

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

Dear colleague,

We kindly invite you to participate in an international survey to explore the impact of Covid-19 pandemics on newborn screening programs.

The study's purpose is to **assess the influence of the Covid-19 pandemic on the execution of national newborn screening programs** and assess the probability of more children being left out of the programs and consequently treated at an inappropriate time.

We kindly ask you to complete the **brief questionnaire; it should take you approximately 15 minutes**. The questionnaire contains questions about the Covid-19 pandemic in your country, its influence on the newborn screening program, the number of screened newborns, further diagnostics and referrals, and communication with the parents.

Our aim is to get information about the possible measures that could be planned for newborn screening application, in case of prolonged pandemics or any similar future disasters of such a scale.

Please complete the survey as soon as possible (preferably until the 17th of February). If the survey is outside the scope of your expertise, please recommend or directly send it to the most appropriate professional in your country to complete the survey.

If your country has different screening programs in regions/provinces/autonomous regions please indicate for **which region/province/autonomous region** in your country you are answering on Page 2. If you are answering for the whole country leave that box blank.

Thank you for your participation.

Feel free to contact us through e-mail (urh.groselj.md@gmail.com) if you have any additional questions.

Sincerely,

Urh Grošelj, MD, PhD; Vanesa Koračin, MD and J. Gerard Loeber, PhD
on behalf of authors, with approval from the ISNS.

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

1. Please fill in your contact details:

Name of
participant:

Email address:

Position:

Institution:

Country:

Region/province/a
utonomous
region:

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

2. How much has your country been affected by COVID-19? (Please determine on the scale)

- A great deal
- A lot
- A moderate amount
- A little
- Not at all

Other (please specify)

3. Which wave of COVID-19 was worse in your country?

- First (from January to June)
- Second (from June to December)
- Both equally

Other (please specify)

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

4. How many children does your center screen with the newborn screening program (NBS) per year? (Please write an approximate number)

5. How many diseases are included with the NBS program in your country/region?

- none
- 1-5
- 6-10
- 11-20
- 21-30
- 31 or more

Please specify:

6. How much was NBS impaired in any way during the COVID-19 pandemic? (Please determine it on the scale)

- A great deal
- A lot
- A moderate amount
- A little
- None at all

Other (please specify)

7. Please describe how was the NBS affected by COVID-19 pandemic?

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

8. Have you noticed more troubles in performing the NBS in the first or in the second wave of the COVID-19 pandemic?

- First
- Second
- Both equally
- In neither one of them
- Other (please specify)

9. Did your country have plans/guidelines for performing NBS in pandemics before the COVID-19 pandemic?

- Yes
- No

Please specify:

10. Does your country have at this moment plans/guidelines for performing NBS in pandemics?

- Yes
- No

Please specify:

11. In case of **borderline/positive result how much was the informing of the family and appointing for control visit influenced during the COVID-19 pandemic? (Please determine it on the scale)**

- A great deal
- A lot
- A moderate amount
- A little
- None at all

Other (please specify)

12. How frequently was the referral of positive children/parents to further diagnostics influenced during the COVID-19 pandemic? (Please determine it on the scale)

- Always
- Often
- Sometimes
- Rarely
- Never

Other (please specify):

13. Did you need to substitute face-to-face control visits by using telemedicine during the COVID-19 pandemic? (Please determine it on the scale)

- Always
- Usually
- Sometimes
- Rarely
- Never

Other (please specify)

14. How often were parents reluctant to come to the maternity ward or hospital for retesting / further tests during the COVID-19 pandemic? (Please determine it on the scale)

- Always
- Often
- Sometimes
- Rarely
- Never

Other (please specify)

15. What was the biggest obstacle in conducting NBS normally during the COVID-19 pandemic?

- Lack of staff
- Lack of financial support
- Providing diagnostic equipment
- Establishing communication with the parents
- Hospitals filled with COVID-19 patients

Other (please specify)

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

16. Was there any **diagnostic delay** due to COVID-19 pandemic?

- A great deal
- A moderate amount
- Occasionally
- Rarely
- Not at all

Other (Please specify):

17. The **diagnostic delay** was due to? (You may check more than one answer)

- Laboratory testing delay
- Delayed clinical procedures
- Due to COVID-19 infections in health care/or laboratory workers
- Due to COVID-19 infection or COVID-19 contact in family

Other (please specify)

18. Have you noticed delays in providing laboratory equipment for NBS during the COVID-19 pandemic?

- A great deal
- A moderate amount
- Occasionally
- Rarely
- Not at all

Please specify

19. How much has the lack of laboratory and/or clinical personnel impacted the NBS during the COVID-19 pandemic? (Please determine it on the scale)

- A great deal
- A lot
- A moderate amount
- A little
- Not at all

Other (please specify)

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

20. Could any of the children with diseases screened by NBS in your country have been missed because of the COVID-19 pandemic?

- Definitely
- Probably
- Probably not
- Definitely not

Please specify:

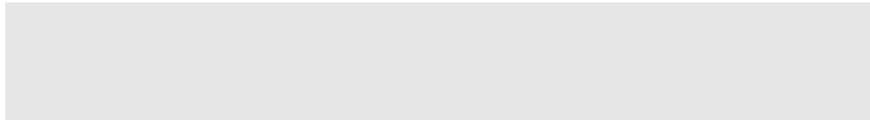
21. Were there cases of metabolic crisis in undiagnosed newborns directly connected to delay in NBS due to the COVID-19 pandemic?

- Definitely
- Probably
- Probably not
- Definitely not

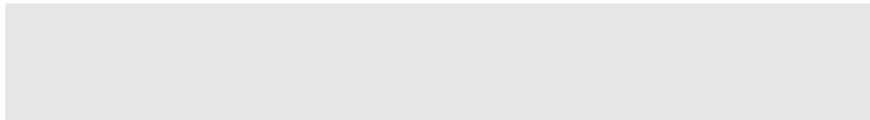
Please specify:

IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

22. Would you like to add another comment on that topic?



23. If available please, provide any references on the influence of COVID-19 pandemic on your NBS program.



IMPACT OF COVID-19 ON NEWBORN SCREENING PROGRAMS – INTERNATIONAL SURVEY

*** 24. In case of publication, all the respondents will be acknowledged in the article. If the journal grants group coauthorship you will be invited to be part of the group by providing us detailed and dedicated responses.**

By answering to this question with "yes" you indicate your consent to participate in this survey voluntarily and to be incorporated into the study and be acknowledged in case of publication.

Yes

No