

EXAMINING THE SELF-DESCRIBED IMPACT OF COVID-19 ON THE LIVES AND INTERACTIONS OF ADULTS WITH PHENYLKETONURIA

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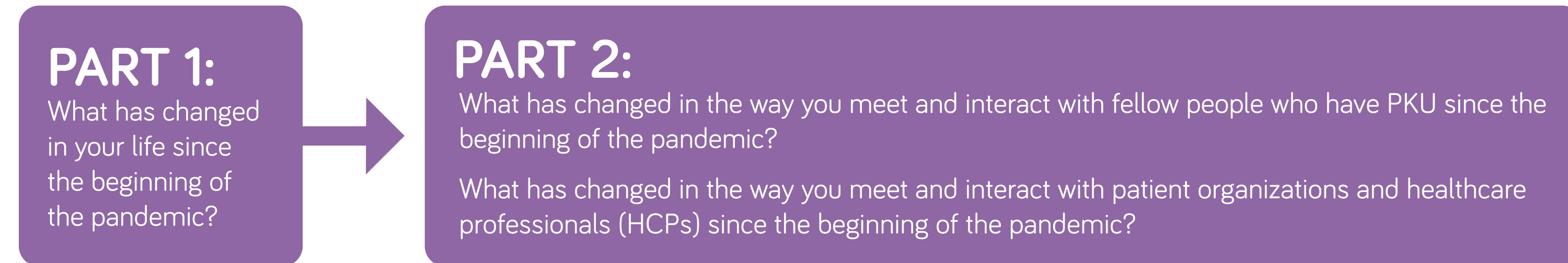


BACKGROUND:

Metabolics Without Borders (MWB) is an online global community of adults with phenylketonuria (PKU) initiated by Danone Specialized Nutrition to help better understand the needs and experiences of this population. The MWB community was surveyed in spring 2021 to understand the changes they experienced during the COVID-19 pandemic.

METHODS:

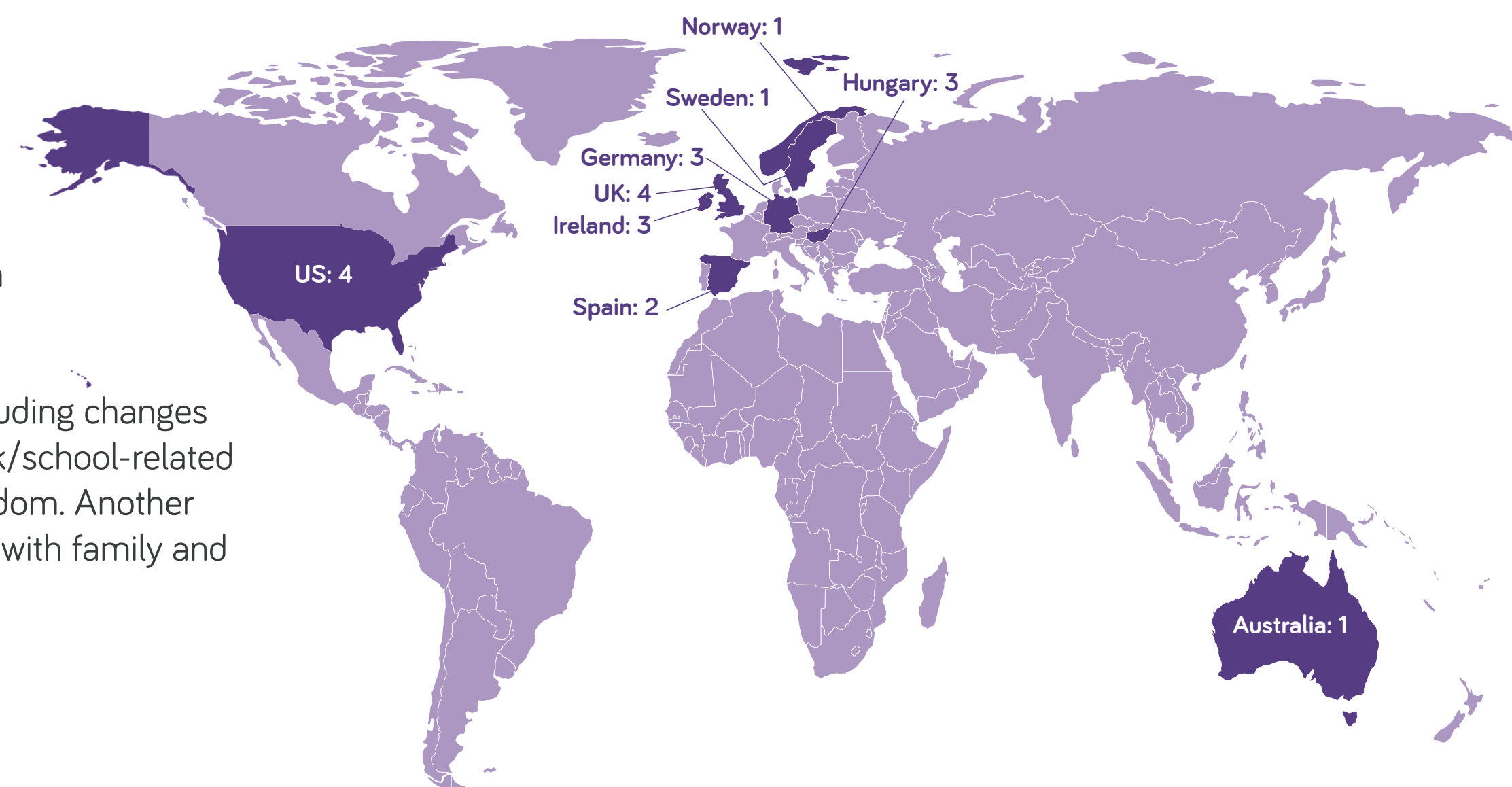
A newsletter was sent to MWB members inviting them to participate in a two-part activity in March/April of 2021. Participants were prompted to post responses on a virtual forum available to other members. The posts were moderated by an Insites Consulting research consultant. Individuals were compensated for their participation. If members posted for Part 1 of the activity, they were invited to post for Part 2. See Part 1 and Part 2 prompts below. The moderator asked follow-up questions of individual participants to clarify responses or obtain more details.



