



Государственная образовательная организация высшего профессионального образования «Донецкий национальный медицинский университет имени М. Горького»

# Перспективы оценки качества жизни институализированных детей

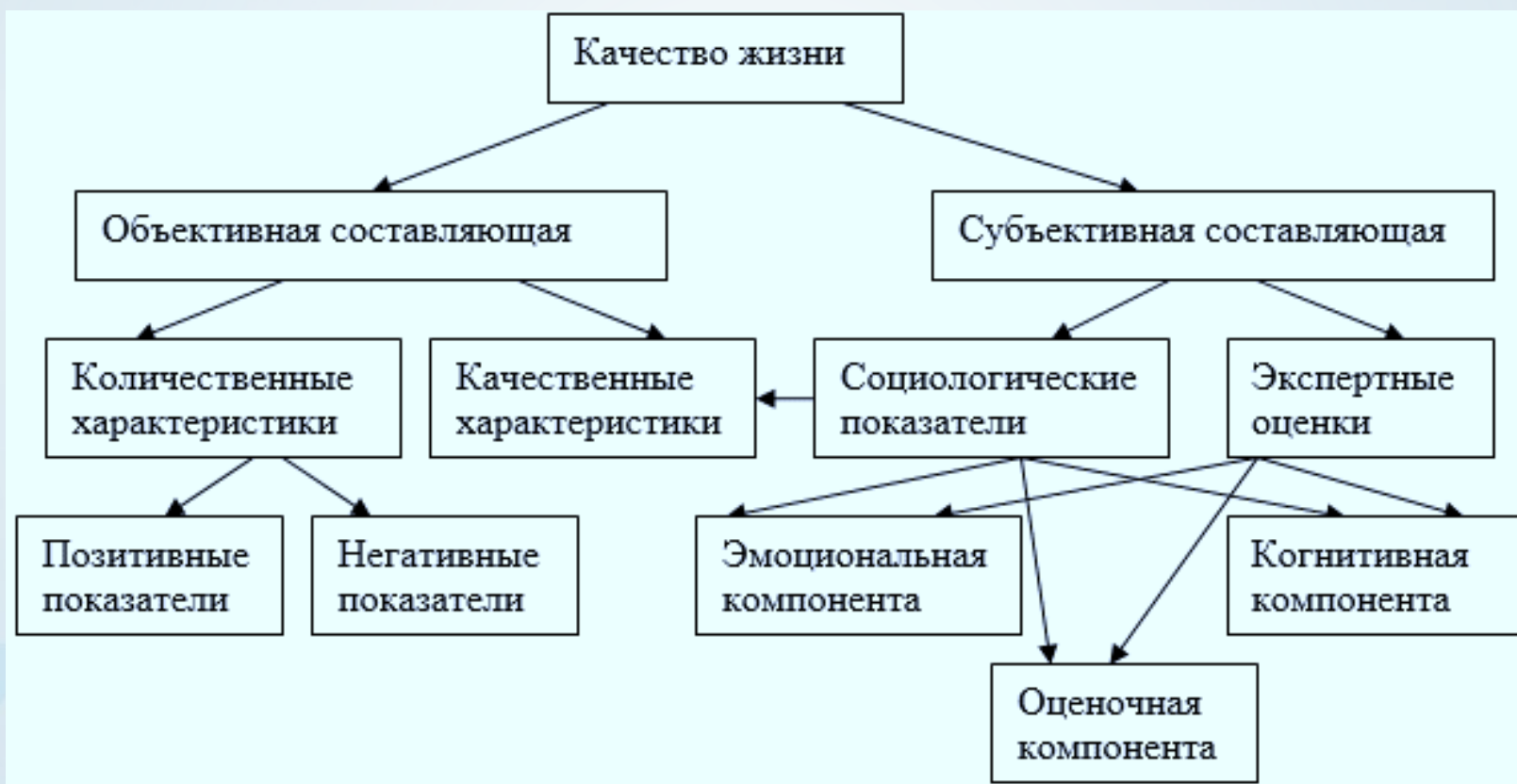
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**Качество жизни** (англ. Quality of Life) – междисциплинарное понятие, включающее эффективность всех сторон жизнедеятельности человека, уровень удовлетворения его потребностей, уровень развития, а также степень обеспечения безопасности жизни.

