

The iCAN Study

BEING PART OF SOMETHING BIGGER THAN YOURSELF

THE PERSONAL VALUE OF BEING
AN ICAN MEMBER

The voice of children, youth, parents & leadership



CHILDREN & YOUTH

“Our audience is always the kids first and foremost, that’s who we champion, and that’s who we look out and support, are the kids. We are here for the kids to give them the opportunities to be a part of the community, and to learn, and to create a better pediatric space.”

Amy Ohmer

Vice President and Executive Director of iCAN



METHODS

■ Focus Group Discussions | The Tree of Values

- Participants: children & youth
- Duration: \pm 30 minutes
- Location: iCAN Summit, Kansas City, USA

■ In-depth interviews | Zoom Interviews

- Participants: children, youth, parents & iCAN Leadership
- Duration: \pm 60 minutes
- Online connection between USA & Europe

FINDINGS

*“I am so excited to see where everything falls in the end,
and watch everything (referring to this study).”*

The Voice of an iCAN Member

FINDINGS.

What is the personal value of being
an iCAN member?



1. Mattering



Adding value (making meaningful contributions) and feeling valued (feeling worthy, acknowledged, and appreciated).

2. Coping



Social support, exchanging experiences, learning about own medical condition(s), turning the lived experience into a meaningful tool – as source of expertise - to make a difference.

3. Empowerment



e.g. safe and welcoming environment, skill development (e.g. presenting, advocacy, problem-solving), gaining critical awareness, striving together, collaborating on a more equal level with professionals.

4. Career Development



e.g. learning about various matters related to pediatric Medicine, Innovation and Research (MIR), but also to Science, Technology, Engineering, and Math (STEM), meeting and collaborating with professionals.

5. Community



e.g. mutual support and understanding, a (global) network with multi-diverse friends, shared experiences and values, sense of belonging and social acceptance.

6. Sense of Summit



e.g. inspiration, being part of something big, meeting peers and professionals from different countries, gaining awareness of challenges, trends and developments related to pediatrics, having fun.

INVOLVEMENT & MATTERING

“I want to be part of something that is going to potentially help other people, it could help four thousand or it could help four hundred or it could help forty or it could help four people, and whether it helps one other person or a hundred other people, it still has helped somebody.”

The Voice of an iCAN Member

INVOLVEMENT & MATTERING

“...then afterwards the excitement, the talk about what they (her sons) did, and being able to tell you very detailed ‘this is what we did’, ‘this is how it helped’, ‘this is what they’re going to do’. I think you can just tell from the body language and the words that they use, and the fact they want to talk about it with you afterwards, that they were very excited that they had a say in something, and somebody listened to what they had to say and took it into account, and possibly used it to make something better.”

The Voice of a Parent



Sense of Mattering

Mattering is both adding value (making meaningful contributions) and feeling valued (feeling worthy, acknowledged, and appreciated).

iCAN members expressed their desire to be part of something bigger than themselves and to make a difference – through meaningful contributions - in the lives of children and youth living with a medical condition. In particular iCAN members who are pediatric patients themselves indicated to have experienced various challenges and unpleasant events such as loneliness during hospitalization, not feeling understood, feeling alienated from friends or classmates, managing school make-up work, missing specific types of support, adhering to medical treatments that do not fit well with personal needs, and missing a voice in own health care. By being a voice through iCAN, children and youth expressed having the opportunity to pursue their goal of preventing and improving such circumstances for other pediatric patients in the community or larger society.

In return, and through their collaborations with professionals who heard and used their voice, iCAN members felt valued, worthy and appreciated. The combination of being able to make meaningful contributions and feeling valued gave iCAN members good feelings such as excitement, a sense of fulfillment, self-appreciation and happiness.



INVOLVEMENT & COPING

“I also think that interacting with each other, even just on a personal level, they all may not have the same condition, and may not have been exactly through the same thing, but they've all been through something that I think it really helps them relate to each other, and I think it helps them on a personal or social level. It can help them because they know they are not alone in the struggles they go through. There are other kids out there going through something similar, if not the same.”

iCAN Leadership

INVOLVEMENT & COPING

“...kids that are going through different stuff and still living their full lives, and just working through things similar to how I am, it's just really nice to see other people that are going through similar stuff, and just kind of know what you're going through...”

The Voice of an iCAN Member



The personal stories of iCAN members living with a medical condition, and that of their parents, revealed that involvement in iCAN activities enhanced coping.

