings and participate in the peer group sessions. After attending a minimum of 2 sessions, or up to 4 sessions, the same questionnaire will be given to the participants once again to fill out. All of the results from the pre and post questionnaires will be compared and evaluated.

The peer support program will consist of monthly meetings, outings, adventures, group projects, and ongoing education offerings for adolescents with T1D. Formal education and meetings will be performed in a classroom, meeting room or conference style location, or built into part of the team building activities. Areas of focus for education include: how to deal with the changes of being teenagers with T1D, how to overcome obstacles and challenges, tips and secrets of keeping T1D under tight control while still being a normal teenager. Certified diabetes educators and licensed health care providers will be contacted through the JDRF and the local children's endocrine clinic to help provide this education.

Participants:

Participants include children with T1D ages 13 to 18. Age of diagnosis and treatment adherence will not be taken into account when choosing participants. Participants are encouraged to attend a minimum of 2 sessions but are welcome to come to as many as possible. If at any time a participant wishes to be excluded from the study they can do so. No monetary compensation or incentive will be offered for participants.

Confidentiality:

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Your child's study record may be reviewed by government agencies and the Nebraska Methodist College Institutional Research Board.

Any information that is obtained in connection with this study and that can be identified with your child will remain confidential and will be disclosed only with your permission or as required by law. No personal identifying information will be collected on the questionnaire or reported in the dissemination of the study results. Data collected will be in paper format, entered into a password protected personal computer. The paper questionnaires collected from participants will then be kept for a minimum of 5 years in a locked file cabinet that only the primary investigator has access to. After the minimum of 5 years the paper form of the questionnaires will be destroyed by shredding. Data stored on the personal computer will have no personal information or identifying markers or codes that would link the data to the participants.

Benefits:

By participating in this study possible benefits include: an improved sense of health related quality of life (HRQL) for adolescents with T1D, and an increased report of disease knowledge, and disease management. Other possible benefits are the creation of a stronger presence of positive peer relationships and influences, and increased diabetes support.

Risks:

Minimal risks have been identified for those participating in this projects. Risks include: discussing personal T1D disease management on a voluntary basis, there is no requirement to discuss if any individual does not feel comfortable. If participation causes any emotional distress please feel free to contact the Children's Hospital and Medical Center's Behavioral Health Department at 402-955-3900.

Primary Goal:

To instill reassurance in these individuals that they are not alone, that T1D is not something that should inhibit them from pursuing their dreams or slow them down, and T1D is manageable.

The Nebraska Methodist College and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.If you have questions regarding your rights as a research subject, you may contact a member of the NMC Institutional Research Board at (402) 354-7263 (ask to speak with the IRB Chair). You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

General information about being a research subject can be found on the Office of Human Research Protections (OHRP) website: http://www.hhs.gov/ohrp/index.html.

Part 2: Parental Consent

I have been asked to give consent for my daughter/son _________________________ to participate in this research study which will involve her/him attending at least two peer sessions and completing two questionnaires. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily for my child to participate as a participant in this study.

Print Name of Participant ____

Signature of Participant____

Print Name of Parent or Guardian _____________________________________

Signature of Parent of Guardian_______________________________________

Date ____________________________

I have witnessed the accurate reading of the consent form to the parent of the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness____

Signature of witness ____

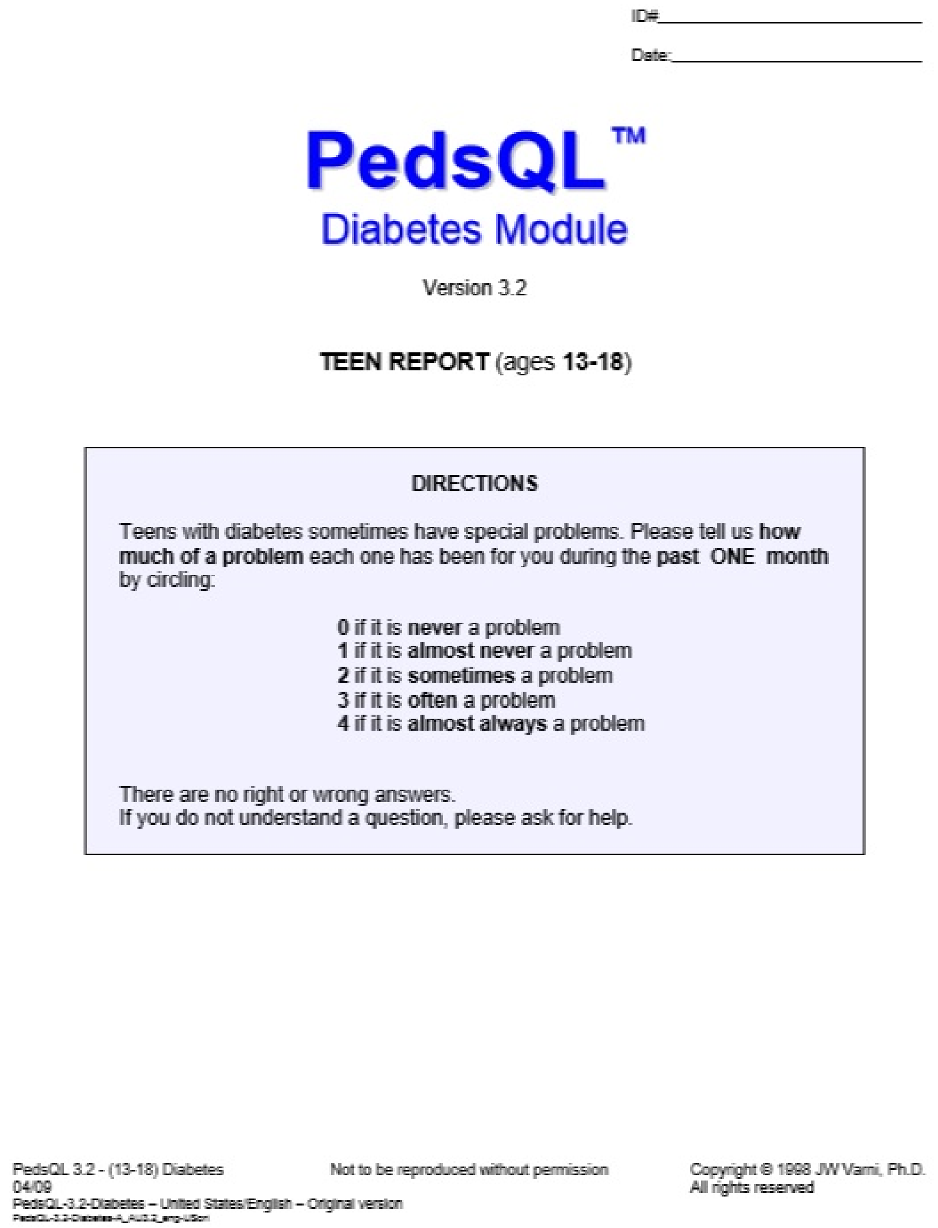
Date ___________________________

Signature of Primary Investigator _________________________________

Date___________________________

Appendix D: PedsQL Forms

1. PedsQL Tool



ID#________________________

Date:________________________

PedsQL™
Diabetes Module

Version 3.2

TEEN REPORT (ages **13-18**)

DIRECTIONS

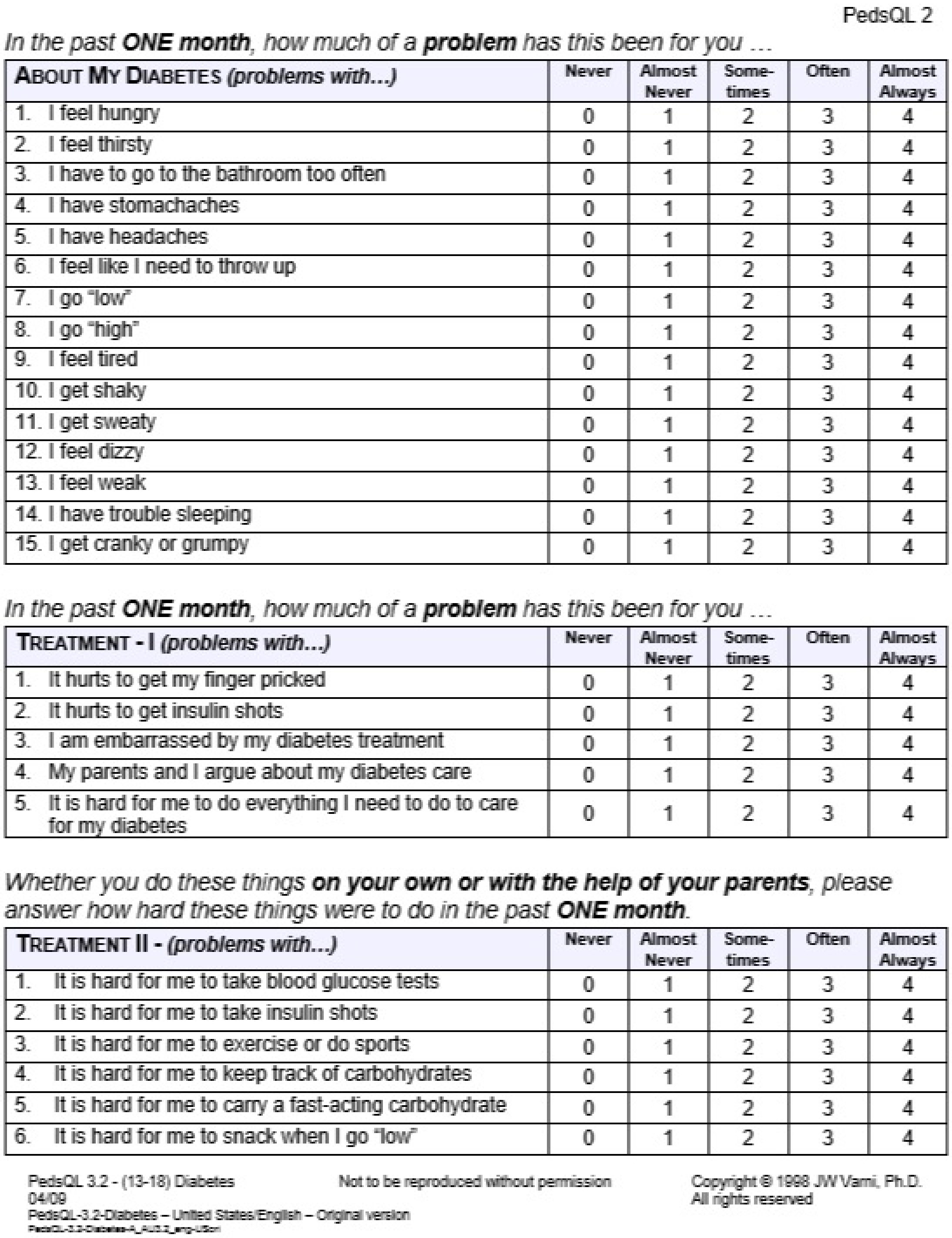
Teens with diabetes sometimes have special problems. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PedsQL 3.2 - (13-18) Diabetes
04/09
PedsQL-3.2-Diabetes – United States/English – Original version

Not to be reproduced without permission



PedsQL 2

In the past ***ONE month****, how much of a* ***problem*** *has this been for you …*

ABOUT MY DIABETES ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel hungry	0	1	2	3	4
2. I feel thirsty	0	1	2	3	4
3. I have to go to the bathroom too often	0	1	2	3	4
4. I have stomachaches	0	1	2	3	4
5. I have headaches	0	1	2	3	4
6. I feel like I need to throw up	0	1	2	3	4
7. I go "low"	0	1	2	3	4
8. I go "high"	0	1	2	3	4
9. I feel tired	0	1	2	3	4
10. I get shaky	0	1	2	3	4
11. I get sweaty	0	1	2	3	4
12. I feel dizzy	0	1	2	3	4
13. I feel weak	0	1	2	3	4
14. I have trouble sleeping	0	1	2	3	4
15. I get cranky or grumpy	0	1	2	3	4

