

# The design of an engaging focus group discussion toolkit involving school-aged children following urotherapy

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## Abstract

Lower urinary tract (LUT) dysfunctions, such as urinary incontinence, are a common condition among school-aged children (8 to 12 years old) and can negatively affect their quality of life. Urotherapy is the recommended first-line treatment, but patient compliance and motivation are low, resulting in a lower success rate. The traditional products used in urotherapy are often paper-based and outdated. In order to improve the products and services supporting urotherapy, it is important to involve users in the design process. This study describes the preparatory process for conducting focus groups and co-creation sessions with children following a 10-day urotherapy group training in the Wilhelmina Children's Hospital of UMC Utrecht, Netherlands. A literature search was conducted to design a focus group/co-creation toolkit and script tailored to the context of research on urotherapy supporting products with children. The toolkit consists of four key exercises: icebreaker and warm up exercise, collaging exercise, anonymous pen and paper exercise and a storyline character exercise. The goal is to optimize the products supporting urotherapy by defining patient needs and desires based on the current context and patient experiences.

## Author keywords

Qualitative research; Focus group discussion; Co-creation; User Centered Design; Incontinence; Urotherapy: Pediatric patients

## Introduction

Lower urinary tract (LUT) dysfunctions, such as urinary incontinence, are one of the most common conditions in school-aged children (5 – 13 years) (Austin et al., 2016; Anka J Nieuwhof-Leppink et al., 2019). Children with LUT dysfunctions often have low self-esteem and feel ashamed and stressed, which negatively affects the child's quality of life (Bower, 2008; Thibodeau et al., 2013). Urotherapy is the recommended first-line treatment (Chang et al., 2017), which involves re-education and rehabilitation of the bladder and pelvic floor muscles. It combines practice at home with regular follow-up counseling by a trained professional. Unfortunately, patient compliance and motivation for urotherapy are low (Nock et al., 2006), con-

tributing to its lower success rate of 40% – 56% (Schäfer et al., 2018; van Gool et al., 2014; Vijverberg et al., 2011).

We believe the products and services supporting urotherapy play a crucial role in the effectiveness of urotherapy. The traditional urotherapy products are often paper-based solutions (e.g. bladder diaries and bedwetting calendars) and the little technology used (e.g. bedwetting alarms and reminder watches), can be perceived as outdated. In addition, the design methodology behind the existing products primarily focuses on scientific evidence to make sure the design complies with evidence-based guidelines. In contrast, users' needs are not or insufficiently investigated during the design process, resulting in products that do not fulfill users' expectations (Klijn et al., 2006; Ku et al., 2004; Kwinten et al., 2020; Myint et al., 2016; A.J. Nieuwhof-Leppink et al., 2019; van Leuteren et al., 2019). To improve the products and services supporting urotherapy, we want to actively involve users in the design process as being experts of their own domain.

Qualitative research in the form of focus groups and co-creation session appears to be ideal to deliver rich insights on users' needs and expectations (Barbour, 1999). However, conducting focus groups and co-creation sessions with children on one hand, and involving a sensitive topic such as incontinence on the other can be challenging. It will be our task to create a safe and inspiring context in which all participating children feel comfortable to share personal experiences in a creative and playful way. We will describe our preparatory process for conducting focus groups and co-creation sessions with children following urotherapy.

## Methods

A literature search was conducted to create an overview of recommendations and examples for conducting focus group discussions and co-creation sessions with school-aged children. The search was designed as an open exploration, rather than an exhaustive systematic search. It was used to design a focus group/co-creation toolkit and script tailored to the context of research on urotherapy supporting products with children (8 to 12 years old), following a 10-day urotherapy group training in the Wilhelmina Children's Hospital of UMC Utrecht. The purpose of the focus group discussion in the follow-up study



is to optimize the products supporting urotherapy by defining patient needs and desires regarding urotherapy products/tools based on the current context and patient experiences, as well as evaluating and optimizing new concepts to support urotherapy in scope of the identified needs and desires

## Results

Our literature search revealed several key recommendations that we took into account in the design of our focus group/co-creation toolkit and script. Specifically, we found that working in small groups of 4 to 5 children was recommended for children aged 8 to 12 years as it allows for facilitators to encourage interactive discussion while also ensuring that the session is not too noisy and difficult to transcribe (M. Gielen, 2013; Morgan et al., 2002). Gielen further recommends to start easy and let children feel they are not being tested as well as rewarding their participation and show appreciation. In addition, it is recommended to use variety in the exercises to keep participants interested and address a variety of skills, which makes the outcomes more diverse.