# Показатель качества жизни является интегральным и отражает степень нарушения жизнедеятельности



В педиатрии существует целый ряд как **общих** (PedsQL, QUALIN, KiddyKINDL и другие), так и **узкоспециализированных опросников**, позволяющих оценивать качество жизни ребенка по различным направлениям (Childhood Asthma Questionnaires, Pediatric Oncology Quality of Life Scale, Diabetes Quality of Life, специальные модули вышеперечисленных **общих опросников** и др.).

# PedsQL™ Sample

## PedsQL™ Pediatric Quality of Life Inventory

Version 2.0  
CROD NUMBER: 0041438

**Instructions:**  
 1. Read the instructions and complete the questionnaire for your child.  
 2. Read the instructions and complete the questionnaire for your child.  
 3. Read the instructions and complete the questionnaire for your child.  
 4. Read the instructions and complete the questionnaire for your child.  
 5. Read the instructions and complete the questionnaire for your child.  
 6. Read the instructions and complete the questionnaire for your child.  
 7. Read the instructions and complete the questionnaire for your child.  
 8. Read the instructions and complete the questionnaire for your child.  
 9. Read the instructions and complete the questionnaire for your child.  
 10. Read the instructions and complete the questionnaire for your child.

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Item	1	2	3	4	5
1. My child has trouble sleeping.					
2. My child has trouble concentrating.					
3. My child has trouble remembering things.					
4. My child has trouble getting along with others.					
5. My child has trouble playing with others.					
6. My child has trouble making friends.					
7. My child has trouble being happy.					
8. My child has trouble being active.					
9. My child has trouble being energetic.					
10. My child has trouble being healthy.					

# Общие опросники

## Quality of Life Questionnaire for Children

Parent/Proxy Questionnaire  
Body ID: 0041438

Dear Parents,

We really appreciate your taking the time to complete this questionnaire about your child's well-being and health-related quality of life.

Since it is a matter of your own assessment of your child's well-being, please complete the questionnaire yourself according to the instructions, i.e. without asking your child.

- Read each question carefully.
- Think about how your child has been feeling during the past week.
- Put a cross in the box corresponding to the answer that fits your child best.

**For example:**

During the past week ...	never	seldom	sometimes	often	all the time
... my child felt like eating ice cream.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

My Child is a: Boy  Girl  Age: \_\_\_\_ Years

Source: Mother  Father  Other \_\_\_\_\_

Date of fill out: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ (day / month / year)

# Узкоспециализированные опросники и специальные модули

Item	English
1.	How often do you feel pain associated with the treatment for your diabetes?
2.	How often are you embarrassed by having to deal with your diabetes in public?
3.	How often do you have low blood sugar?
4.	How often do you feel physically ill?
5.	How often does your diabetes interfere with your far
6.	How often do you have a bad night's sleep?
7.	How often do you find your diabetes limiting your so relationships and friendships?
8.	How often do you feel good about yourself?
9.	How often do you feel restricted by your diet?
10.	How often does your diabetes interfere with your se
11.	How often does your diabetes keep you from driving using a machine (e.g. a typewriter)?
12.	How often does your diabetes interfere with your ex
13.	How often do you miss work, school or household d because of your diabetes?
14.	How often do you find yourself explaining what it me have diabetes?
15.	How often do you find that your diabetes interrupts y leisure-time activities?
16.	How often do you tell others about your diabetes?
17.	How often are you teased because you have diabet
18.	How often do you feel that because of your diabetes to the bathroom more than others?
19.	How often do you find that you eat something you s rather than tell someone that you have diabetes?
20.	How often do you hide from others the fact that you having insulin reactions?