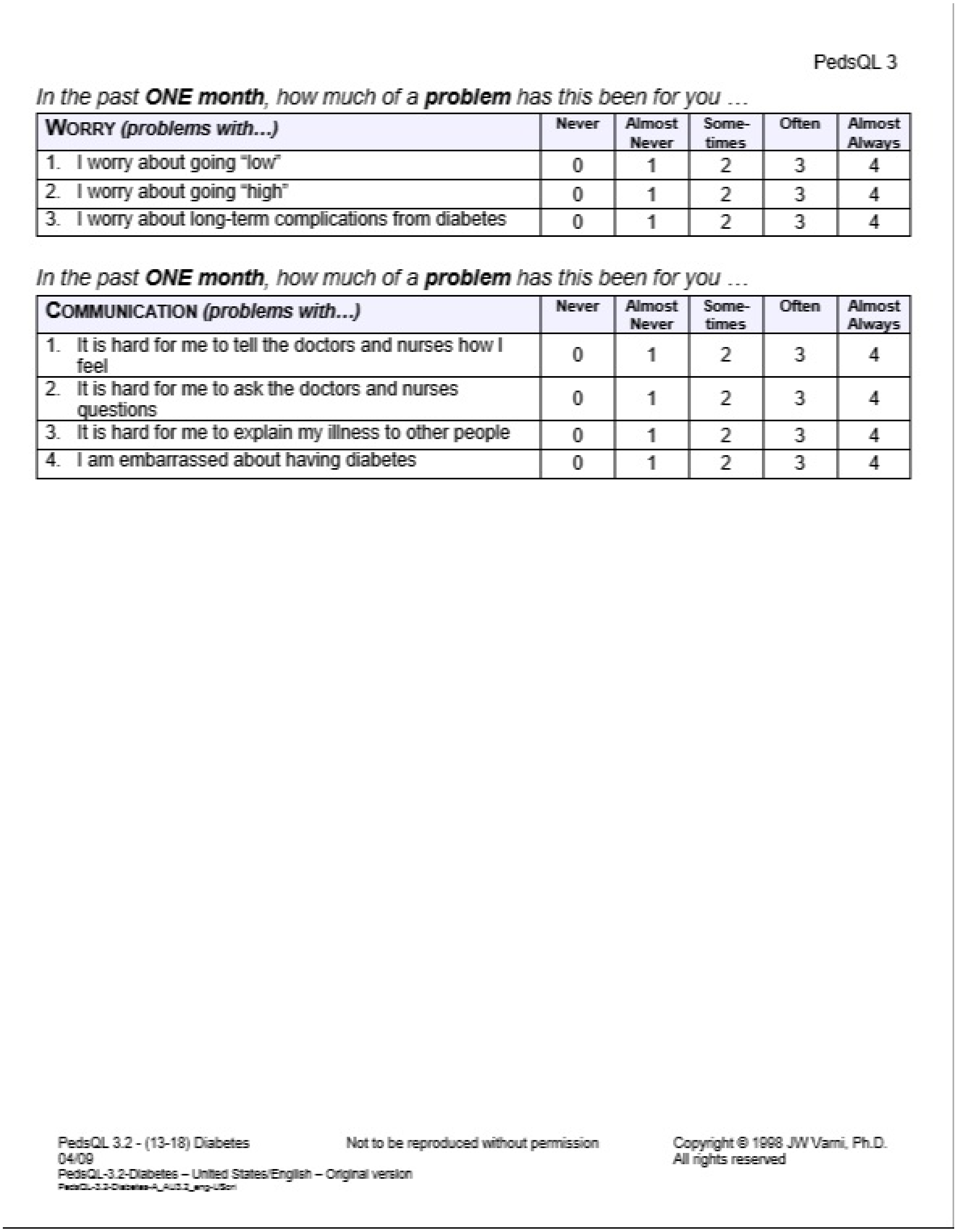
In the past ***ONE month****, how much of a* ***problem*** *has this been for you …*

TREATMENT - I ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It hurts to get my finger pricked	0	1	2	3	4
2. It hurts to get insulin shots	0	1	2	3	4
3. I am embarrassed by my diabetes treatment	0	1	2	3	4
4. My parents and I argue about my diabetes care	0	1	2	3	4
5. It is hard for me to do everything I need to do to care for my diabetes	0	1	2	3	4

Whether you do these things ***on your own or with the help of your parents****, please answer how hard these things were to do in the past* ***ONE month****.*

TREATMENT II - ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to take blood glucose tests	0	1	2	3	4
2. It is hard for me to take insulin shots	0	1	2	3	4
3. It is hard for me to exercise or do sports	0	1	2	3	4
4. It is hard for me to keep track of carbohydrates	0	1	2	3	4
5. It is hard for me to carry a fast-acting carbohydrate	0	1	2	3	4
6. It is hard for me to snack when I go "low"	0	1	2	3	4

PedsQL 3.2 - (13-18) Diabetes
04/09
PedsQL-3.2-Diabetes – United States/English – Original version
PedsQL-3.2-Diabetes-A_AU3.2_eng-USori



PedsQL 3

*In the past **ONE month**, how much of a **problem** has this been for you …*

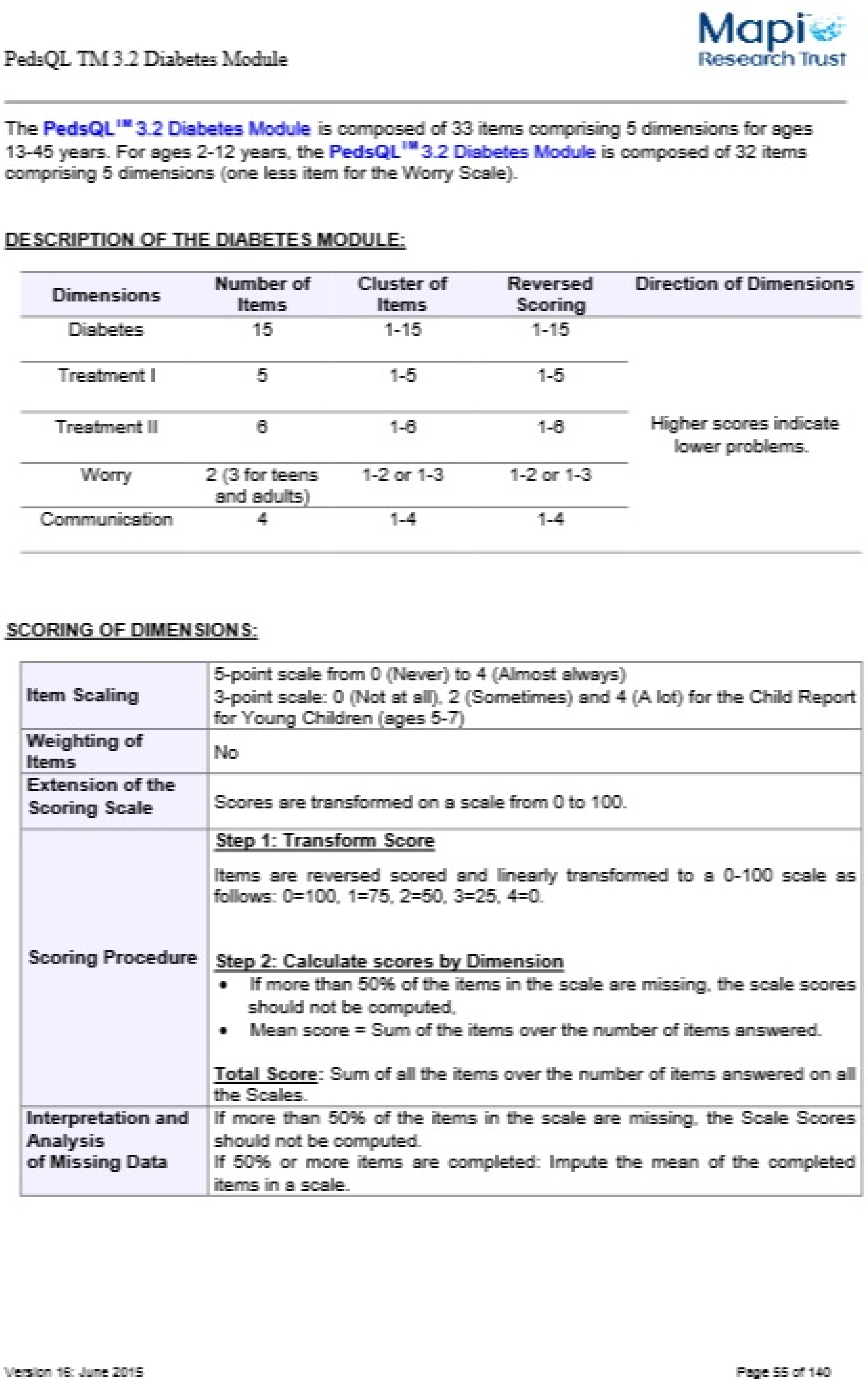
WORRY ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I worry about going "low"	0	1	2	3	4
2. I worry about going "high"	0	1	2	3	4
3. I worry about long-term complications from diabetes	0	1	2	3	4

*In the past **ONE month**, how much of a **problem** has this been for you …*

COMMUNICATION ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my illness to other people	0	1	2	3	4
4. I am embarrassed about having diabetes	0	1	2	3	4

PedsQL 3.2 - (13-18) Diabetes
04/09
PedsQL-3.2-Diabetes – United States/English – Original version
PedsQL-3.2-Diabetes-A_AU3.2_eng-USori

D.2 PedsQL Scoring Instructions



PedsQL TM 3.2 Diabetes Module

Mapi Research Trust

The **PedsQL™ 3.2 Diabetes Module** is composed of 33 items comprising 5 dimensions for ages 13-45 years. For ages 2-12 years, the **PedsQL™ 3.2 Diabetes Module** is composed of 32 items comprising 5 dimensions (one less item for the Worry Scale).

DESCRIPTION OF THE DIABETES MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes	15	1-15	1-15	Higher scores indicate lower problems.
Treatment I	5	1-5	1-5	
Treatment II	6	1-6	1-6	
Worry	2 (3 for teens and adults)	1-2 or 1-3	1-2 or 1-3	
Communication	4	1-4	1-4	

SCORING OF DIMENSIONS:

Item Scaling	5-point scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	**Step 1: Transform Score** Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. **Step 2: Calculate scores by Dimension** • If more than 50% of the items in the scale are missing, the scale scores should not be computed, • Mean score = Sum of the items over the number of items answered. **Total Score**: Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.

Version 16: June 2015

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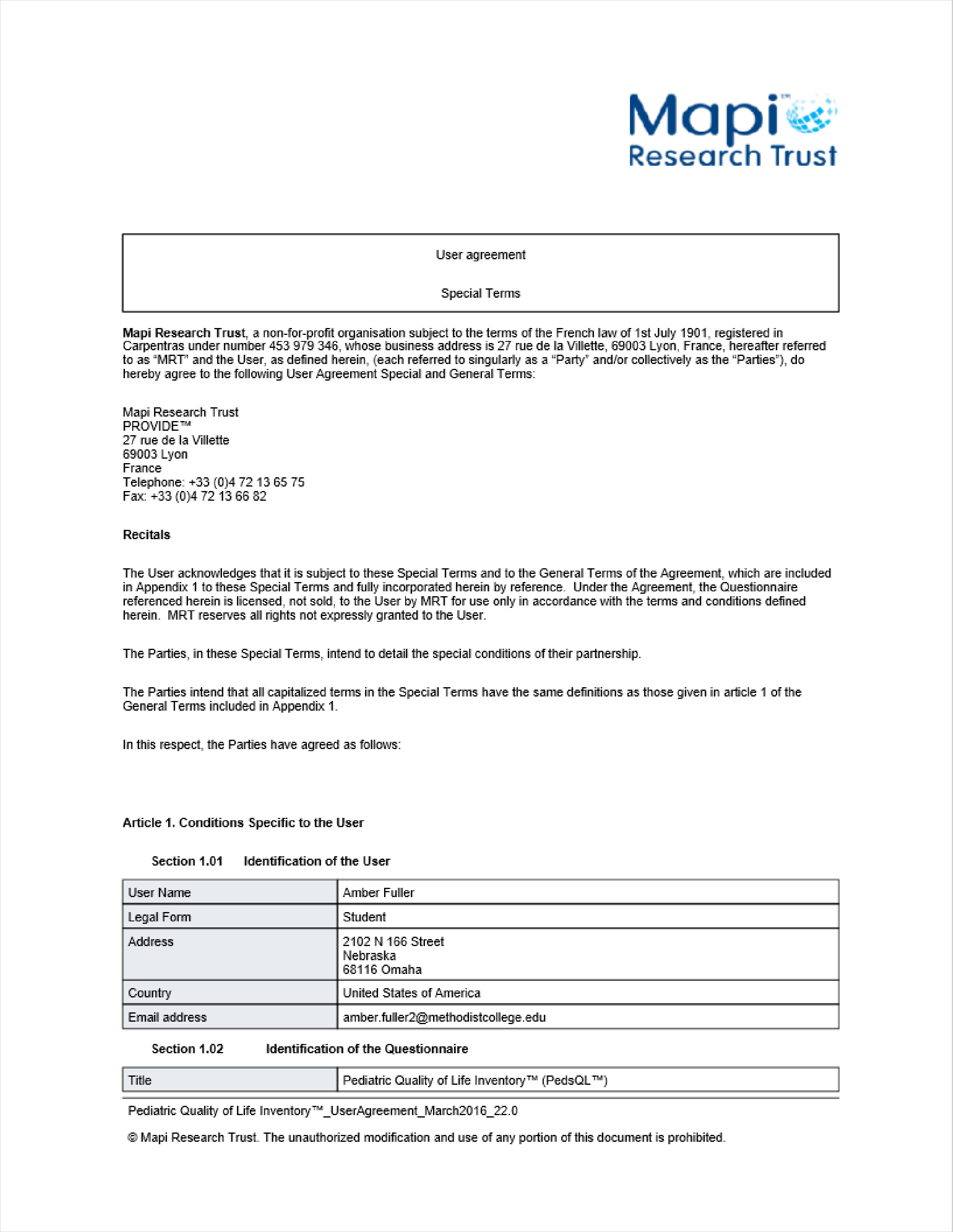
D.3 PedsQL User Agreement and Permission to use tool