In the design of our toolkit and script, we ensured that it was adapted to fit children's cognitive and social-emotional skills. However, according to Hansen (2017), children possess a high degree of open-mindedness, enabling them to see new and creative opportunities beyond the mere function of an object or idea. To tap into this potential, we incorporated creative tasks involving imagination and play in our toolkit, as this was found by Starke (2012) to be a good outlet for children. We aim to use the toolkit to involve children in a playful and interactive way, allowing them to express their thoughts and ideas freely. Our focus group script includes several exercises with breaks in between to maintain the quality of comments and keep the children engaged. This was informed by Morgan et al.'s (2002) finding that the quality of comments began to decrease when the discussions carried on for longer than 45 minutes. To make the most of these breaks, Morgan et al. recommend keeping the cameras and audio recording on to capture any spontaneous or informal interactions that may occur. Finally, to enhance the validity and richness of our findings, we will follow the advice of Gielen (2013) to use informants who know the participants to evaluate the outcomes of the focus group discussions and co-creation sessions. In our case, the urotherapists who work closely with the children during the bladder training will serve as these informants.

The aforementioned use of recordings leads us to ethical considerations and data privacy, which emerged as crucial aspects during the literature review. They are of paramount importance in pediatric research, as children are considered vulnerable subjects (European Medicines Agency, 2016). In general, all studies involving human subjects must be submitted for review by an independent ethics committee (IEC) to ensure compliance with applicable standards and laws, including the Good Clinical Practice standard (European Medicines Agency, 2016) and the General Data Protection Regulation (The European Parliament and the council of the EU, 2016). However, studies involving children require special attention, particularly with regards to obtaining informed consent. The age at which children can legally provide consent to participate in research varies across countries (European Medicines Agency, 2019). In cases where a child is unable to provide legal consent, their assent should be sought, and consent from their parents or legal guardians is mandatory. To

ensure that children can make informed decisions, it is important that the information provided to them about the study is comprehensive and explained in developmentally appropriate language (Heary et al., 2002). Clark (2010) recommends using simplified language and supporting pictures to help children understand the purpose of the study and their role in a focus group interview. Additionally, Heary et al. (2002) suggest explaining the importance of confidentiality in the introduction of the focus group, including how the children's information will be processed. In line with this recommendation, we will explain confidentiality and request verbal consent for the recording at the start of the focus group, in addition to the written consent already obtained. Following transcription of the focus group, we will delete the original recordings and store only the transcriptions with anonymized codes.

In addition to the preceding general recommendations, we used the literature to design specific exercises that form the four key components of our customized focus group/co-creation toolkit and script: (1) icebreaker and warm up exercise, (2) collaging exercise, (3) anonymous pen and paper exercise and (4) a storyline character exercise. These exercises were carefully selected and tailored to the specific objectives of our research on urotherapy supporting products with children. We will present these exercises in detail to provide a comprehensive understanding of how the literature was used to inform the design of our toolkit and script, and how it has been adapted to fit the specific context of our research.

### 1. Icebreaker and warm up exercise

The objective of the icebreaker and warm-up activities is to facilitate group communication, make participants feel relaxed, and establish an environment where sharing and listening are valued (Gibson, 2007). These activities also serve to reinforce the importance of participation and stimulate the minds of the participants (Visser et al., 2005). An example of an icebreaker activity found in the literature (Morgan et al., 2002) is throwing a ball to a group member, who upon catching it, must say their name and a personal fact and then throw the ball to another group member. Another example is a group mind-mapping activity, where associations are made in group to a given theme (M. Gielen, 2013).

