



How to Sign Up to the JOIN-HD Registry

Setting Up Your Account:

- 1) After a screening call with the JOIN-HD coordinator, you will be sent the JOIN-HD website URL and a Participant ID number. To set up your account, type or paste the website URL into an internet browser. Please note that Chrome works best to view the platform.

A screenshot of a mobile browser displaying the JOIN-HD registry login page. The browser's address bar shows the URL 'johdregistry.hdyo.org' with a pink arrow pointing to it. Below the address bar, there are navigation icons for Apps, Maps, and a search bar containing 'Huntington's Disea...'. The page header includes 'My hApp' and an 'online' status indicator. The main content area features the JOIN-HD logo and the text 'The Juvenile-Onset Initiative for Huntington's Disease'. Below the logo are two input fields: 'E-mail / Id' and 'Password'. A large blue 'Log in' button is positioned below the input fields. At the bottom of the page, there are links for 'Forgot your password?' and 'Public Access'.

Thank you for participating in the JOIN-HD registry
Email registry@hdyo.org for any questions



How to Sign Up to the JOIN-HD Registry

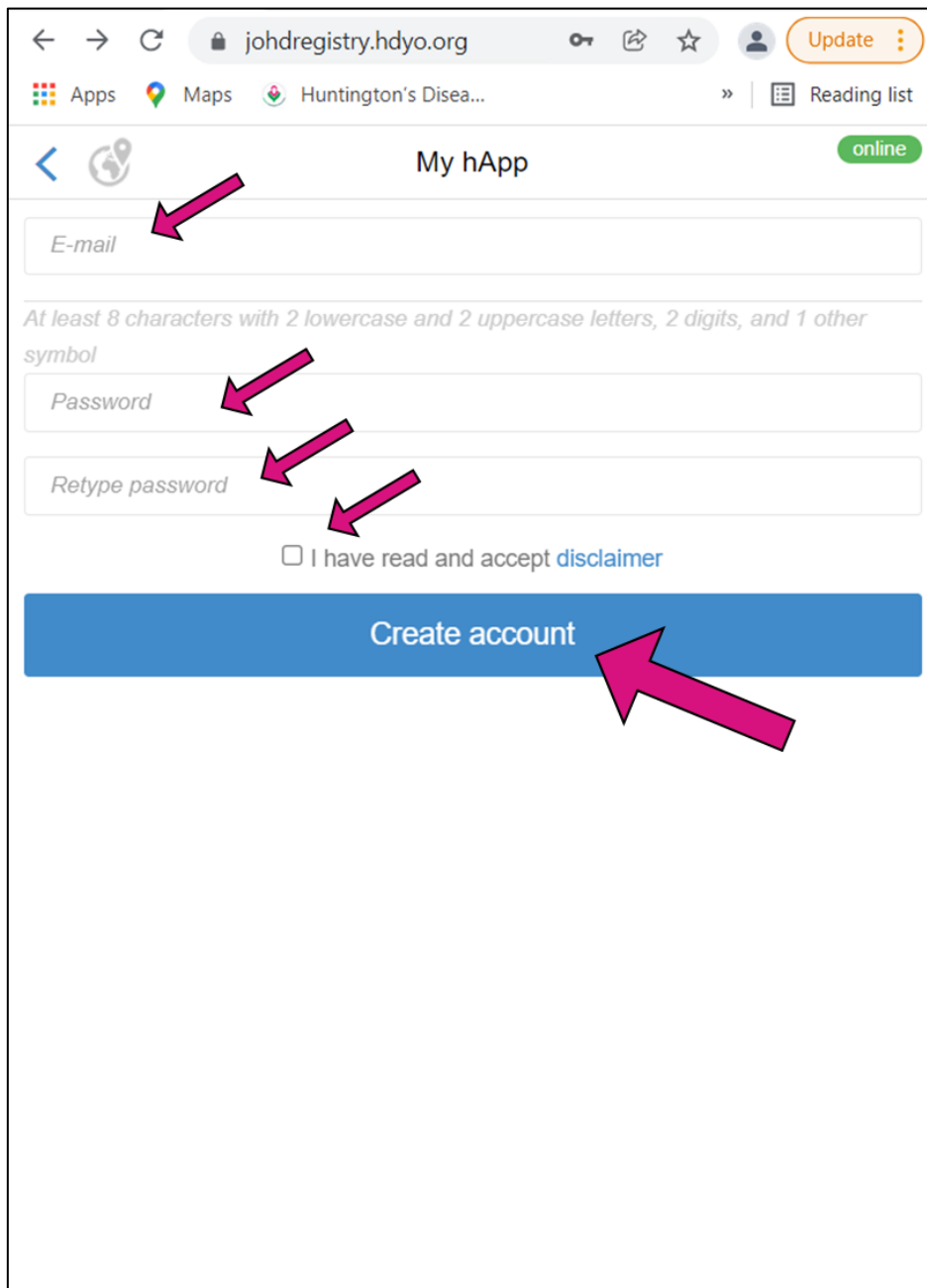
- 2) Next, enter your Participant ID into the 'E-mail/ ID' box and click the blue 'Log in' button. You can ignore the password the first time you enter the site (the Participant ID number is only used to set up your account – you will not need it again).