Mapi Research Trust

User agreement

Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "MRT" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
PROVIDE™
27 rue de la Villette
69003 Lyon
France
Telephone: +33 (0)4 72 13 65 75
Fax: +33 (0)4 72 13 66 82

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User

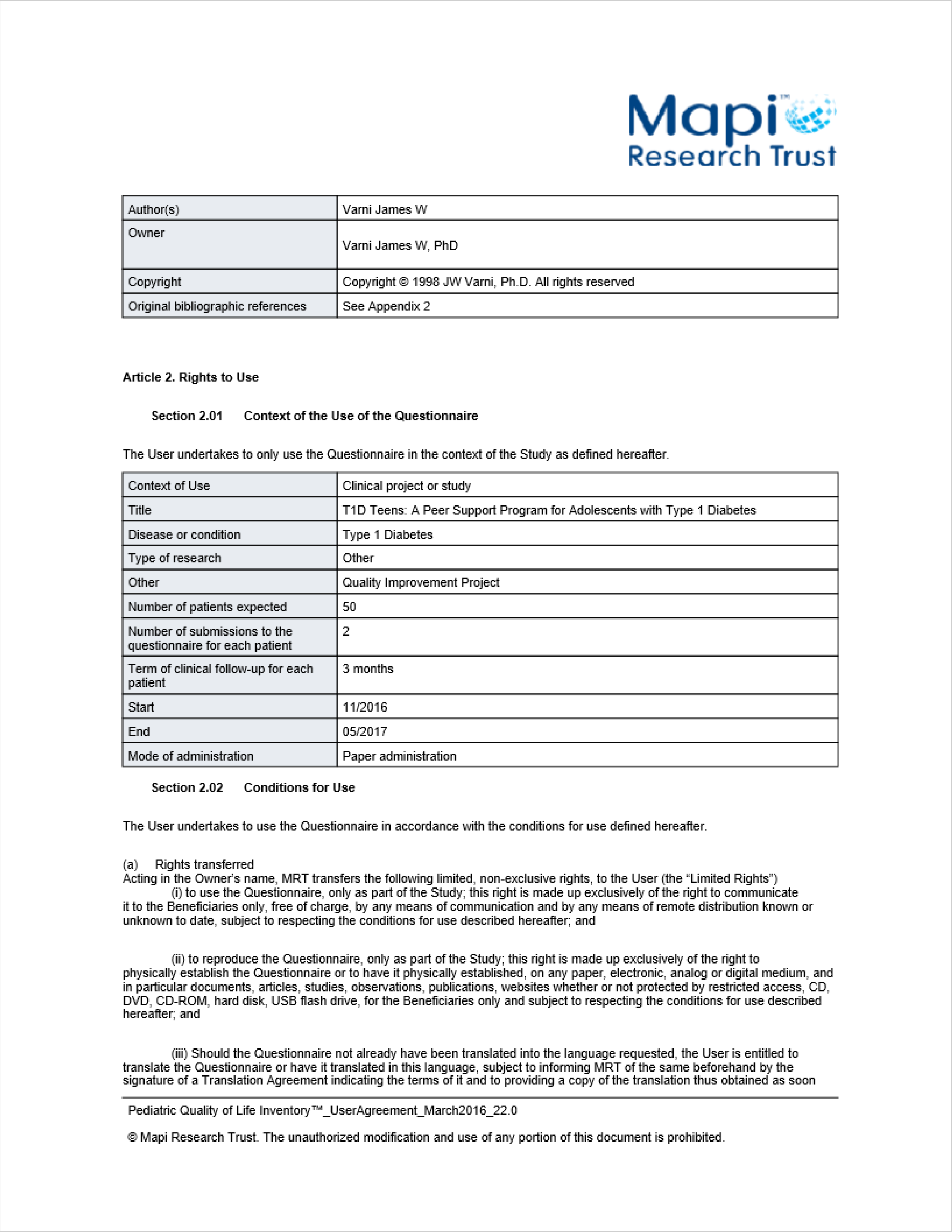
Section 1.01 Identification of the User

User Name	Amber Fuller
Legal Form	Student
Address	2102 N 166 Street Nebraska 68116 Omaha
Country	United States of America
Email address	amber.fuller2@methodistcollege.edu

Section 1.02 Identification of the Questionnaire

Title	Pediatric Quality of Life Inventory™ (PedsQL™)

Pediatric Quality of Life Inventory™_UserAgreement_March2016_22.0



Mapi Research Trust

Author(s)	Varni James W
Owner	Varni James W, PhD
Copyright	Copyright © 1998 JW Varni, Ph.D. All rights reserved
Original bibliographic references	See Appendix 2

Article 2. Rights to Use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

Context of Use	Clinical project or study
Title	T1D Teens: A Peer Support Program for Adolescents with Type 1 Diabetes
Disease or condition	Type 1 Diabetes
Type of research	Other
Other	Quality Improvement Project
Number of patients expected	50
Number of submissions to the questionnaire for each patient	2
Term of clinical follow-up for each patient	3 months
Start	11/2016
End	05/2017
Mode of administration	Paper administration

Section 2.02 Conditions for Use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter.

(a) Rights transferred
Acting in the Owner's name, MRT transfers the following limited, non-exclusive rights, to the User (the "Limited Rights")
(i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, free of charge, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and

(ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and

(iii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing MRT of the same beforehand by the signature of a Translation Agreement indicating the terms of it and to providing a copy of the translation thus obtained as soon

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Pediatric Quality of Life Inventory™_UserAgreement_March2016_22.0

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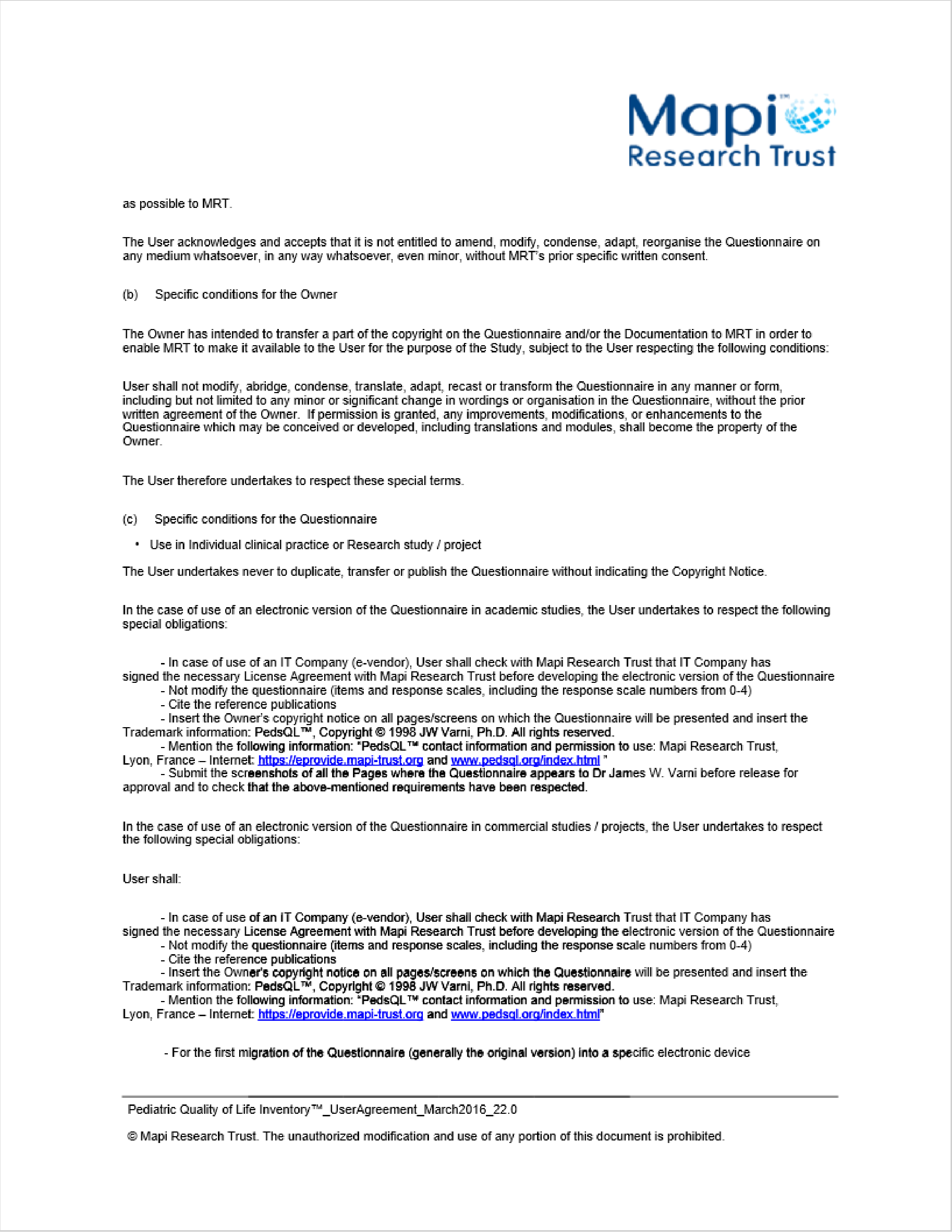


as possible to MRT.

The User acknowledges and accepts that it is not entitled to amend, modify, condense, adapt, reorganise the Questionnaire on any medium whatsoever, in any way whatsoever, even minor, without MRT's prior specific written consent.

(b) Specific conditions for the Owner

The Owner has intended to transfer a part of the copyright on the Questionnaire and/or the Documentation to MRT in order to enable MRT to make it available to the User for the purpose of the Study, subject to the User respecting the following conditions:

User shall not modify, abridge, condense, translate, adapt, recast or transform the Questionnaire in any manner or form, including but not limited to any minor or significant change in wordings or organisation in the Questionnaire, without the prior written agreement of the Owner. If permission is granted, any improvements, modifications, or enhancements to the Questionnaire which may be conceived or developed, including translations and modules, shall become the property of the Owner.

The User therefore undertakes to respect these special terms.

(c) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project

The User undertakes never to duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice.

In the case of use of an electronic version of the Questionnaire in academic studies, the User undertakes to respect the following special obligations:

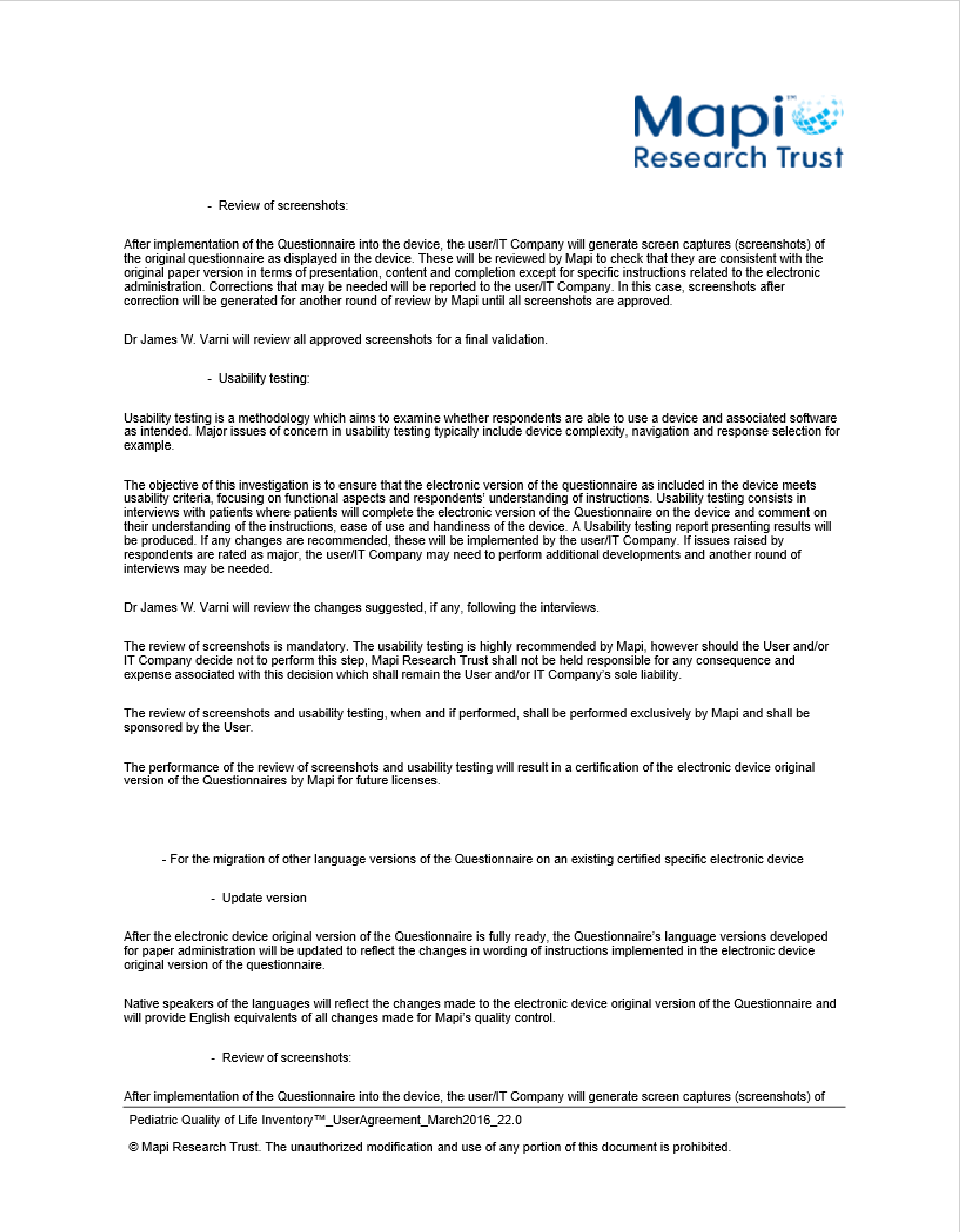
- In case of use of an IT Company (e-vendor), User shall check with Mapi Research Trust that IT Company has signed the necessary License Agreement with Mapi Research Trust before developing the electronic version of the Questionnaire
- Not modify the questionnaire (items and response scales, including the response scale numbers from 0-4)
- Cite the reference publications
- Insert the Owner's copyright notice on all pages/screens on which the Questionnaire will be presented and insert the Trademark information: **PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved.**
- Mention the following information: "PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: https://eprovide.mapi-trust.org and www.pedsql.org/index.html "
- Submit the screenshots of all the Pages where the Questionnaire appears to Dr James W. Varni before release for approval and to check that the above-mentioned requirements have been respected.