Details of questionnaire items is shown in Table 2.

**Table 2:-** Details of Questionnaire Items for the Quality of Life in Patients with Asthma.

No	Variable
	Health
1.	In the last 4 weeks, how often have you coughed?
2.	In the last 4 weeks, how often were you breathless?
3.	In the last 4 weeks, how often did asthma wake you up in the night/early morning?
	Emotional
	Weeks, how often were you worried about not getting medicine?
	Weeks, how often were you worried and depressed about your disease?
	Weeks, did you feel uncomfortable/unhappy?
	Weeks, how often did asthma disturb your interaction with other?
	Weeks, how often were you disturbed by dust?
	Weeks, how often were you disturbed by cigarette smoke?
	Weeks, how often were you disturbed by air pollution?
	Weeks, how often were you disturbed by the weather (cold/warm)?
	Weeks, how often did asthma disturb your interaction with animals?
	Weeks, how often did asthma disturb your work (office, household, school activity, etc)?
	Weeks, how often did asthma disturb your daily activities (eating, bathing, climbing stairs, etc)?
	Weeks, how often did asthma disturb your sport or heavy physical activities?
	Weeks, how often did asthma disturb your social activities (organizing, visiting friends, social

## Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child)

### Child Report Questionnaire (9-12 years)

The next 3 questions are asking how you feel about using parts of your body, not whether you can use parts of your body

#### How do you feel about ...

	Very Unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
the way you use your arms?	1	2	3	4	5	6	7	8	9
the way you use your legs?	1	2	3	4	5	6	7	8	9
the way you use your hands?	1	2	3	4	5	6	7	8	9

The next 3 questions are asking how you feel about your ability to complete daily activities, not whether you can complete the activities

#### How do you feel about ...

	Very Unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
your ability to dress yourself?	1	2	3	4	5	6	7	8	9
your ability to eat or drink independently?	1	2	3	4	5	6	7	8	9
your ability to use the toilet by yourself?	1	2	3	4	5	6	7	8	9

#### Special Equipment

	Very Unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
the special equipment you have at home? (eg. special seating, standing frames, wheelchairs, walkers) OR <input type="checkbox"/> I do not need any special equipment at home	1	2	3	4	5	6	7	8	9
the special equipment you have at your school? (eg. special seating, standing frames, wheelchairs, walkers) OR <input type="checkbox"/> I do not need any special equipment at my school	1	2	3	4	5	6	7	8	9
the special equipment that is available in the community? (ramps, escalators, wheelchair access) OR <input type="checkbox"/> I do not need any special equipment in the community	1	2	3	4	5	6	7	8	9

#### Pain and bother

The next few questions ask about things that may bother you.

	Not at all bothered	1	2	3	4	5	6	7	8	9	Very bothered
Are you bothered by hospital visits?	1	2	3	4	5	6	7	8	9		
Are you bothered when you miss school for health reasons?	1	2	3	4	5	6	7	8	9		
Are you bothered by being handled by other people?	1	2	3	4	5	6	7	8	9		