Various coping-related benefits were expressed such as learning more about own medical condition(s), problem-solving for other pediatric patients (mattering), talking about personal experiences and challenges with others (and not keep that bubbled up inside), and feeling understood and supported in return. iCAN members valued meeting other children and youth with similar or other conditions, which gave them the feeling of not being alone in their personal struggles, and increased empathy for the self and others. At the same time, being surrounded by peers with various medical conditions helped iCAN members put their own lived experience and health challenges into perspective, during which they realized that others may experience more, or bigger, condition-related challenges compared to their own. This increased their appreciation of what they do have or still can do, and the feeling that they can help and support their fellow iCAN members.

Involvement in iCAN activities also provides iCAN members with the unique opportunity to use their experiences with a medical condition as a meaningful tool – that is, a valuable source of experiential knowledge. This in turn adds a positive meaning to their disease(s) and related experiences., and it helps iCAN members to take control over their medical condition rather than letting their medical condition control them.



INVOLVEMENT & EMPOWERMENT

*‘I feel empowered to share my voice.
If feel like there's nothing that I can say that's right or wrong,
it's just an open way to explain how it feels when you're kid, to be in the hospital,
and explain what it's like from my point of view,
and ways that we can adapt and change the way hospital is right now.’*

The Voice of an iCAN Member

INVOLVEMENT & EMPOWERMENT

*“Were being treated as almost equals with people that have a say and actually affecting things.
It’s almost like an advocacy type of thing where we’re trying to
both learn things ourselves, and express it and spread it.”*

The Voice of an iCAN Member

Empowerment

Being involved through iCAN was found to empower children and youth in various ways. Five examples are given. First, the safe and welcoming environment of iCAN stimulates iCAN members to voice their true opinions, needs, ideas and experiences, which enhanced their belief that their voice matter, is understood and valued, and has a right to be heard. Second, through iCAN, children and youth build skills such as presenting, (self-) advocacy, collaborating, and problem-solving, which increases their self-confidence to apply these skills not only through iCAN, but also in their own health care or other settings such as their school.

Third, especially through the summits, children and youth gain critical awareness of the various issues at hand in the field of pediatrics, the needs of pediatric patients, and the perspectives of various professionals in the field. This helps them understand the context – including values, norms and practices - in which they aim to make a difference. Fourth, collaborating with professionals on a more equal level and being heard increases iCAN members' confidence that they are capable of bringing about change. Fifth, being together with other iCAN members that strive for the same values as their own, makes their conviction stronger as well as their collective sense of empowerment; "they all want to share their voice, they all want to give back and help out."



INVOLVEMENT & CAREER DEVELOPMENT

*‘I’ve been with iCAN for I think about four years.
I joined, because I’m very interested in the healthcare profession and field of medicine.’*

The Voice of an iCAN Member

INVOLVEMENT & CAREER DEVELOPMENT

“Honestly, just anything I can (learn), I am really interested in Science and Math, those are probably my two favorite subjects, so I feel like anything I would enjoy (learning). I think it will also help me choose a career path.”

The Voice of an iCAN Member

Career Development

Career development was frequently expressed to be among the values of child and youth involvement in iCAN activities. Many iCAN members revealed their interest in pursuing a career in the medical field, and of becoming a doctor or nurse. Additionally, Math and Science were often mentioned as favorite school subjects. Being involved through iCAN was therefore considered to be a good opportunity to learn about various matters related to pediatric Medicine, Innovation and Research (MIR), but also to Science, Technology, Engineering, and Math (STEM). At the same time, iCAN members are able to meet with - and talk to - doctors, scientists, researchers or other professionals who are on their desired career path and may function as role models.

iCAN members also expressed their desire to learn more about the challenges in the field of pediatrics and of the needs and experiences of pediatric patients (which includes fellow iCAN members living with a medical condition). Such an increased awareness was considered to be valuable for their future profession. For example, including the voice of patients was something iCAN members planned to do when being professionals themselves. Next to learning about various matters, iCAN members liked the opportunities where they could see sections of the hospital, participate in a lab tour or other field trips, and seeing the latest trends at interactive conferences.



INVOLVEMENT & COMMUNITY

“I really like our iCAN KIDS Chapter, because the kids that are involved all have gone through some form of medical condition, and so they have spent their time in the hospital either now or in the past, and I think it's really nice to be surrounded with kids your age who understand what you're going through, and also have the same....they want to share their voice, they all want to give back and help out. So I think that's really nice, it's like a support group, you make friends and you can find your area where you can explain what it's been like, and the good things and the bad things.”