In the case of use of an electronic version of the Questionnaire in commercial studies / projects, the User undertakes to respect the following special obligations:

User shall:

- In case of use of an IT Company (e-vendor), User shall check with Mapi Research Trust that IT Company has signed the necessary License Agreement with Mapi Research Trust before developing the electronic version of the Questionnaire
- Not modify the questionnaire (items and response scales, including the response scale numbers from 0-4)
- Cite the reference publications
- Insert the Owner's copyright notice on all pages/screens on which the Questionnaire will be presented and insert the Trademark information: **PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved.**
- Mention the following information: "PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: https://eprovide.mapi-trust.org and www.pedsql.org/index.html"

- For the first migration of the Questionnaire (generally the original version) into a specific electronic device



- Review of screenshots:

After implementation of the Questionnaire into the device, the user/IT Company will generate screen captures (screenshots) of the original questionnaire as displayed in the device. These will be reviewed by Mapi to check that they are consistent with the original paper version in terms of presentation, content and completion except for specific instructions related to the electronic administration. Corrections that may be needed will be reported to the user/IT Company. In this case, screenshots after correction will be generated for another round of review by Mapi until all screenshots are approved.

Dr James W. Varni will review all approved screenshots for a final validation.

- Usability testing:

Usability testing is a methodology which aims to examine whether respondents are able to use a device and associated software as intended. Major issues of concern in usability testing typically include device complexity, navigation and response selection for example.

The objective of this investigation is to ensure that the electronic version of the questionnaire as included in the device meets usability criteria, focusing on functional aspects and respondents' understanding of instructions. Usability testing consists in interviews with patients where patients will complete the electronic version of the Questionnaire on the device and comment on their understanding of the instructions, ease of use and handiness of the device. A Usability testing report presenting results will be produced. If any changes are recommended, these will be implemented by the user/IT Company. If issues raised by respondents are rated as major, the user/IT Company may need to perform additional developments and another round of interviews may be needed.

Dr James W. Varni will review the changes suggested, if any, following the interviews.

The review of screenshots is mandatory. The usability testing is highly recommended by Mapi, however should the User and/or IT Company decide not to perform this step, Mapi Research Trust shall not be held responsible for any consequence and expense associated with this decision which shall remain the User and/or IT Company's sole liability.

The review of screenshots and usability testing, when and if performed, shall be performed exclusively by Mapi and shall be sponsored by the User.

The performance of the review of screenshots and usability testing will result in a certification of the electronic device original version of the Questionnaires by Mapi for future licenses.

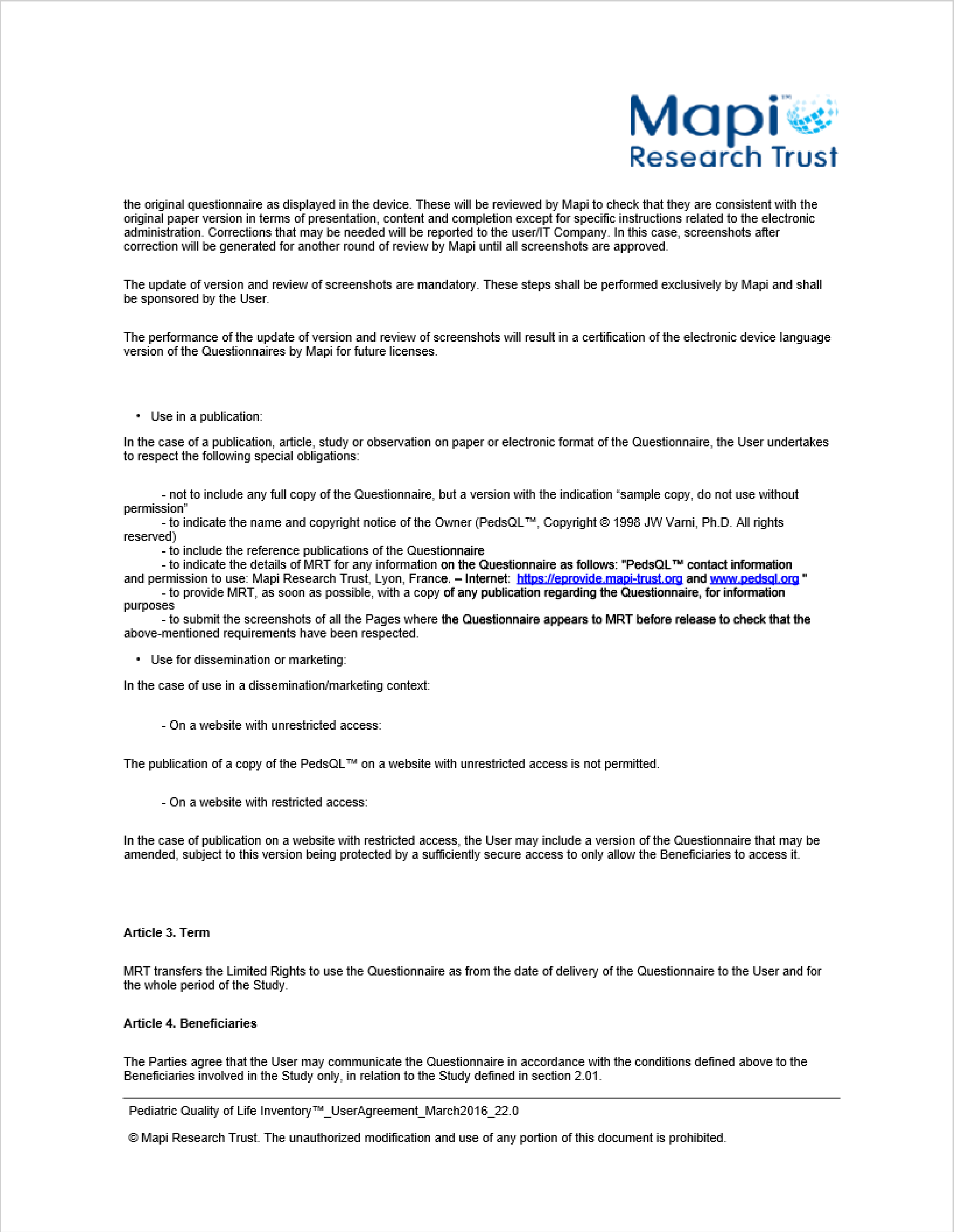
- For the migration of other language versions of the Questionnaire on an existing certified specific electronic device
  - Update version

After the electronic device original version of the Questionnaire is fully ready, the Questionnaire's language versions developed for paper administration will be updated to reflect the changes in wording of instructions implemented in the electronic device original version of the questionnaire.

Native speakers of the languages will reflect the changes made to the electronic device original version of the Questionnaire and will provide English equivalents of all changes made for Mapi's quality control.

- Review of screenshots:

After implementation of the Questionnaire into the device, the user/IT Company will generate screen captures (screenshots) of



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the original questionnaire as displayed in the device. These will be reviewed by Mapi to check that they are consistent with the original paper version in terms of presentation, content and completion except for specific instructions related to the electronic administration. Corrections that may be needed will be reported to the user/IT Company. In this case, screenshots after correction will be generated for another round of review by Mapi until all screenshots are approved.

The update of version and review of screenshots are mandatory. These steps shall be performed exclusively by Mapi and shall be sponsored by the User.

The performance of the update of version and review of screenshots will result in a certification of the electronic device language version of the Questionnaires by Mapi for future licenses.

- Use in a publication:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a version with the indication "sample copy, do not use without permission"
- to indicate the name and copyright notice of the Owner (PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved)
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information **on the Questionnaire as follows: "PedsQL™ contact information** and permission to use: Mapi Research Trust, Lyon, France. **– Internet:** https://eprovide.mapi-trust.org **and** www.pedsql.org **"**
- to provide MRT, as soon as possible, with a copy **of any publication regarding the Questionnaire, for information** purposes
- to submit the screenshots of all the Pages where **the Questionnaire appears to MRT before release to check that the** above-mentioned requirements have been respected.

- Use for dissemination or marketing:

In the case of use in a dissemination/marketing context:

- On a website with unrestricted access:

The publication of a copy of the PedsQL™ on a website with unrestricted access is not permitted.

- On a website with restricted access:

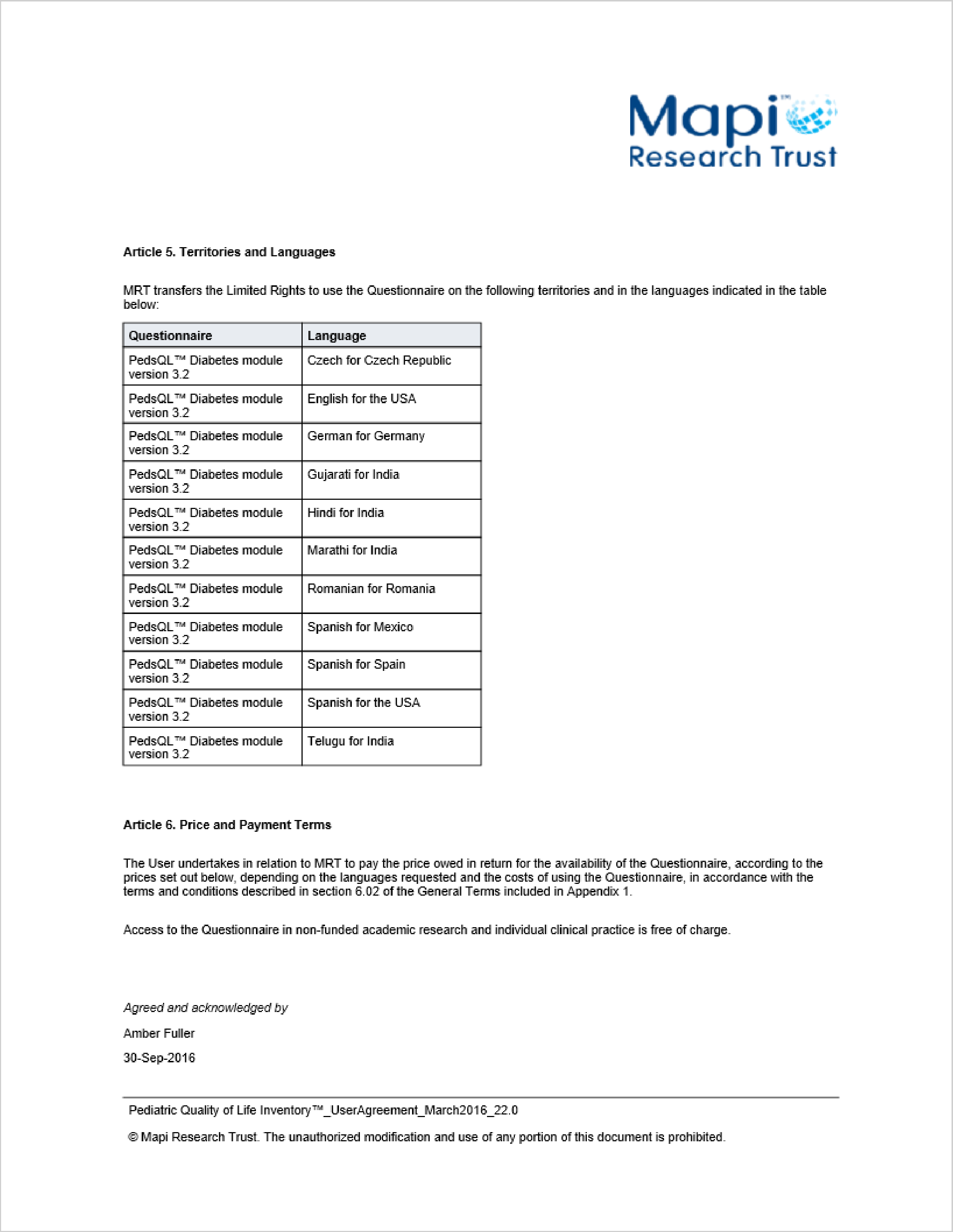
In the case of publication on a website with restricted access, the User may include a version of the Questionnaire that may be amended, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it.