In order to tailor these activities to the context of urotherapy, we have modified the traditional icebreaker game of throwing a ball around the group by replacing it with a toilet roll (Fig. 1). The first round of the game involves participants sharing per-



**Figure 1.** Icebreaker and warm up exercise: toilet rolls for personal facts and mind-mapping

sonal facts, such as their name, age, and hobbies, while passing around the toilet roll. In the second round, the research topic is introduced in the form of a group mind-mapping activity. A timer is set, and the researcher starts the game by saying a word related to urotherapy such as urinating, drinking, or bladder training. The child catching the toilet roll must say the first word that comes to mind, associated with the word the researcher said, and then throw the toilet roll to another child. This continues until the timer runs out, and the goal is to come up with as many words as possible before the timer goes off.

## 2. Collaging exercise

The collaging exercise in our toolkit is designed to elicit information about children's experiences and perceptions of urotherapy products and tools within different contexts. The process of creating collages allows children to access and express their experiences in a creative and interactive manner. After creating their collages, children will be asked to present it to the group. As demonstrated in previous research (M. Gielen, 2013; Stappers et al., 2004; Visser et al., 2005) this process facilitates deeper reflection revealing unmet needs and exposing aspirations for the future. Such insights are valuable for designers seeking to create effective solutions. To design our collaging exercise, we followed the guidelines recommended by Visser et al. (2005) which include using a diverse range of images with different contexts, people that reflect diversity in age, gender, and race, and a balance between positive and negative images and between specific and abstract images. Visser et al. also recommend to avoid using over-aesthetic images in one consistent style, but instead use a mix of styles that are open to interpretation. This approach allows for ambiguous images to be interpreted in many different ways, which is useful for helping different participants express their feelings and dreams. Gielen (2013) used a collaging map as a research tool to investigate children's fears. The children were asked to create several collages for different contexts: home, school and other locations. They were asked to make a collage with pictures and words describing their emotions connected to each place. This method allowed Gielen to have an in-depth understanding of the children's fears within different contexts.

The collaging exercise is tailored to the context of urotherapy by providing participants with the materials and instructions to create collage maps describing their experiences and emotions related to four different contexts of urotherapy and pediatric incontinence: home, school, individual doctor appointments, and in-hospital group bladder training (Fig. 2). A mix of specific images such as standard urotherapy prod-

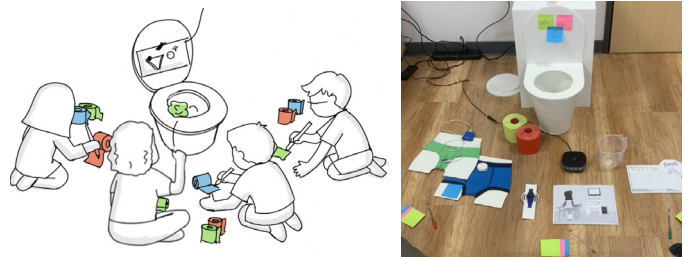


**Figure 2.** Collaging exercise: A3 with four quadrants (home, school, doctor and hospital), mix of black and white images to cut out and box with crayons.

ucts, including bedwetting alarms, paper bladder diaries, and toilet accessories, and abstract images reflecting emotions are used. Furthermore, the images used in the collaging exercise are printed in black and white to allow for ambiguity and diversity. Additionally, crayons are provided to allow the children to add color to the images, which can further enhance their creativity and imagination. The collages created will provide valuable insights into the children's patient pathway and inform the design of future urotherapy products.

## 3. Anonymous pen and paper exercises

The use of pen and paper exercises provides an opportunity for children to reflect on their ideas and experiences without the pressure of an immediate question to answer (Morgan et al., 2002). This can also encourage more introverted children to participate by making the results anonymous (M. A. Gielen, 2008). In a study of children with asthma, Morgan et al. (2002) used this approach, where children were asked to write or draw 'good' and 'bad' things about having asthma, using pens and two large pieces of paper on the floor. The open-ended nature of this exercise was found to be extremely fruitful in elucidating children's values (Morgan et al., 2002).