A screenshot of a mobile web browser displaying the JOIN-HD registry login page. The browser's address bar shows 'johdregistry.hdyo.org'. The page header includes 'My hApp' and an 'online' status indicator. The main content area features the JOIN-HD logo and the text 'The Juvenile-Onset Initiative for Huntington's Disease'. Below the logo is a login form with two input fields: the first contains the Participant ID '32915455634229' and the second is labeled 'Password'. A pink arrow points to the ID field. A blue 'Log in' button is positioned below the fields. At the bottom of the form, there are links for 'Forgot your password?' and 'Public Access'.

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- 3) This will take you to a new page to create your account. On this page, enter your email address in to the 'E-mail' box and create a password which meets the specified requirements (please note – each account needs a unique email address, so if you are setting up two accounts you will need two email addresses to do this). This email address and password will be your log in details for the website from this point on. Check the 'I have read and accept disclaimer' box and then click the blue 'Create account' button.



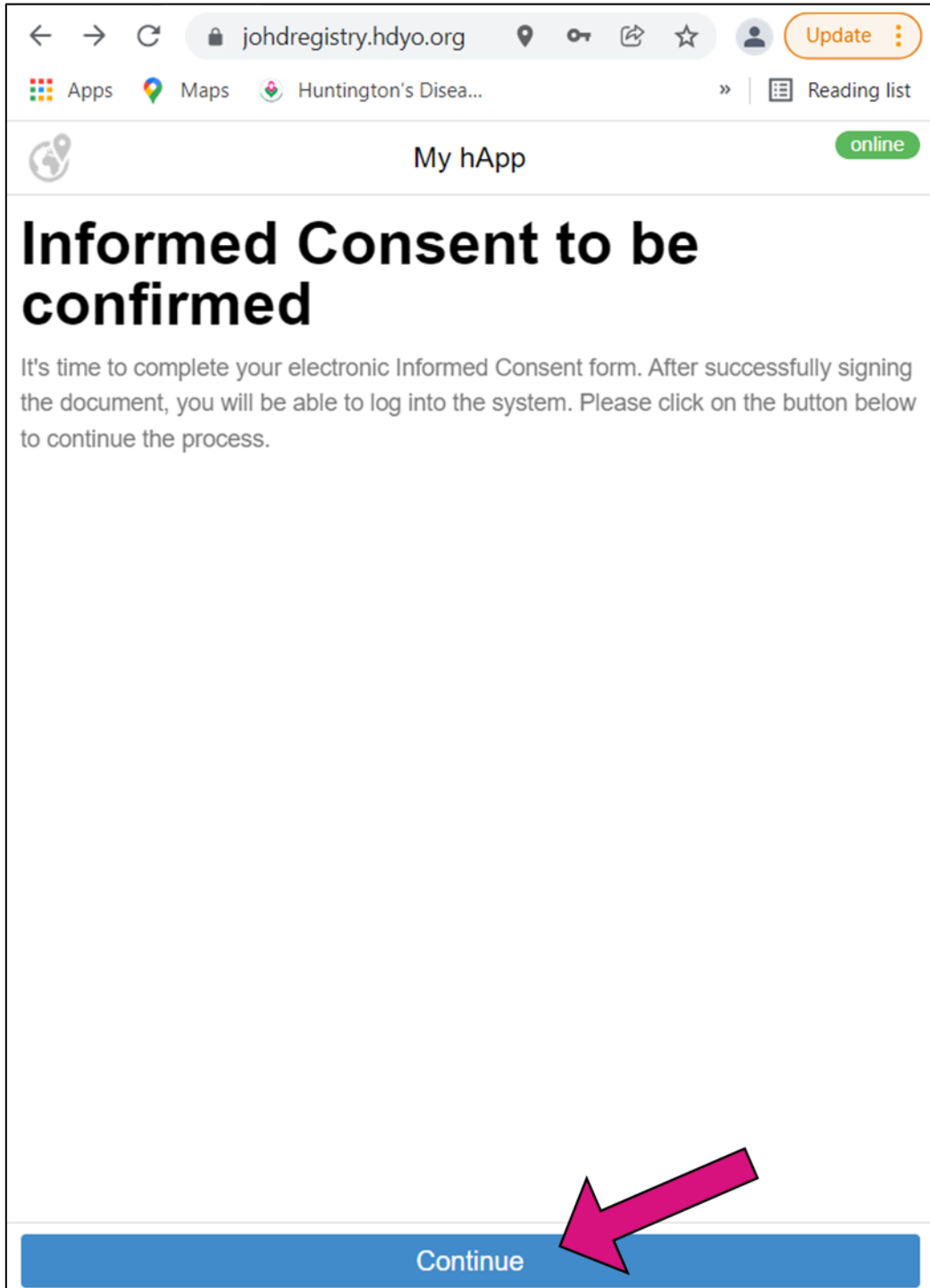
The screenshot shows a mobile browser interface for the JOIN-HD Registry. The address bar displays 'johdregistry.hdyo.org'. The page title is 'My hApp' with an 'online' status indicator. The form includes an 'E-mail' input field, a password field with a requirement note: 'At least 8 characters with 2 lowercase and 2 uppercase letters, 2 digits, and 1 other symbol', and a 'Retype password' field. Below the password fields is a checkbox labeled 'I have read and accept disclaimer'. A prominent blue 'Create account' button is at the bottom. Pink arrows point to the 'E-mail' field, the password field, the 'Retype password' field, and the 'Create account' button.