RESULTS:

Twenty-two individuals between the ages of 18-65 years old and from 9 different countries participated in the activity, which yielded 72 participant posts.

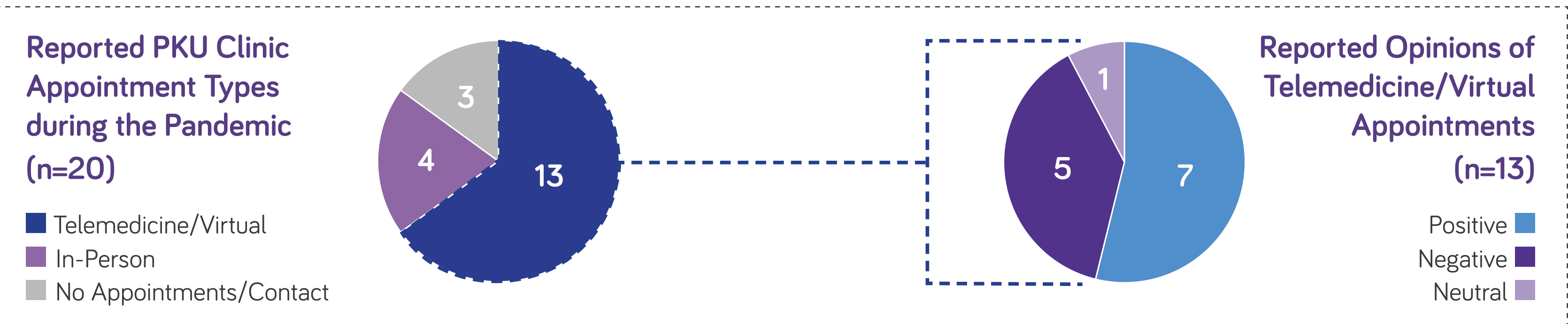
In **Part 1**, numerous themes emerged, including changes to diet and exercise habits; increased work/school-related stress; and increased loneliness and boredom. Another theme was mostly improved connections with family and friends via virtual platforms.



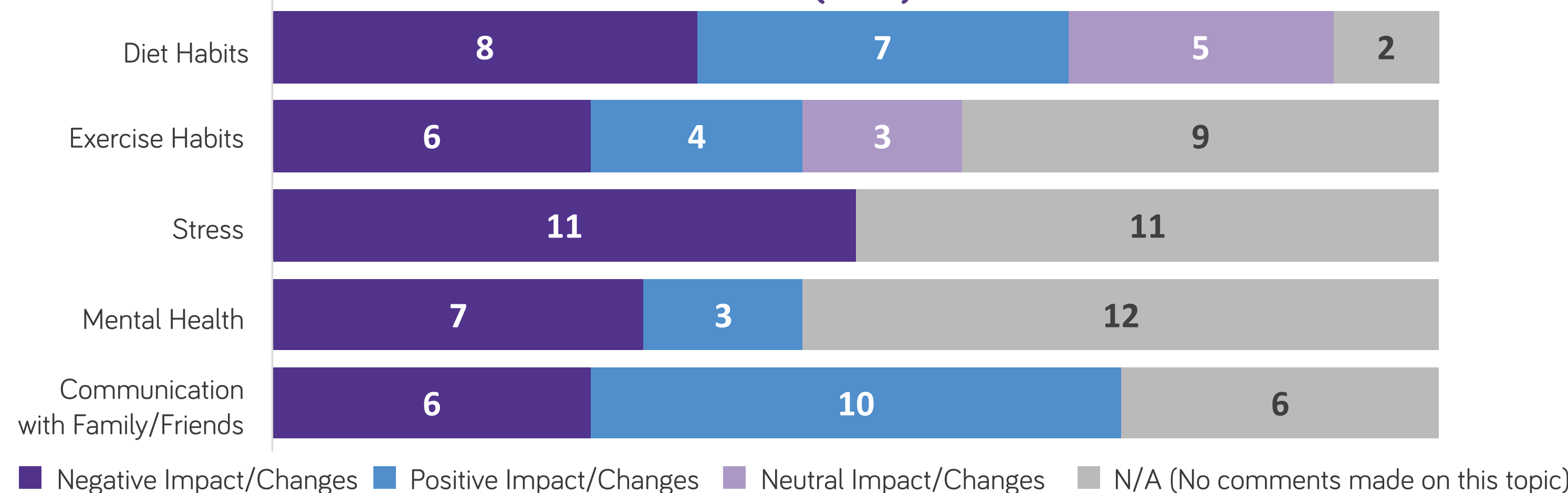
RESULTS (CONTINUED):