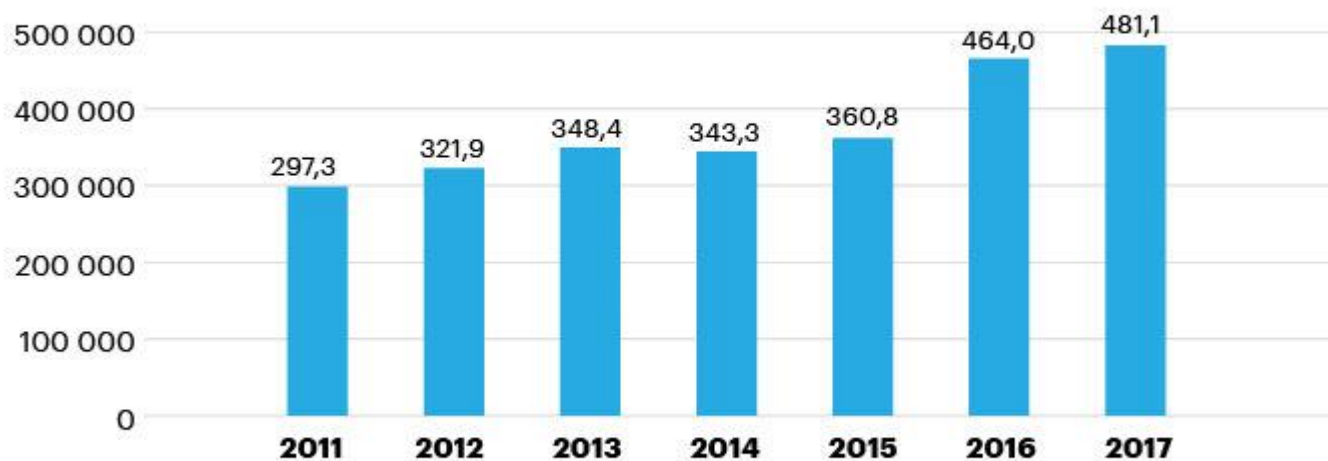
	Never	Rarely	Sometimes	Often	Always
Do you worry about who will take care of you in the future?	1	2	3	4	5

**Институализация** (*лат. institutum – учреждение, то есть помещение ребенка в интернатное учреждение*) **значительно нарушает состояние ребенка.**

**Институализацию в настоящее время рассматривают как хроническую стрессовую реакцию, а состояние ребенка, находящегося в условиях закрытого коллектива – как особый вид депрессии.**

**Согласно оценкам С. Desmond и соавт., по состоянию на 2015 год в учреждениях государственной опеки находились от 3,18 миллионов до 9,42 миллионов детей**

**Численность детей-сирот и детей, оставшихся без попечения родителей, в возрасте до 18 лет**



Информация по данным Росстата

**РАПСИ** Российское агентство правовой и судебной информации



Однако, на сегодняшний день **не существует специализированных опросников, оценивающих качество жизни детей, подвергшихся институционально-депривационному стрессу**

**Нами был проведен анализ применимости двух опросников: формы для родителей детей от 2 до 4 лет общего модуля опросника PedsQL 4.0 Generic Core (автор – James W. Varni), а также KiddyKINDL (для родителей детей от 3 до 6 лет)**

## **Выявлен ряд сложностей:**

- по ряду показателей оценка не возможна в силу объективных причин: в опроснике PedsQL по шкале «Жизнь в детском саду», для KiddyKINDL – по шкалам «Семья» и «Подготовительный класс/детский сад»
- отмечен ряд «парадоксальных» результатов (более высокие показатели по субшкалам, оценивающим физическое состояние).

**Расчитанный коэффициент  $\alpha$  Кронбаха составил:**

- **для PedsQL 4.0 Generic Core = 0,34**
- **для KiddyKINDL = 0,82**

**Изучавшиеся опросники продемонстрировали хорошие показатели чувствительности в субшкалах, касающихся эмоционального состояния**



## **Выводы**

- 1. Из проанализированных опросников лучшими психометрическими характеристиками обладает родительская форма KiddyKINDL (для родителей детей от 3 до 6 лет), применявшаяся, однако, без шкал «Семья» и «Подготовительный класс/детский сад»**
- 2. Требуется научная разработка и валидизация специализированных опросников, оценивающих качество жизни у детей, лишенных материнской опеки**

## **Выводы**

**3. Кроме «традиционных» шкал опросники должны содержать также показатели, страдающие у институализированных детей: качество сна, проявления псевдоаутизма, самостимуляции и т.д.**

**4. Шкала «физическое/телесное самочувствие» должна быть переработана с учетом особенностей двигательного режима воспитанников домов ребенка.**



**Благодарим за внимание!**