Article 3. Term

MRT transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Article 4. Beneficiaries

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.



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Article 5. Territories and Languages

MRT transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Questionnaire	Language
PedsQL™ Diabetes module version 3.2	Czech for Czech Republic
PedsQL™ Diabetes module version 3.2	English for the USA
PedsQL™ Diabetes module version 3.2	German for Germany
PedsQL™ Diabetes module version 3.2	Gujarati for India
PedsQL™ Diabetes module version 3.2	Hindi for India
PedsQL™ Diabetes module version 3.2	Marathi for India
PedsQL™ Diabetes module version 3.2	Romanian for Romania
PedsQL™ Diabetes module version 3.2	Spanish for Mexico
PedsQL™ Diabetes module version 3.2	Spanish for Spain
PedsQL™ Diabetes module version 3.2	Spanish for the USA
PedsQL™ Diabetes module version 3.2	Telugu for India

Article 6. Price and Payment Terms

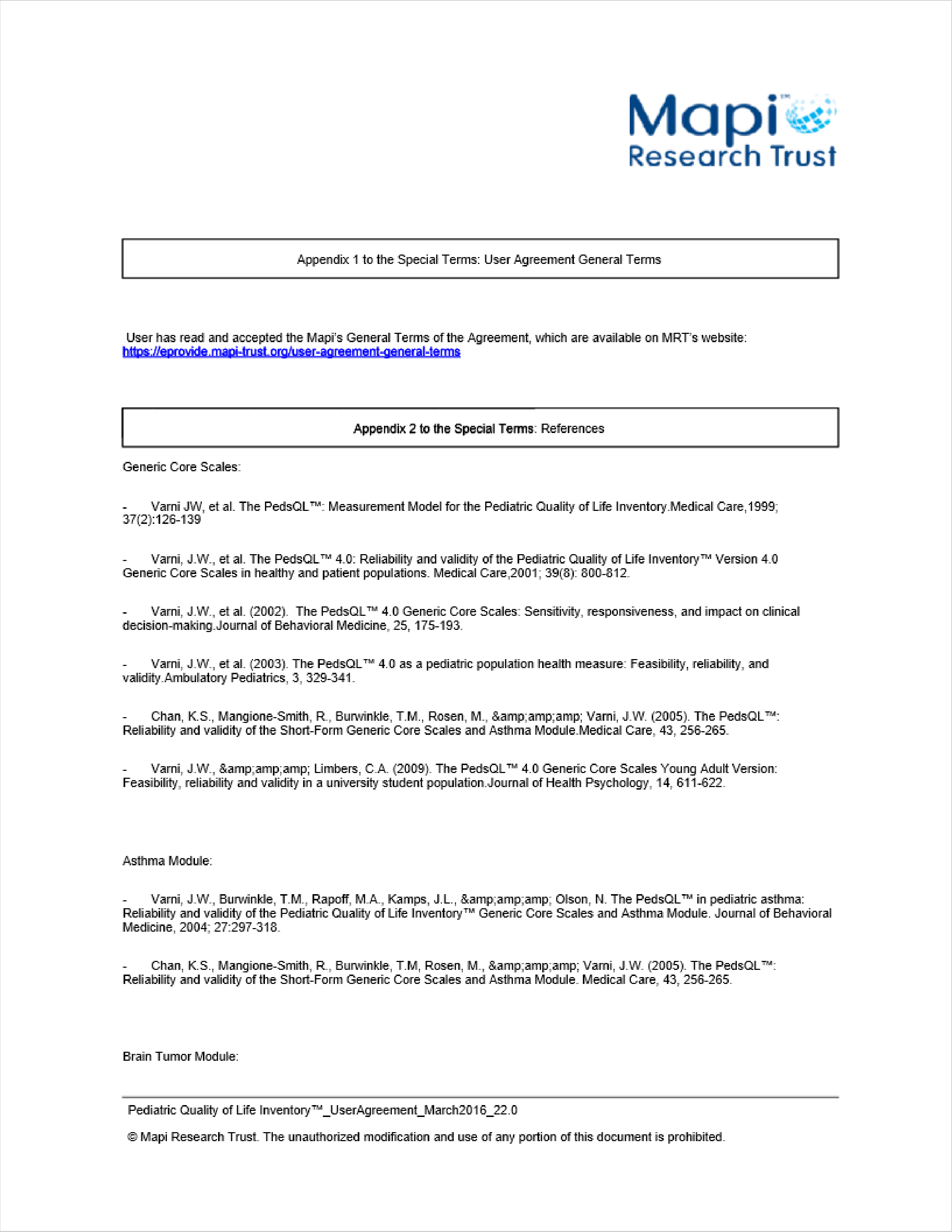
The User undertakes in relation to MRT to pay the price owed in return for the availability of the Questionnaire, according to the prices set out below, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

Access to the Questionnaire in non-funded academic research and individual clinical practice is free of charge.

Agreed and acknowledged by

Amber Fuller

30-Sep-2016



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Appendix 1 to the Special Terms: User Agreement General Terms

User has read and accepted the Mapi's General Terms of the Agreement, which are available on MRT's website: https://eprovide.mapi-trust.org/user-agreement-general-terms

Appendix 2 to the Special Terms: References

Generic Core Scales:

- Varni JW, et al. The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory.Medical Care,1999; 37(2):126-139

- Varni, J.W., et al. The PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations. Medical Care,2001; 39(8): 800-812.

- Varni, J.W., et al. (2002). The PedsQL™ 4.0 Generic Core Scales: Sensitivity, responsiveness, and impact on clinical decision-making.Journal of Behavioral Medicine, 25, 175-193.

- Varni, J.W., et al. (2003). The PedsQL™ 4.0 as a pediatric population health measure: Feasibility, reliability, and validity.Ambulatory Pediatrics, 3, 329-341.

- Chan, K.S., Mangione-Smith, R., Burwinkle, T.M., Rosen, M., &amp;amp; Varni, J.W. (2005). The PedsQL™: Reliability and validity of the Short-Form Generic Core Scales and Asthma Module.Medical Care, 43, 256-265.

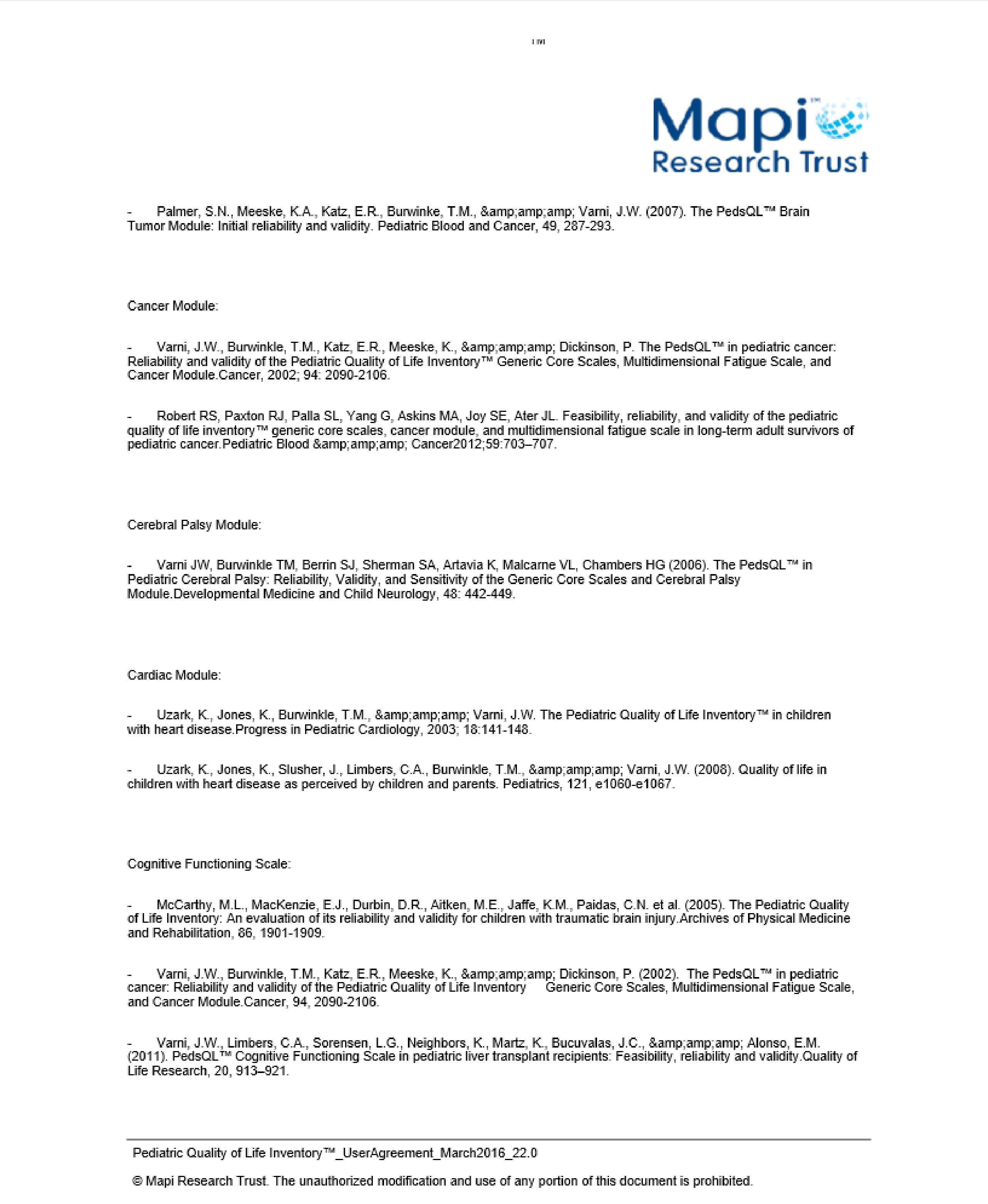
- Varni, J.W., &amp;amp; Limbers, C.A. (2009). The PedsQL™ 4.0 Generic Core Scales Young Adult Version: Feasibility, reliability and validity in a university student population.Journal of Health Psychology, 14, 611-622.

Asthma Module:

- Varni, J.W., Burwinkle, T.M., Rapoff, M.A., Kamps, J.L., &amp;amp; Olson, N. The PedsQL™ in pediatric asthma: Reliability and validity of the Pediatric Quality of Life Inventory™ Generic Core Scales and Asthma Module. Journal of Behavioral Medicine, 2004; 27:297-318.

- Chan, K.S., Mangione-Smith, R., Burwinkle, T.M, Rosen, M., &amp;amp; Varni, J.W. (2005). The PedsQL™: Reliability and validity of the Short-Form Generic Core Scales and Asthma Module. Medical Care, 43, 256-265.

Brain Tumor Module:



- Palmer, S.N., Meeske, K.A., Katz, E.R., Burwinke, T.M., &amp;amp; Varni, J.W. (2007). The PedsQL™ Brain Tumor Module: Initial reliability and validity. Pediatric Blood and Cancer, 49, 287-293.

Cancer Module:

- Varni, J.W., Burwinkle, T.M., Katz, E.R., Meeske, K., &amp;amp; Dickinson, P. The PedsQL™ in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory™ Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module.Cancer, 2002; 94: 2090-2106.

- Robert RS, Paxton RJ, Palla SL, Yang G, Askins MA, Joy SE, Ater JL. Feasibility, reliability, and validity of the pediatric quality of life inventory™ generic core scales, cancer module, and multidimensional fatigue scale in long-term adult survivors of pediatric cancer.Pediatric Blood &amp;amp; Cancer2012;59:703–707.

Cerebral Palsy Module:

- Varni JW, Burwinkle TM, Berrin SJ, Sherman SA, Artavia K, Malcarne VL, Chambers HG (2006). The PedsQL™ in Pediatric Cerebral Palsy: Reliability, Validity, and Sensitivity of the Generic Core Scales and Cerebral Palsy Module.Developmental Medicine and Child Neurology, 48: 442-449.

Cardiac Module:

- Uzark, K., Jones, K., Burwinkle, T.M., &amp;amp; Varni, J.W. The Pediatric Quality of Life Inventory™ in children with heart disease.Progress in Pediatric Cardiology, 2003; 18:141-148.

