

OC Children's Screening Registry

OC Children's Screening Registry Frequently Asked Questions

General Information

1. What is the OC Children's Screening Registry?

The OC Children's Screening Registry is an online database designed to enable primary health care providers and community-based providers to view and/or enter developmental and behavioral screening data and share information on referrals and outcomes. The OC Children's Screening Registry also allows for the documentation of a county level screening rate for children living in Orange County.

2. Which screening tools can the OC Children's Screening Registry accommodate?

The OC Children's Screening Registry has been developed to accommodate the following five screening tools: Ages and Stages Questionnaires -Third Edition (ASQ-3), ASQ: Social Emotional-2 (ASQ: SE-2), Parents Evaluation of Developmental Status (PEDS) and Modified Checklist for Autism in Toddler, Revised with Follow-up (M-CHAT R/F), Pediatrics ACEs Screening and Related Life-events Screener (PEARLS).

3. What types of organizations can use the Registry?

The types of organizations can be, but are not limited to: primary health care providers; early care and education providers; community based organizations that conduct developmental screenings; and service providers and therapists. These organizations must complete an Application Packet and receive this executed documentation from CHOC Legal prior to receiving access for their staff.

4. Who can see the developmental screening results?

Screening results can be viewed by users that have signed the Terms of Use document. Although some users may have certain restrictions, all organizations will be able to view the data which they have entered themselves.

Child screening results can be shared between service providers IF certain conditions are in place:

The user types with privileges/restrictions are as follows:

1. The **Treating-providers**: Service Provider is considered a Treating Provider AND the Service Provider has a treatment relationship with the Child that would warrant a benefit to the child if screening results were shared. These users will be able to see screenings entered by themselves *and* other organizations after attesting they have a treatment relationship with the child.

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- 2. The **Non-treating providers:** Service Provider is NOT a Treating Provider but has obtained a written, valid HIPAA Authorization from the child's parent/legal guardian to allow access to view screening results obtained from another provider AND the Service Provider has a relationship with the Child that would warrant a benefit to the child if screening results were shared. If authorization does not exist, then only the screening results the participant has entered will be accessible.
- 3. The **Data Entry providers:** Service Providers may use the data they collect and enter into the registry for internal purposes only and will not view records from other service providers.

5. Can parents log into the Registry?

No. The Registry is intended for use by: health care providers; early care and education providers; community based organizations; and service providers and therapists.

6. How long will a child's information remain in the Registry?

Registry users will be able to view a child's screening results through 17 years of age.

7. How long does it take to enter a child and the screening results?

The following table demonstrates an estimated entry time based on continual entries of 12 children and their corresponding screening results (shown for a specific tool with varying results):

Tool	Average time to enter results per child (minutes : seconds)
Ages and Stages Questionnaire (ASQ)- 3	1:34

*Inputs for the ASQ-SE 2, PEDS, and M-CHAT-R/F are expected to take less time because there are less required fields.

8. How can the Registry support the work that my organization does?

The Registry can be used as a repository for organizations that do not have a database to store screenings results. It allows organizations to make direct referrals to Help Me Grow and view the outcome of this referral. It can also be used as a method of sharing information with the child's physician. Organizations will be able to generate reports for the data they have entered. Additionally, depending on the type of user, the Registry allows users to see pre-existing children that have been entered by other organizations and they will have the ability to continue adding to the file.

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9. Is there a fee to use the Registry?

There is no fee for using the OC Children's Screening Registry.

Getting Started

10. How can my organization gain access to the Registry?

Organizations must first complete an "Application Packet" and receive the executed documentation prior to their staff gaining access. To request an Application Packet use the "To Learn More about the Registry" button found on the Registry landing page:

<http://ocscreeningregistry.com>

In the request, please include: (1) organization name, (2) name and title of person making the request, (3) email address, and (4) phone number.

Once submitted, an email will be sent from the Screening Registry Coordinator with the application packet.

11. What is included in the application packet?

1. A participation agreement
2. The application (Exhibit A)
3. Terms of Use (Exhibit B)
4. An overview of the OC Children's Screening Registry (Exhibit C)
5. A Business Associates Agreement (Exhibit D)
6. A separate Terms of Use PDF for applicant to print copies for each intended user to sign

12. I received my application packet. Now what?

Unless signing electronically, follow the next steps:

1. Print out the documents.
2. Make sure to print out multiple separate Terms of Use PDF attachment if needed (Each staff member that needs an account for the registry needs to personally sign a separate TOU).
3. Review, complete, sign, scan and email all documents (included multiple TOUs if applicable) back to ocscreeningregistry@choc.org
4. CHOC Children's will then sign and the application will be returned, via email, to the designated participant liaison.

13. How do I know if my application was approved?

When your application is approved, CHOC will sign the application and the Screening Registry Coordinator will email the participant liaison a copy as an executed document.

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Also, you will receive an email confirming the approval of the application from ocscreeningregistry@choc.org. This email will also contain additional information/requests for the participant liaison such as: a reminder to have all staff that signed a TOU request an individual account through the registry; a request to send a list of programs that need to be entered under the organization; and a request to designate which users belong to which program.

14. What does it mean to be the “Participant Liaison” for my organization?

The Participant Liaison for your organization will be responsible for:

- Identifying if multiple programs will be listed under the organization
- Providing Help Me Grow with a list of Authorized Users and will communicate the need to request accounts.
- Identifying which users are assigned to each program.
- Communicating within 24 hours of becoming aware of any changes with Authorized Users (example long-term departure, permanent departure, termination of employment).
- Being the main point of contact between Help Me Grow and organization.
- Creating reports for by entire organization if multiple programs exist under the organization.

