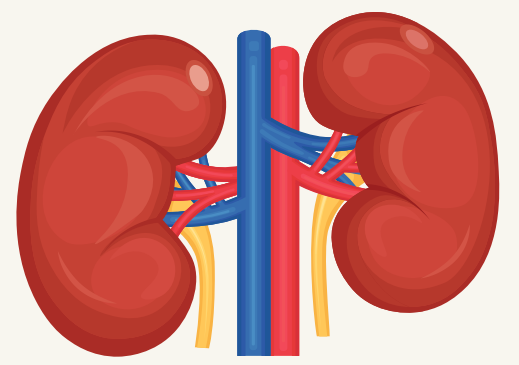


Understanding Motivations for Adolescents with Type 1 Diabetes to Participate in Kidney Research



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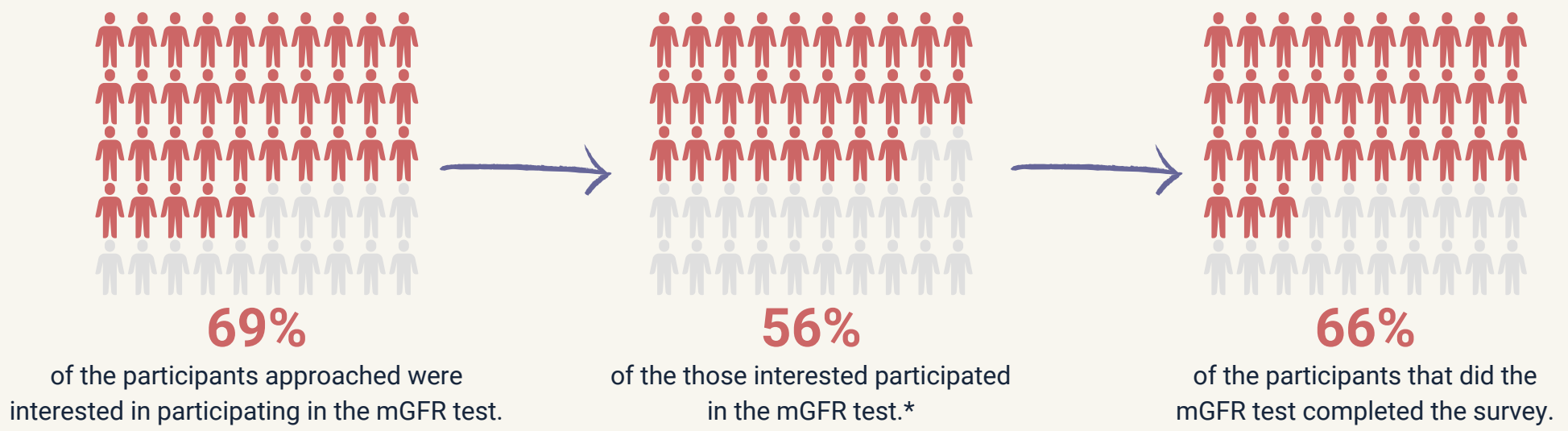
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Our Questions

1. What motivated our participants (adolescents with type 1 diabetes) to consent to participate in a measured glomerular filtration rate (mGFR) test, knowing that the test is long and invasive?
2. What was their participation experience?
3. What would they like to know regarding the results of the study?

Method

- Online survey
- 31 questions and statements regarding their:
 - Study experience.
 - Understanding of why the test was being done and the risks associated
 - Motivations to participate
 - Barriers to participate



*All interested participants could not be booked for the mGFR test due to a scheduling conflict and/ or the COVID-19 outbreak.

Factors Influencing Participation

"I personally benefit because I get health tests done that provide a health update that otherwise would be very hard to get. My heart, eyes and kidneys are being tested regularly which is amazing."

92%
Personal Benefit

"I love my researchers, I absolutely adore them, and I think the work they are doing is incredible. I never want to let them down so I always participate."

86%
Study Team

- "I was curious to see how my kidney's were functioning and how the test was going to be."
- "Interested in the general results of the test."
- "My results and how they could differ from others."

74%
Curiosity

"The monetary compensation motivated me to participate!"

49%
Monetary Compensation

"I wanted to be involved within the study because diabetes is a big factor of my life and if I can help the future of diabetics I would choose to do that everyday."

46%
Altruism

"I would do anything to be at SickKids as often as I can because that hospital feels very safe, and is part of my childhood. Participating in the kidney function test meant I could be there for a whole day!"

9%
Nostalgia

What Do Participants Want to Know?

"Any information that can be provided to me. That is the entire reason I participate in the study is know more about my diabetes."

46%
Personal Results

"I would like to know an overview of how many participants there were, the average results of the kidney tests, the possible impacts, implications, or correlations found between kidney functioning and diabetes that is new or that is more supported through this study."

34%
Overall Results

- "I'd like to know the implications of the study."
- "I would like to know if the study resulted in new medical advances."

26%
Impact of the Study

Participants' Experience

- "It was a very relaxing experience for me, I watched Netflix in bed all day."
- "I was super sleepy and slept most of the time! Overall, 10/10!"

54%
Positive

"The actual test itself was slightly more painful than I had originally thought; one of the IVs hurt more than the other."

31%
Uncomfortable

"The staff and doctors were very friendly, they took their time to explain everything, and I felt at ease through the entire process."

26%
Study Team was Amazing

Lessons Learned

1 Adolescents affected by T1D participated in the mGFR test because doing so benefits themselves and others.

2 Participants enjoy engaging with the study team; their relationship with the study team greatly influences their decision to participate in a study.

3 Participants would like to know their personal results, along with the overall results and the impact of the study.