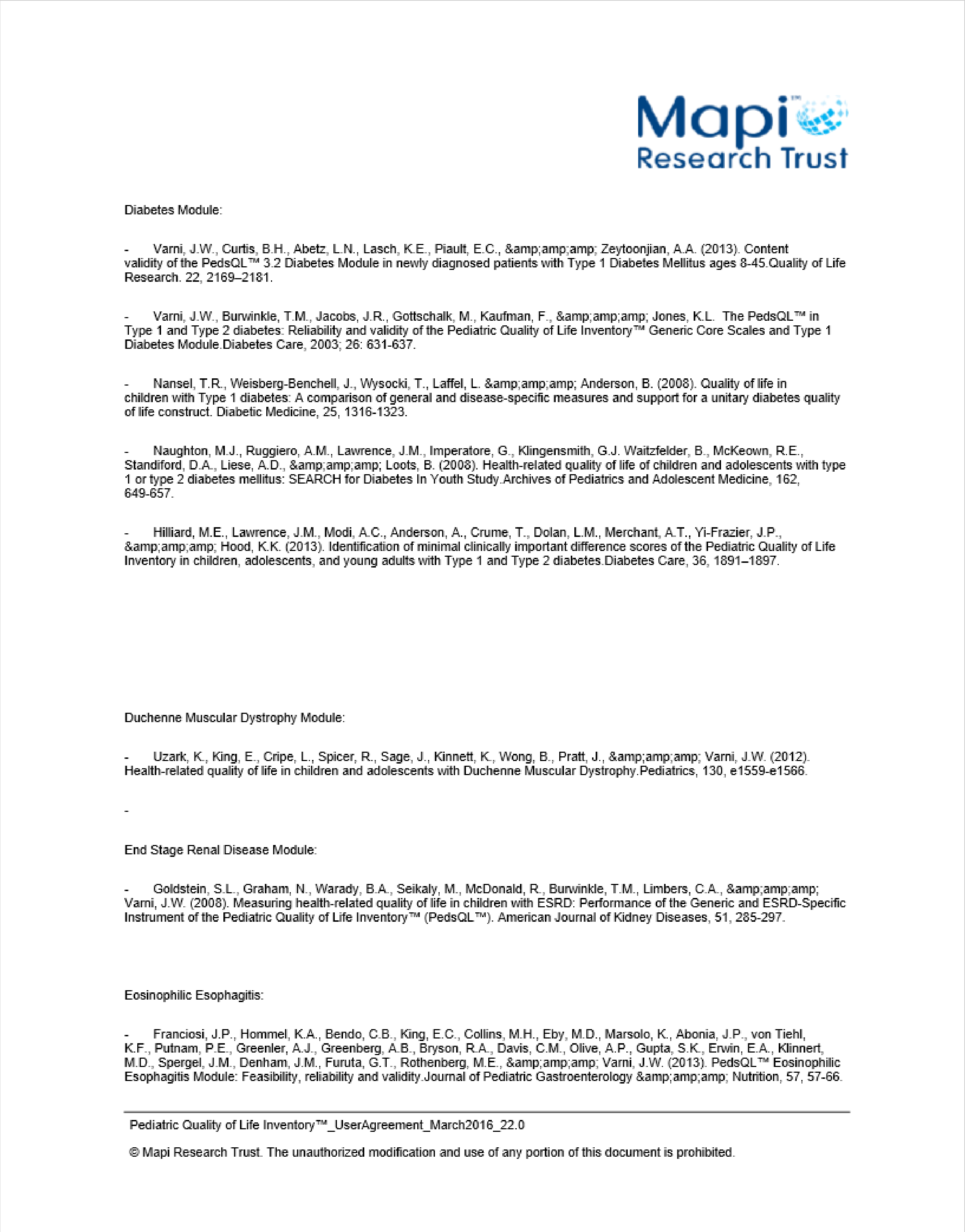
- Uzark, K., Jones, K., Slusher, J., Limbers, C.A., Burwinkle, T.M., &amp;amp; Varni, J.W. (2008). Quality of life in children with heart disease as perceived by children and parents. Pediatrics, 121, e1060-e1067.

Cognitive Functioning Scale:

- McCarthy, M.L., MacKenzie, E.J., Durbin, D.R., Aitken, M.E., Jaffe, K.M., Paidas, C.N. et al. (2005). The Pediatric Quality of Life Inventory: An evaluation of its reliability and validity for children with traumatic brain injury.Archives of Physical Medicine and Rehabilitation, 86, 1901-1909.

- Varni, J.W., Burwinkle, T.M., Katz, E.R., Meeske, K., &amp;amp; Dickinson, P. (2002). The PedsQL™ in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module.Cancer, 94, 2090-2106.

- Varni, J.W., Limbers, C.A., Sorensen, L.G., Neighbors, K., Martz, K., Bucuvalas, J.C., &amp;amp; Alonso, E.M. (2011). PedsQL™ Cognitive Functioning Scale in pediatric liver transplant recipients: Feasibility, reliability and validity.Quality of Life Research, 20, 913–921.



Diabetes Module:

- Varni, J.W., Curtis, B.H., Abetz, L.N., Lasch, K.E., Piault, E.C., &amp;amp; Zeytoonjian, A.A. (2013). Content validity of the PedsQL™ 3.2 Diabetes Module in newly diagnosed patients with Type 1 Diabetes Mellitus ages 8-45.Quality of Life Research. 22, 2169–2181.

- Varni, J.W., Burwinkle, T.M., Jacobs, J.R., Gottschalk, M., Kaufman, F., &amp;amp; Jones, K.L. The PedsQL™ in Type 1 and Type 2 diabetes: Reliability and validity of the Pediatric Quality of Life Inventory™ Generic Core Scales and Type 1 Diabetes Module.Diabetes Care, 2003; 26: 631-637.

- Nansel, T.R., Weisberg-Benchell, J., Wysocki, T., Laffel, L. &amp;amp; Anderson, B. (2008). Quality of life in children with Type 1 diabetes: A comparison of general and disease-specific measures and support for a unitary diabetes quality of life construct. Diabetic Medicine, 25, 1316-1323.

- Naughton, M.J., Ruggiero, A.M., Lawrence, J.M., Imperatore, G., Klingensmith, G.J. Waitzfelder, B., McKeown, R.E., Standiford, D.A., Liese, A.D., &amp;amp; Loots, B. (2008). Health-related quality of life of children and adolescents with type 1 or type 2 diabetes mellitus: SEARCH for Diabetes In Youth Study.Archives of Pediatrics and Adolescent Medicine, 162, 649-657.

- Hilliard, M.E., Lawrence, J.M., Modi, A.C., Anderson, A., Crume, T., Dolan, L.M., Merchant, A.T., Yi-Frazier, J.P., &amp;amp; Hood, K.K. (2013). Identification of minimal clinically important difference scores of the Pediatric Quality of Life Inventory in children, adolescents, and young adults with Type 1 and Type 2 diabetes.Diabetes Care, 36, 1891–1897.

Duchenne Muscular Dystrophy Module:

- Uzark, K., King, E., Cripe, L., Spicer, R., Sage, J., Kinnett, K., Wong, B., Pratt, J., &amp;amp; Varni, J.W. (2012). Health-related quality of life in children and adolescents with Duchenne Muscular Dystrophy.Pediatrics, 130, e1559-e1566.

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End Stage Renal Disease Module:

- Goldstein, S.L., Graham, N., Warady, B.A., Seikaly, M., McDonald, R., Burwinkle, T.M., Limbers, C.A., &amp;amp; Varni, J.W. (2008). Measuring health-related quality of life in children with ESRD: Performance of the Generic and ESRD-Specific Instrument of the Pediatric Quality of Life Inventory™ (PedsQL™). American Journal of Kidney Diseases, 51, 285-297.

Eosinophilic Esophagitis:

- Franciosi, J.P., Hommel, K.A., Bendo, C.B., King, E.C., Collins, M.H., Eby, M.D., Marsolo, K., Abonia, J.P., von Tiehl, K.F., Putnam, P.E., Greenler, A.J., Greenberg, A.B., Bryson, R.A., Davis, C.M., Olive, A.P., Gupta, S.K., Erwin, E.A., Klinnert, M.D., Spergel, J.M., Denham, J.M., Furuta, G.T., Rothenberg, M.E., &amp;amp; Varni, J.W. (2013). PedsQL™ Eosinophilic Esophagitis Module: Feasibility, reliability and validity.Journal of Pediatric Gastroenterology &amp;amp; Nutrition, 57, 57-66.

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Family impact Module:

- Varni, J.W., Sherman, S.A., Burwinkle, T.M., Dickinson, P.E., &amp;amp; Dixon, P. (2004). The PedsQL™ Family Impact Module: Preliminary reliability and validity. Health and Quality of Life Outcomes; 2 (55), 1-6.

- Medrano, G.R., Berlin, K.S., &amp;amp; Davies, W.H. (2013). Utility of the PedsQL™ Family Impact Module: Assessing the psychometric properties in a community sample.Quality of Life Research. 22, 2899-2907.

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- Mano, K.E., Khan, K.A., Ladwig, R.J., &amp;amp; Weisman, S.J. (2011). The impact of pediatric chronic pain on parents' health-related quality of life and family functioning: Reliability and validity of the PedsQL 4.0 Family Impact Module.Journal of Pediatric Psychology, 36, 517-527.

Gastrointestinal Symptoms Module:

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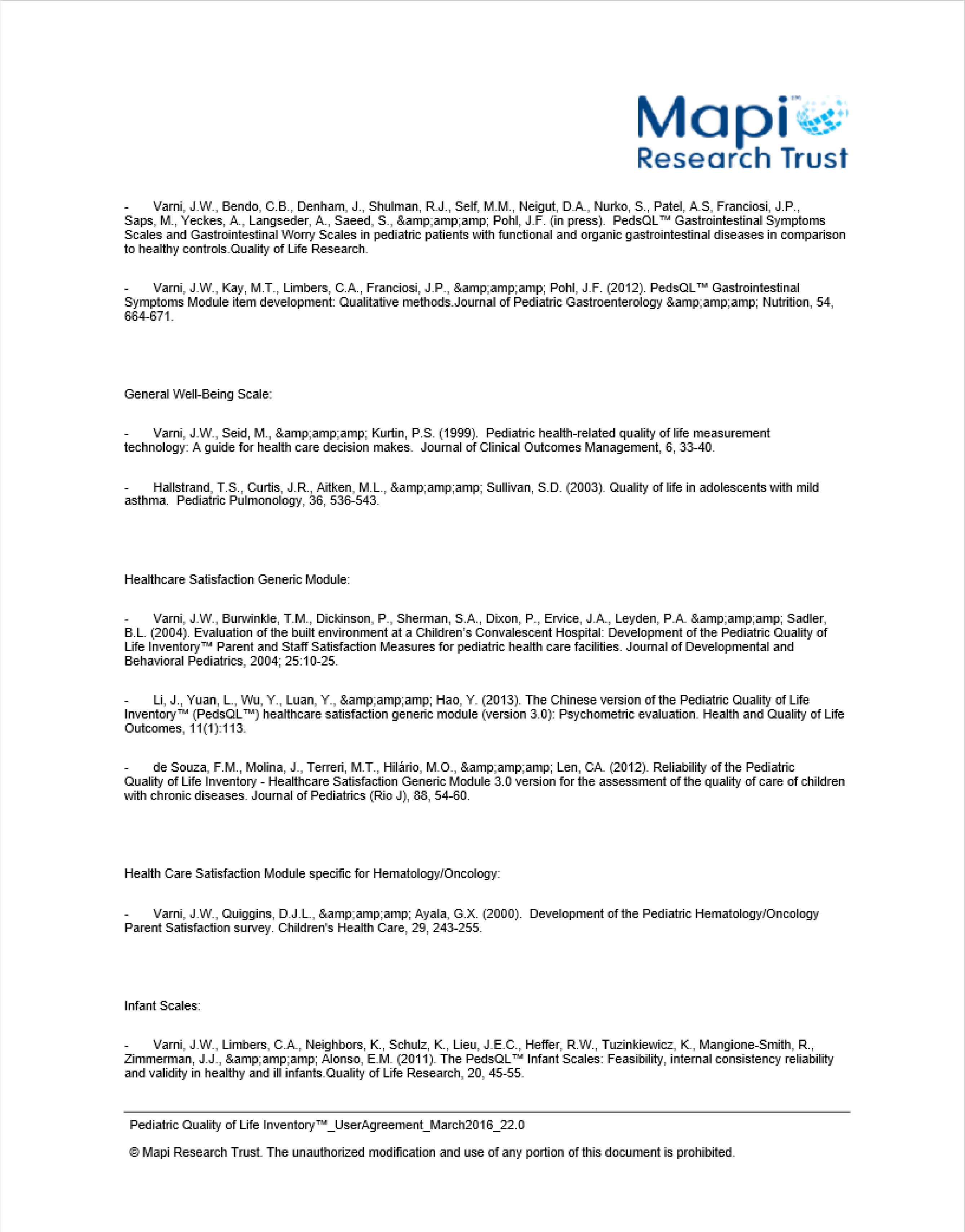
Gastrointestinal Symptoms Scales:

- Varni, J.W., Bendo, C.B., Denham, J., Shulman, R.J., Self, M.M., Neigut, D.A., Nurko S., Patel, A.S, Franciosi, J.P., Saps, M., Verga, B., Smith, A., Yeckes, A., Heinz, N., Langseder, A., Saeed, S., Zacur, G.M., &amp;amp; Pohl, J.F. (2014). PedsQL™ Gastrointestinal Symptoms Module: Feasibility, reliability, and validity. Journal of Pediatric Gastroenterology &amp;amp; Nutrition,59, 347–355.



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- Varni, J.W., Bendo, C.B., Denham, J., Shulman, R.J., Self, M.M., Neigut, D.A., Nurko, S., Patel, A.S, Franciosi, J.P., Saps, M., Yeckes, A., Langseder, A., Saeed, S., &amp;amp; Pohl, J.F. (in press). PedsQL™ Gastrointestinal Symptoms Scales and Gastrointestinal Worry Scales in pediatric patients with functional and organic gastrointestinal diseases in comparison to healthy controls.Quality of Life Research.