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Completing Your Consent Form:

- 1) The following page will appear, telling you that it is time to complete your JOIN-HD consent form. To continue, click on the blue 'Continue' button:



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How to Sign Up to the JOIN-HD Registry

Please read the consent statements, and if you agree and would like to take part in JOIN-HD, enter your log in details (email and password) in the appropriate boxes and click the blue 'Confirm' button. If at any point you change your mind about taking part in JOIN-HD and would like to withdraw, you can do so by emailing registry@hdyo.org.

JOIN-HD Consent Form

I have received the JOIN-HD Participant Information Sheet and had the opportunity to ask any questions I may have. I understand that my/my child's data (without my/their name attached) may be reviewed by individuals from sponsors, funders, and researchers.

I understand that I may be contacted by HDYO about further research, including future stages of JOIN-HD, but that I am under no obligation to take part in further research unless I want to.

My participation in JOIN HD is voluntary and I am free to withdraw at any time.

If you agree to the above and would like to take part in JOIN-HD, re-enter your log in details and click the **confirm** button below to begin sharing your information.

Sign below

Please enter your E-mail address and Password below

registry@hdyo.org

.....

Confirm

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- 2) For security, you will be taken back to the sign in page to re-enter your log in details.

← → ↻ johdregistry.hdyo.org Update

Apps Maps Huntington's Disea... Reading list

My hApp online

The Juvenile-Onset Initiative for Huntington's Disease

registry@hdyo.org

.....