**Figure 3.** Anonymous pen and paper exercise: cardboard toilet prop, sheets of paper in three different colors for 'good', 'bad' and 'ideas' and representations of the different urotherapy products.

In order to tailor this exercise to the context of urotherapy, we created a cardboard toilet prop (Fig. 3). The children will sit around the cardboard toilet and will be asked to write their thoughts about urotherapy products on three different sheets of paper: one for things they find 'good', one for things they find 'bad', and one for their 'ideas' for these products. The products include standard items such as bedwetting alarms, timer watches, paper bladder diaries, and uroflowmetry toilets, as well as new concepts. The children will complete this task individually and anonymously in the group setting. Afterwards, the research team will be able to link the answers to the individual participants by using a difference in ink color of the pens. Once the children finish writing, they will crumple up the paper and try to throw it into the cardboard toilet. The researcher will then randomly select a piece of paper and read it aloud to the group, starting a group discussion. This exercise is similar to the popular game "black box" and allows for a fun and interactive way for children to share their thoughts and feelings about urotherapy products, while also allowing for anonymity and encouraging participation from more introverted children.

## 4. Storyline character exercise

The use of a storyline character as a tool for children's understanding and interpretation of a research subject can

promote free thinking and imagination, as it allows them to detach from the limitations of their personal context. Gielen (2008) utilized a character creation exercise in a study on children's outdoor play, in which participants were provided with a collection of images of various body parts and asked to create a collage character. This character was then used as the protagonist in subsequent storytelling exercises, as a means of exploring the children's understanding and perceptions of outdoor play (M. A. Gielen, 2008).



**Figure 4.** Storyline character exercise: arts and crafts material to create a superhero with a bladder problem

In order to apply this concept to the context of urotherapy, we will provide children with various arts and crafts materials and ask them to create a fictional character, a 'superhero', who also happens to have a bladder problem (Fig. 4). By analyzing the characteristics and traits of the superhero created by the children, the researchers can gain further insights into the children's perspectives and desires related to urotherapy products. This exercise is implemented at the end of the toolkit to conclude the session on a fun and positive note.

## Discussion

In this paper, we described our preparatory process for conducting focus groups and co-creation sessions with school-aged children on the sensitive topic of incontinence and urotherapy. Our literature search was conducted as an open exploration and is not exhaustive. However, we hope it can

serve as a useful guide and inspiration for others to apply similar approaches in their own research contexts. We emphasized the importance of thoroughly planning and conducting qualitative research in the form of focus group discussions to ensure the most valuable insights are obtained. In our view, this toolkit holds significant relevance as it has the potential to engage children and generate rich insights, in contrast to a traditional conversational question-and-answer method. Additionally, we consider it our obligation to reduce the burden on children during the research process and to ensure that their participation is a pleasant experience, as they are generously contributing their time to our research. Our research process, like our design process, should prioritize the needs and comfort of our participants, particularly in the case of pediatric patients. With this engaging toolkit, we believe that we can improve the overall research outcome, which can be used as input for design, ultimately leading to improved products.

In the next phase, it is essential to conduct pilot tests to identify any potential improvements in the toolkit and script. These evaluations will be incorporated into our subsequent study, where we will implement the toolkit with children who undergo a 10-day urotherapy group training at the Wilhelmina Children's Hospital of UMC Utrecht in the Netherlands.

## Conclusion

In conclusion, a child-friendly and engaging focus group discussion toolkit tailored to the context of urotherapy for school-aged children (8 to 12 years old) suffering from incontinence was developed. The toolkit consists of four key exercises: icebreaker and warm up exercise, collaging exercise, anonymous pen and paper exercise and a storyline character exercise. This toolkit aims to facilitate researchers to gain a deeper understanding of the experiences and needs of pediatric patients in regards to existing and newly proposed urotherapy products. The toolkit was designed with a literature-based foundation and will be evaluated in a pilot study with children following urotherapy. The findings from the pilot study will be used to improve the toolkit and support future research in this area.

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