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General Well-Being Scale:

- Varni, J.W., Seid, M., &amp;amp; Kurtin, P.S. (1999). Pediatric health-related quality of life measurement technology: A guide for health care decision makes. Journal of Clinical Outcomes Management, 6, 33-40.

- Hallstrand, T.S., Curtis, J.R., Aitken, M.L., &amp;amp; Sullivan, S.D. (2003). Quality of life in adolescents with mild asthma. Pediatric Pulmonology, 36, 536-543.

Healthcare Satisfaction Generic Module:

- Varni, J.W., Burwinkle, T.M., Dickinson, P., Sherman, S.A., Dixon, P., Ervice, J.A., Leyden, P.A. &amp;amp; Sadler, B.L. (2004). Evaluation of the built environment at a Children's Convalescent Hospital: Development of the Pediatric Quality of Life Inventory™ Parent and Staff Satisfaction Measures for pediatric health care facilities. Journal of Developmental and Behavioral Pediatrics, 2004; 25:10-25.

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- de Souza, F.M., Molina, J., Terreri, M.T., Hilário, M.O., &amp;amp; Len, CA. (2012). Reliability of the Pediatric Quality of Life Inventory - Healthcare Satisfaction Generic Module 3.0 version for the assessment of the quality of care of children with chronic diseases. Journal of Pediatrics (Rio J), 88, 54-60.

Health Care Satisfaction Module specific for Hematology/Oncology:

- Varni, J.W., Quiggins, D.J.L., &amp;amp; Ayala, G.X. (2000). Development of the Pediatric Hematology/Oncology Parent Satisfaction survey. Children's Health Care, 29, 243-255.

Infant Scales:

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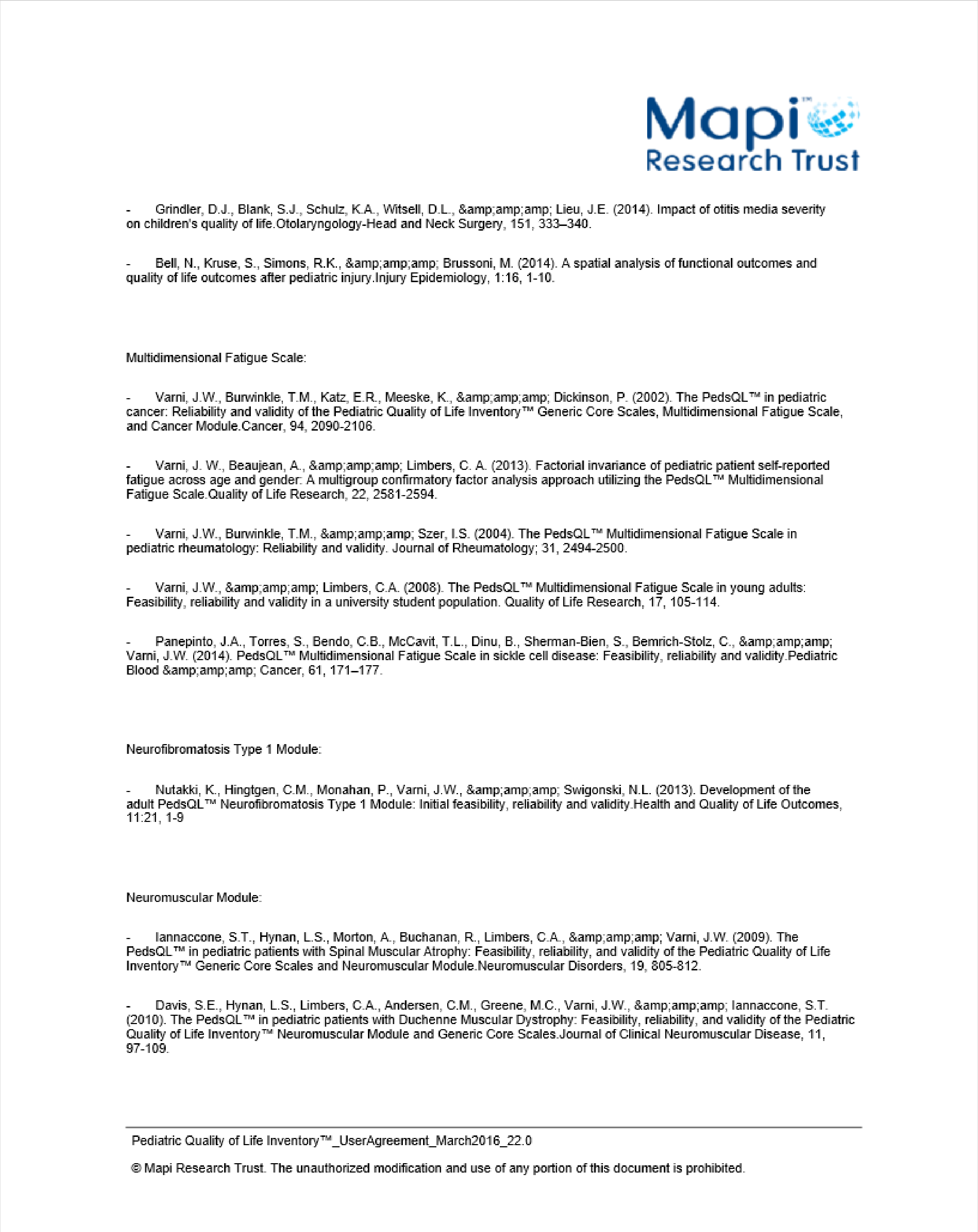

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- Bell, N., Kruse, S., Simons, R.K., &amp;amp; Brussoni, M. (2014). A spatial analysis of functional outcomes and quality of life outcomes after pediatric injury.Injury Epidemiology, 1:16, 1-10.

Multidimensional Fatigue Scale:

- Varni, J.W., Burwinkle, T.M., Katz, E.R., Meeske, K., &amp;amp; Dickinson, P. (2002). The PedsQL™ in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory™ Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module.Cancer, 94, 2090-2106.

- Varni, J. W., Beaujean, A., &amp;amp; Limbers, C. A. (2013). Factorial invariance of pediatric patient self-reported fatigue across age and gender: A multigroup confirmatory factor analysis approach utilizing the PedsQL™ Multidimensional Fatigue Scale.Quality of Life Research, 22, 2581-2594.

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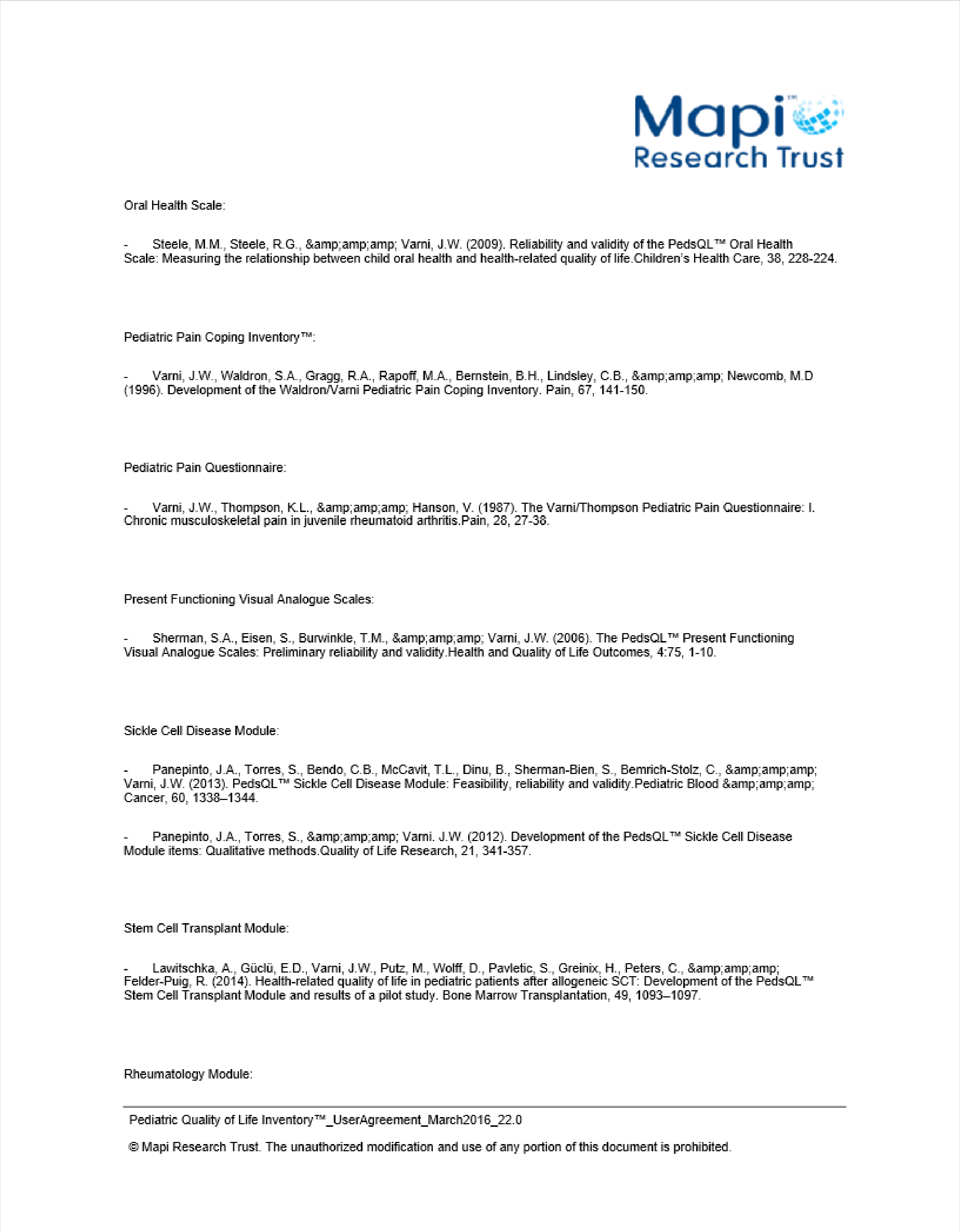
Neurofibromatosis Type 1 Module:

- Nutakki, K., Hingtgen, C.M., Monahan, P., Varni, J.W., &amp;amp; Swigonski, N.L. (2013). Development of the adult PedsQL™ Neurofibromatosis Type 1 Module: Initial feasibility, reliability and validity.Health and Quality of Life Outcomes, 11:21, 1-9

Neuromuscular Module:

- Iannaccone, S.T., Hynan, L.S., Morton, A., Buchanan, R., Limbers, C.A., &amp;amp; Varni, J.W. (2009). The PedsQL™ in pediatric patients with Spinal Muscular Atrophy: Feasibility, reliability, and validity of the Pediatric Quality of Life Inventory™ Generic Core Scales and Neuromuscular Module.Neuromuscular Disorders, 19, 805-812.

- Davis, S.E., Hynan, L.S., Limbers, C.A., Andersen, C.M., Greene, M.C., Varni, J.W., &amp;amp; Iannaccone, S.T. (2010). The PedsQL™ in pediatric patients with Duchenne Muscular Dystrophy: Feasibility, reliability, and validity of the Pediatric Quality of Life Inventory™ Neuromuscular Module and Generic Core Scales.Journal of Clinical Neuromuscular Disease, 11, 97-109.



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Oral Health Scale:

- Steele, M.M., Steele, R.G., &amp;amp; Varni, J.W. (2009). Reliability and validity of the PedsQL™ Oral Health Scale: Measuring the relationship between child oral health and health-related quality of life.Children's Health Care, 38, 228-224.

Pediatric Pain Coping Inventory™:

- Varni, J.W., Waldron, S.A., Gragg, R.A., Rapoff, M.A., Bernstein, B.H., Lindsley, C.B., &amp;amp; Newcomb, M.D (1996). Development of the Waldron/Varni Pediatric Pain Coping Inventory. Pain, 67, 141-150.

Pediatric Pain Questionnaire:

- Varni, J.W., Thompson, K.L., &amp;amp; Hanson, V. (1987). The Varni/Thompson Pediatric Pain Questionnaire: I. Chronic musculoskeletal pain in juvenile rheumatoid arthritis.Pain, 28, 27-38.

Present Functioning Visual Analogue Scales:

- Sherman, S.A., Eisen, S., Burwinkle, T.M., &amp;amp; Varni, J.W. (2006). The PedsQL™ Present Functioning Visual Analogue Scales: Preliminary reliability and validity.Health and Quality of Life Outcomes, 4:75, 1-10.

Sickle Cell Disease Module:

- Panepinto, J.A., Torres, S., Bendo, C.B., McCavit, T.L., Dinu, B., Sherman-Bien, S., Bemrich-Stolz, C., &amp;amp; Varni, J.W. (2013). PedsQL™ Sickle Cell Disease Module: Feasibility, reliability and validity.Pediatric Blood &amp;amp; Cancer, 60, 1338–1344.

- Panepinto, J.A., Torres, S., &amp;amp; Varni. J.W. (2012). Development of the PedsQL™ Sickle Cell Disease Module items: Qualitative methods.Quality of Life Research, 21, 341-357.