15. How does the Registry function if my organization has multiple programs that conduct screening?

The Participant Liaison will communicate to the Screening Registry Coordinator that their organization operates multiple programs in order for the programs to be added in the Registry under the organization. He/she will also indicate which users belong to which programs so they can be given access to their designated program. The Users with program access can run reports only for the program they have access to and have the ability to enter data.

16. How do I get my individual user account?

After the organization has submitted the application packet and it has been approved, the Users with a completed Terms of Use will need to go to the Registry’s landing page to request a “New User Account”. Use the URL below to access the landing page:

<http://ocscreeningregistry.com>

17. What is the difference between having organizational access and program access?

- A user with organization access can only run reports for their organization; if their organization has multiple programs, they can run reports for all the

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programs separately as well. This access type does not allow the user to enter data unless they have program access too.

- A user with program access can enter data and run reports for their specific program; however, they cannot run reports for the entire organization with multiple programs unless they have been given organization access too.

18. Can an organization have a generic user account that is used by multiple people?

No. Each account must have a single person with a separate email address. Each user must have a personally signed Term of Use prior to being given access.

19. Do I need to obtain consent from an individual before entering their child's information into the Registry?

A signed consent is not required. However, your organization must notify involved individuals of your organization's participation in the Registry.

20. How do I notify involved individuals?

You can notify them by: (1) explaining the OC Children's Screening Registry and its intent; (2) ensuring individuals understand they can 'opt out' of sharing their child's information in the Registry; and (3) informing them that they may contact your organization or Help Me Grow if they would like to be removed (see questions 29 & 30).

Existing Registry Users

21. I forgot my Password and/username? What can I do?

The user will go to the Registry's Landing page <http://ocscreeningregistry.com> and click "To learn more about the registry" and submit their request to change password or request username. User needs to keep in mind that the answer to their security questions will be asked before the Screening Registry Coordinator releases their Username or resets their password.

22. Can I make referrals using the Registry?

Yes, referrals can be made to Help Me Grow using the Registry. The Registry also gives users the option to document any other referrals they have made aside from Help Me Grow.

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23. Can other referrals besides those to Help Me Grow be viewed for outcomes?

The only referrals that will have follow-up related to outcomes in the Registry are the ones made to Help Me Grow. The User will be able to see the status of the referral, the category of referral, and the outcome.

24. Who can run reports?

All users will be able to run reports. Those with “organizational access” will be able to generate reports at the organizational level and those with “program access” will be able to generate reports for their program. The Participant Liaison will need to indicate which users they want to have at which level of access; or they can indicate if certain users will be denied this function.

25. What else can I do besides enter developmental screening results?

In addition to entering developmental screening results, a user can:

- Generate reports
- Gain access to a child’s existing file and add to it
- Make direct referrals to Help Me Grow or note other referrals that have been made by the user
- View information entered by other users if a Treating Provider or a Non-Treating provider with an uploaded valid HIPAA Authorization form

26. What is the Authorization Form? (Pertains to a Non-treating Provider User)

A Non-treating Provider needs to obtain a signed, valid HIPAA Authorization from the child’s parent/guardian to gain access to view screening results entered by another user. An example of such valid HIPAA Authorization is available on the Help Me Grow website. This Authorization must be uploaded into the child’s file in the OC Children’s Screening Registry.

27. As a Data Entry only user, what information can I view on an existing child?

Data entry users can only view the information such as: screening results, referrals to HMG, or other referrals that they have entered. Data entry only users will be able to view a child’s name, DOB, sex, if a file exists for the purpose of adding additional screening results to the child’s file.

28. I made a mistake/typo in the child’s name, etc., how can it be corrected?

A typo correction for a child’s name, DOB, or sex can only be made by the Help Me Grow Screening Registry Coordinator. A user can request the change on the Registry landing page by clicking on “To Learn More about the Registry” and submitting the edit request.

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29. What happens if parent does not want to be part of the registry?

If a parent does not want their child information to be part of the registry, the organization should not add the child in the Registry. If a child's legal guardian would like to opt-out of participating in the Registry, they must notify the Participating Organization in writing prior to the Organization entering the child's information into the Registry. This opt-out notification prevents the Participating Organization from entering any of the child's information in the Registry.

30. What happens if the child is already in the Registry and the parents want the information removed?

Once a child's data is entered into the Registry, it becomes part of the Registry's aggregate data which cannot be retracted from the Registry by the Organization. If the child's patient information already exists in the Registry when the opt-out is received from the legal guardian, the Organization must then notify Help Me Grow in writing of the legal guardian's opt-out request. Upon receipt of the notification, Help Me Grow will remove the patient from the Registry in a timely manner, approximately 3 business days. The notification can be delivered to HMG by mail to 1200 W. La Veta Ave. Ste 450 Orange, CA 92868 or by email at OCScreeningRegistry@choc.org

31. Who do I contact to inactivate a User that no longer needs access to the Registry?

The Participant Liaison needs to maintain an active list of Users for their organization. When the Participant Liaison becomes aware of a user that no longer needs access to the Registry, he/she will communicate the need to inactivate the account within 24 hours to the Screening Registry Coordinator by email at OCScreeningRegistry@choc.org or the landing page

32. How can I add another User to the Registry for our organization?

The organization needs to provide the new user with the Terms of Use form and then submit the signed form to Help Me Grow at ocscreeningregistry@choc.org. Please be certain to identify the new user's organization and the program he/she will need access to. Once Help Me Grow receives the signed Terms of Use, the Screening Registry Coordinator will notify the Participant Liaison that the new user needs to submit a "New Account Request" on the OC Children's Screening Registry landing page.

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