Participant Quotes Related to Positive & Negative Changes Experienced During the Pandemic		
	NEGATIVE IMPACT/CHANGES	POSITIVE IMPACT/CHANGES
DIET HABITS	"Lots of emotional eating (not good with PKU). Some days I eat everything in sight, some days I have to force myself to eat."	"During working from home and lockdown, I've been much better able to manage my diet and have seen my levels decrease steadily. Being at home means I can prepare free lunches (with LP bread etc.) and have been able to make our own dinners rather than rely on take-aways. I've also been able to have my PKU drinks as intended (chilled and straight from the fridge) rather than from the cooler bag!"
EXERCISE HABITS	"I'm not able to do as many sports and do not have enough room to exercise indoor, so reliant on gyms reopening."	"Signing up to a workout app and buying weights. This was great! I never have to go back to a gym again."
MENTAL HEALTH	"Anxiety may be too strong of a word, but a general feeling that things aren't 'quite right'... Difficulty concentrating/focusing mentally and remembering. Kind of like a PKU fog but I know my levels are in a good range"	"Improved my coping mechanisms from therapy and allowed myself to be introspective."
COMMUNICATION WITH FAMILY/FRIENDS	"Our social life has also been limited...I feel like a lot of people are also tense because there is no real personal contact. It would be much better if you could already meet your friends in person at last. We are much more limited in online space. You can't hug someone, etc."	"My social life however changed drastically and transformed to a digital level. I've just a few people I'm seeing regularly but the friendships strengthened a lot... I'm now a quite experienced zoom/skype user. It also allowed to catch up with old friends which now live across the country or abroad."

In **Part 2**, participants shared information about their interactions. For those who previously communicated with others who have PKU primarily online, there was little change during the pandemic. For those who previously relied on in-person events, interactions moved to a virtual setting, using social media, group chats, texting, emailing, and online events. HCP interactions became almost entirely virtual. Participants' responses to this shift in HCP interactions were mixed: some stated telemedicine was an improvement over in-person interactions, while others felt it was impersonal.



Participants' Assessment of Life Changes During the Pandemic (n=22)



PARTICIPANT QUOTES RELATED TO TELEMEDICINE/VIRTUAL APPOINTMENTS

NEGATIVE IMPACT/CHANGES	POSITIVE IMPACT/CHANGES
"I had a phone consultation with my metabolic clinic in May last year. I do not like this way because I like to travel up to [city name] and I cannot hear very well on the phone very well...so there was a lot of 'what did you say?' etc, so no I like face to face contact."	"Telemedicine for routine visits is great!! No driving to the clinic, parking hassles, checking in, waiting... Just join the online meeting and go. Obviously, this won't work for some medical conditions where physical care is needed. But for mental health, routine physical health, PKU clinic visits, it is amazing."
"My PKU clinic now is doing virtual visits and my laptop does not like their [video appointment] app for the visits so I have to do the calls on my phone. Because I take [Pegvaliase], I have calls quarterly. I miss going to my clinic and being in person with my team."	"I liked checking in via email for my clinic appointment. It usually takes half a day (or longer) to drive to the appointment in a busy city, find childcare, find parking, pay a couple of hundred dollars for just a few minutes of an appointment, etc... Interacting via email was efficient, affordable, and met my needs."

CONCLUSIONS:

The increased stress and mental health burden caused by the COVID-19 pandemic made many of the components of PKU management more difficult for the surveyed adults with PKU. Digital communication methods were useful for interactions with family, friends, other people with PKU, and HCPs. However, participants still largely found these methods lacking compared to in-person communication.