Stem Cell Transplant Module:

- Lawitschka, A., Güclü, E.D., Varni, J.W., Putz, M., Wolff, D., Pavletic, S., Greinix, H., Peters, C., &amp;amp; Felder-Puig, R. (2014). Health-related quality of life in pediatric patients after allogeneic SCT: Development of the PedsQL™ Stem Cell Transplant Module and results of a pilot study. Bone Marrow Transplantation, 49, 1093–1097.

Rheumatology Module:

Appendix E: Teaching Points

Outline for Edcational Sessions

- Session 1: January 2017

  Education/Discussion:

  1. What are some of the challenges that adolescents face?
  2. How does T1D effect these?
  3. What can we do to overcome the challenges or make T1D management easier during this time?

- Session 2: February 2017

  Education:

  1. Tips/Tricks for T1D management
  2. Provide an open forum for participants to share their ideas and ask questions

- Session 3: March 2017

  Education

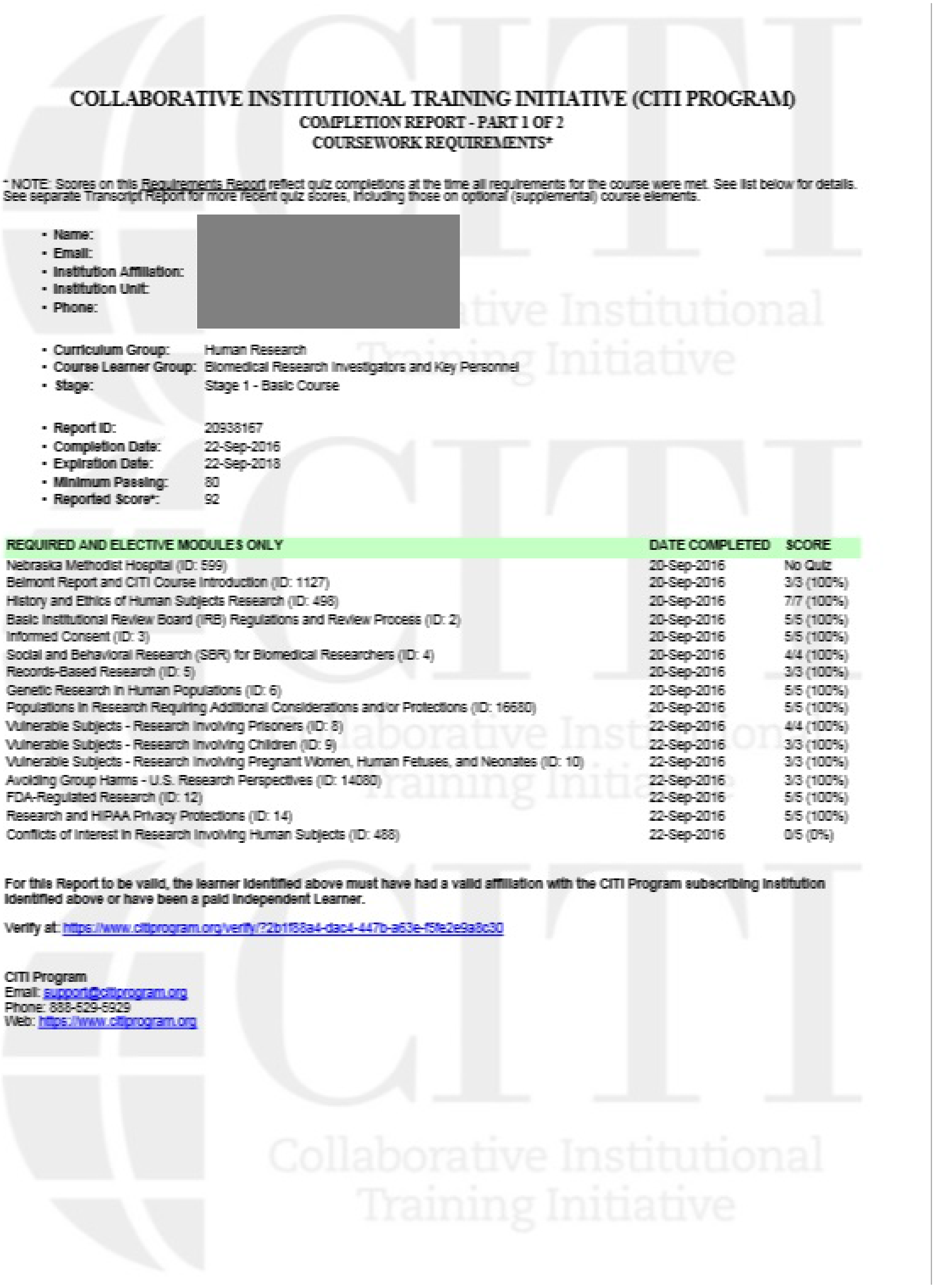
  1. Going Off to College
  2. Do’s and Don’ts of Self-Management, transition from parents to self-care

- Session 4: April 2017

  Education:

  1. Opportunity to ask questions or discuss fears or challenges (panel of T1D experts: Endocrinologist health providers and Certified Diabetic Educators)
     a. Can ask questions during discussion
     b. Can write questions on a card and place in a box to ask then anonymously

Appendix F: CITI Training Certificate



COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 1 OF 2

COURSEWORK REQUIREMENTS*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- **Name:**
- **Email:**
- **Institution Affiliation:**
- **Institution Unit:**
- **Phone:**

[redacted]

- **Curriculum Group:** Human Research
- **Course Learner Group:** Biomedical Research Investigators and Key Personnel
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 20938167
- **Completion Date:** 22-Sep-2016
- **Expiration Date:** 22-Sep-2018
- **Minimum Passing:** 80
- **Reported Score*:** 92

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Nebraska Methodist Hospital (ID: 599)	20-Sep-2016	No Quiz
Belmont Report and CITI Course Introduction (ID: 1127)	20-Sep-2016	3/3 (100%)
History and Ethics of Human Subjects Research (ID: 498)	20-Sep-2016	7/7 (100%)
Basic Institutional Review Board (IRB) Regulations and Review Process (ID: 2)	20-Sep-2016	5/5 (100%)
Informed Consent (ID: 3)	20-Sep-2016	5/5 (100%)
Social and Behavioral Research (SBR) for Biomedical Researchers (ID: 4)	20-Sep-2016	4/4 (100%)
Records-Based Research (ID: 5)	20-Sep-2016	3/3 (100%)
Genetic Research in Human Populations (ID: 6)	20-Sep-2016	5/5 (100%)
Populations in Research Requiring Additional Considerations and/or Protections (ID: 16680)	20-Sep-2016	5/5 (100%)
Vulnerable Subjects - Research Involving Prisoners (ID: 8)	22-Sep-2016	4/4 (100%)
Vulnerable Subjects - Research Involving Children (ID: 9)	22-Sep-2016	3/3 (100%)
Vulnerable Subjects - Research Involving Pregnant Women, Human Fetuses, and Neonates (ID: 10)	22-Sep-2016	3/3 (100%)
Avoiding Group Harms - U.S. Research Perspectives (ID: 14080)	22-Sep-2016	3/3 (100%)
FDA-Regulated Research (ID: 12)	22-Sep-2016	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	22-Sep-2016	5/5 (100%)
Conflicts of Interest in Research Involving Human Subjects (ID: 488)	22-Sep-2016	0/5 (0%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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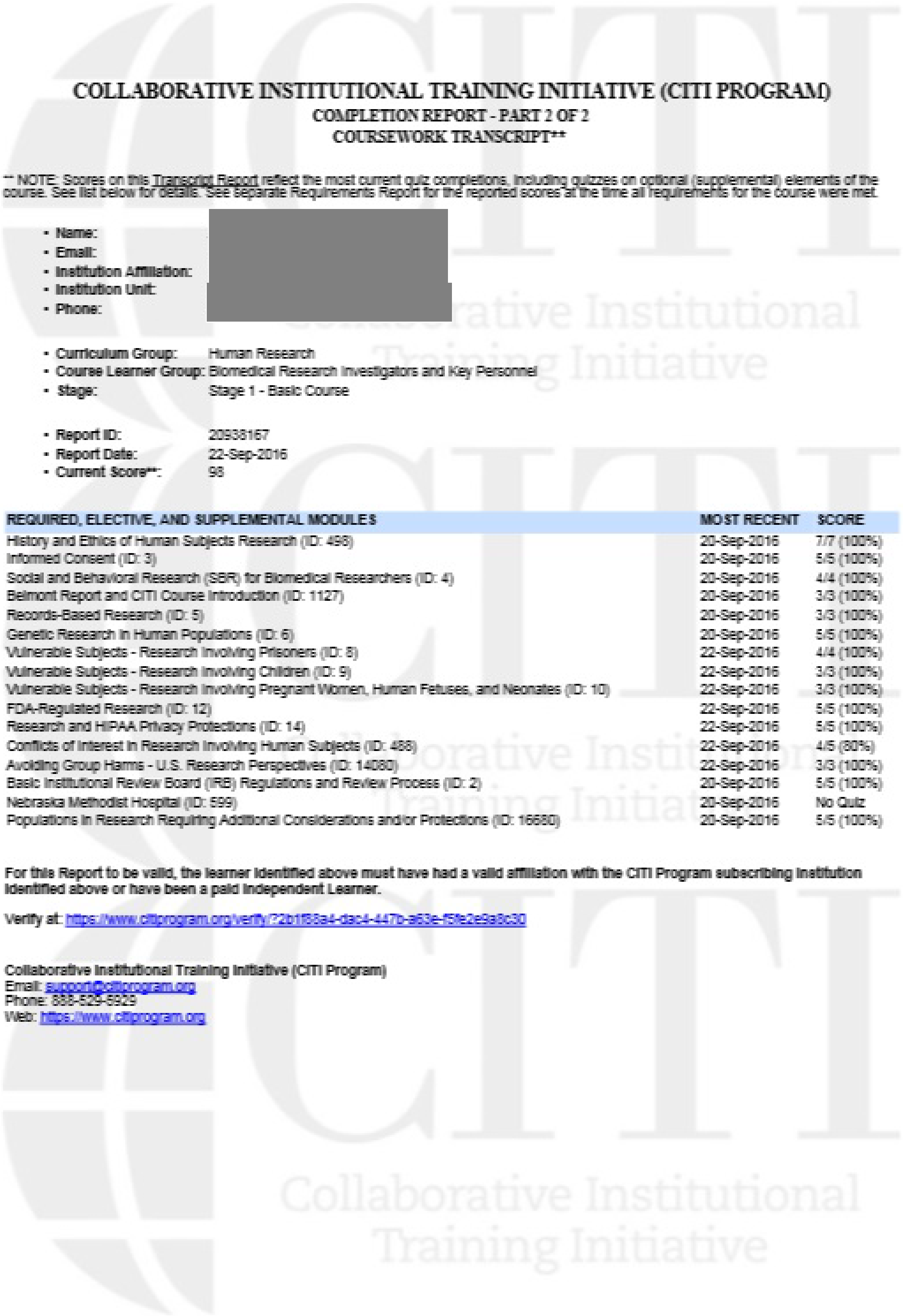

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 2 OF 2
COURSEWORK TRANSCRIPT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** [redacted]
- **Email:**
- **Institution Affiliation:**
- **Institution Unit:**
- **Phone:**

- **Curriculum Group:** Human Research
- **Course Learner Group:** Biomedical Research Investigators and Key Personnel
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 20938167
- **Report Date:** 22-Sep-2016
- **Current Score**:** 98

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
History and Ethics of Human Subjects Research (ID: 498)	20-Sep-2016	7/7 (100%)
Informed Consent (ID: 3)	20-Sep-2016	5/5 (100%)
Social and Behavioral Research (SBR) for Biomedical Researchers (ID: 4)	20-Sep-2016	4/4 (100%)
Belmont Report and CITI Course Introduction (ID: 1127)	20-Sep-2016	3/3 (100%)
Records-Based Research (ID: 5)	20-Sep-2016	3/3 (100%)
Genetic Research in Human Populations (ID: 6)	20-Sep-2016	5/5 (100%)
Vulnerable Subjects - Research Involving Prisoners (ID: 8)	22-Sep-2016	4/4 (100%)
Vulnerable Subjects - Research Involving Children (ID: 9)	22-Sep-2016	3/3 (100%)
Vulnerable Subjects - Research Involving Pregnant Women, Human Fetuses, and Neonates (ID: 10)	22-Sep-2016	3/3 (100%)
FDA-Regulated Research (ID: 12)	22-Sep-2016	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	22-Sep-2016	5/5 (100%)
Conflicts of Interest in Research Involving Human Subjects (ID: 488)	22-Sep-2016	4/5 (80%)
Avoiding Group Harms - U.S. Research Perspectives (ID: 14080)	22-Sep-2016	3/3 (100%)
Basic Institutional Review Board (IRB) Regulations and Review Process (ID: 2)	20-Sep-2016	5/5 (100%)
Nebraska Methodist Hospital (ID: 599)	20-Sep-2016	No Quiz
Populations in Research Requiring Additional Considerations and/or Protections (ID: 16680)	20-Sep-2016	5/5 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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