The Voice of an iCAN Member

INVOLVEMENT & COMMUNITY

“...being exposed and being a part of large groups of diverse people, whether that’s what they dress like or act like or what they have medically going on, or mentally or physically going on. I think you will learn so much in groups that are just build with different kinds of people.”

The Voice of an iCAN Member



Community

Just like the stem of a flower, the trunk of a tree, and the foundation of a house, a sense of community was found to be an important value for long-term child and youth involvement and personal development (incl. mattering, empowerment and coping). Being surrounded with peers who share similar experiences and values was found to strengthen iCAN members' emotional connection, feelings of kinship toward one another as well as their sense of (collective) solidarity with pediatric patients in the community and larger society. The feeling of 'being in this together' increased iCAN members' confidence that they *can* (collectively) strive for the recognition of the (pediatric) youth voice and attain shared goals. iCAN members therefore expressed their desire to recruit more children and youth in order to build a larger community, with more youth voices to strive, and youth ideas to learn and tap from. At the same time, iCAN members valued being part of each other's personal stories, and to contribute to mutual support and understanding within the global iCAN - and local KIDS Chapter - community.

Multi-diversity was found to be a core component; being part of a (large) group of child and youth members with divergent backgrounds (such as their medical, cultural, geographical, and educational background), not only broadened iCAN members' (global) network with multi-diverse friends, it also contributed to their feeling of being accepted and included. Thus, a sense of belonging to a community where being your unique self is welcomed.



INVOLVEMENT & THE SUMMIT

“They check in on each other, they follow each other on Instagram, and comment on each other’s post, they definitely do, and he will say ‘I have friends around the world because of iCAN’”

The Voice of a Parent

INVOLVEMENT & THE SUMMIT

*“...there are kids from all around the world and from different countries,
and different professionals that are there coming in,
it's just really interesting and empowering to see us all unite together..”*

The Voice of an iCAN Member



Sense of Summit

The summit can be regarded as the tip of the mountain; the point that brings everything together, provides an overview ('the whole story in one room'), and unites iCAN members and professionals from various global regions. The yearly summit was found to be an inspiring aspect of child and youth involvement, as it gave iCAN members the feeling of being part of something big; traveling to another place to share, learn and connect. This in turn enhanced their sense of collective empowerment, and the realization that pediatric patients all over the world experience similar kind of challenges as their own.

iCAN members and their parents expressed valuing the opportunity they get through the summit to exchange - and being updated on – (country/region)specific healthcare challenges, personal experiences, learnings, solutions, and trends and developments related to the field of pediatrics or certain medical conditions. In addition, collaborating with professionals and learning about various topics through lectures, dialog, and hands-on activities nurtured iCAN members' early career development. iCAN members also enjoyed the KIDS Chapter poster presentations and assisting the iCAN Leadership with the organization of the summit itself. An essential part of the summit were the social activities, which was expressed to be fun (!) and key in nurturing and building a good summit atmosphere, friendships, and a (global) network of children and youth that can stay in touch through social media.



INVOLVEMENT & TIPS FOR PROFESSIONALS

The Voice of Children, Youth, Parents & Leadership

1.

Timing



Children are engaged as early as possible to make optimal use of their views, opinions and ideas regarding both the purpose and content of the CY(P)E activity.

2.

Meaningful Objective(s)



The CY(P)E activity has a clear – well thought out – objective that children understand, agree with and have interest in. Children understand what the value is of their involvement and of the objective(s) of the activity.

3.

Capability Appropriate



Children are capable to provide the type of input professionals seek.

4.

Mutual Benefits



Both professionals and engaged children benefit from the CY(P)E activity (e.g. being educated, experiencing something new and having fun).

5.

Safe, Welcoming and Valuing



Children feel comfortable to express their true views, opinions and ideas freely, without a fear of being judged. Children feel heard, valued, respected, encouraged, and supported.

6.

Feedback



After the CY(P)E activity, children receive feedback on how - and to what extent - their input was eventually used (or not used), so that they feel acknowledged, valued or taken seriously.

INVOLVEMENT

‘Honestly, if I saw someone on the street and they asked me about it, I would advise them to join some sort of child and youth engagement, because I think it's a really important thing and I think a lot of people could definitely do well from it.’

The Voice of an iCAN Member



THANK YOU!

“I just think that the more someone learns and is exposed to things, they grow [..], and more well-rounded, and educated, and involved, and so I see this (iCAN) being a great place, with a lot of opportunities to do that. I think she'll grow as a person...”

The Voice of a Parent