Log in

[Forgot your password?](#)

[Public Access](#)

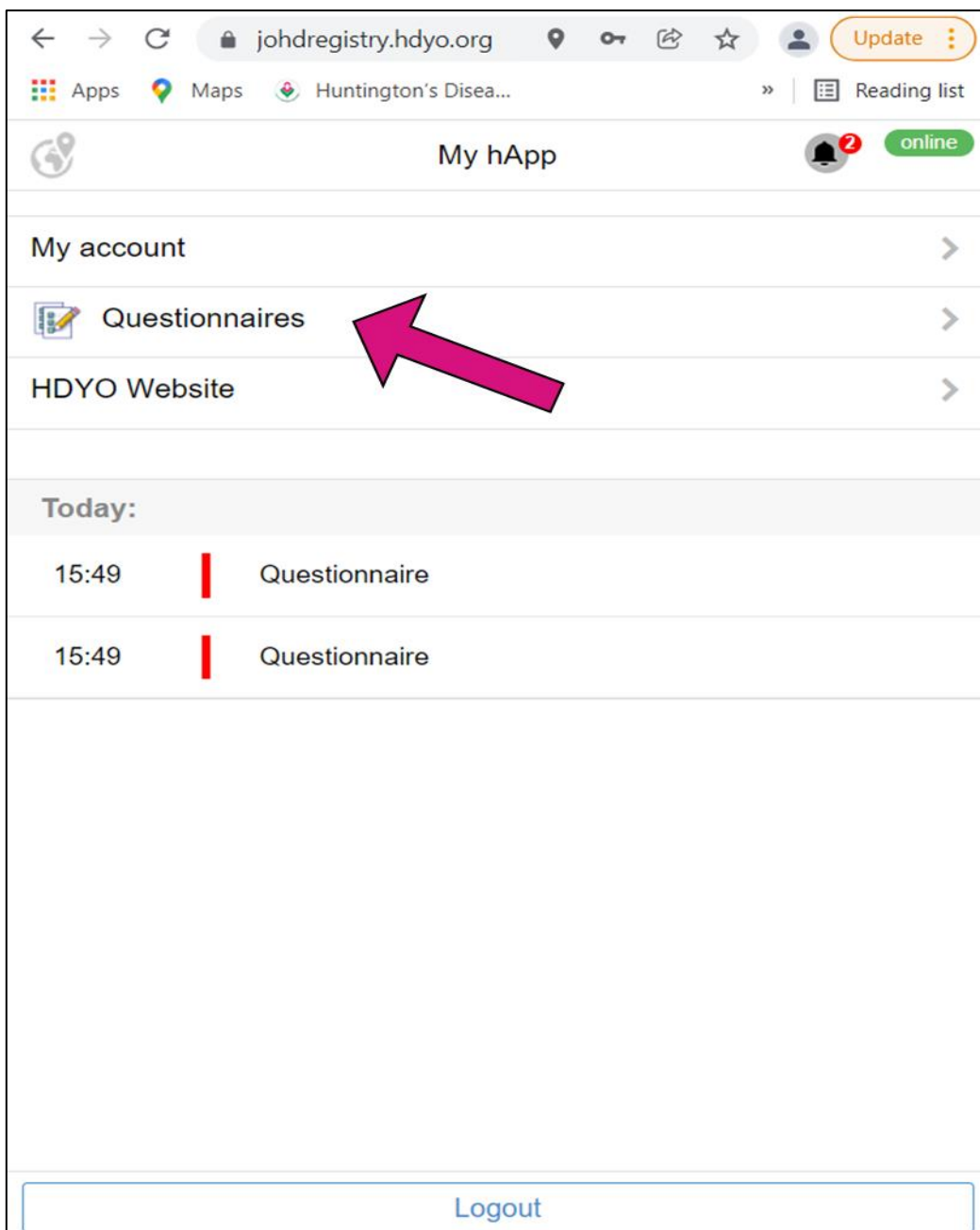
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Completing Questionnaires:

This will bring you to your account home page. From here you can click on any questionnaires that have been assigned to you to fill in. To find all questionnaires waiting to be done, click on the 'Questionnaires' button underneath 'My account'.

***Please note - once you begin a questionnaire, you cannot save to continue editing at a future time. You will lose all data if you exit the site. It's a good idea to ensure you have any medical, background or demographic information ready to reference as needed in these questionnaires.*

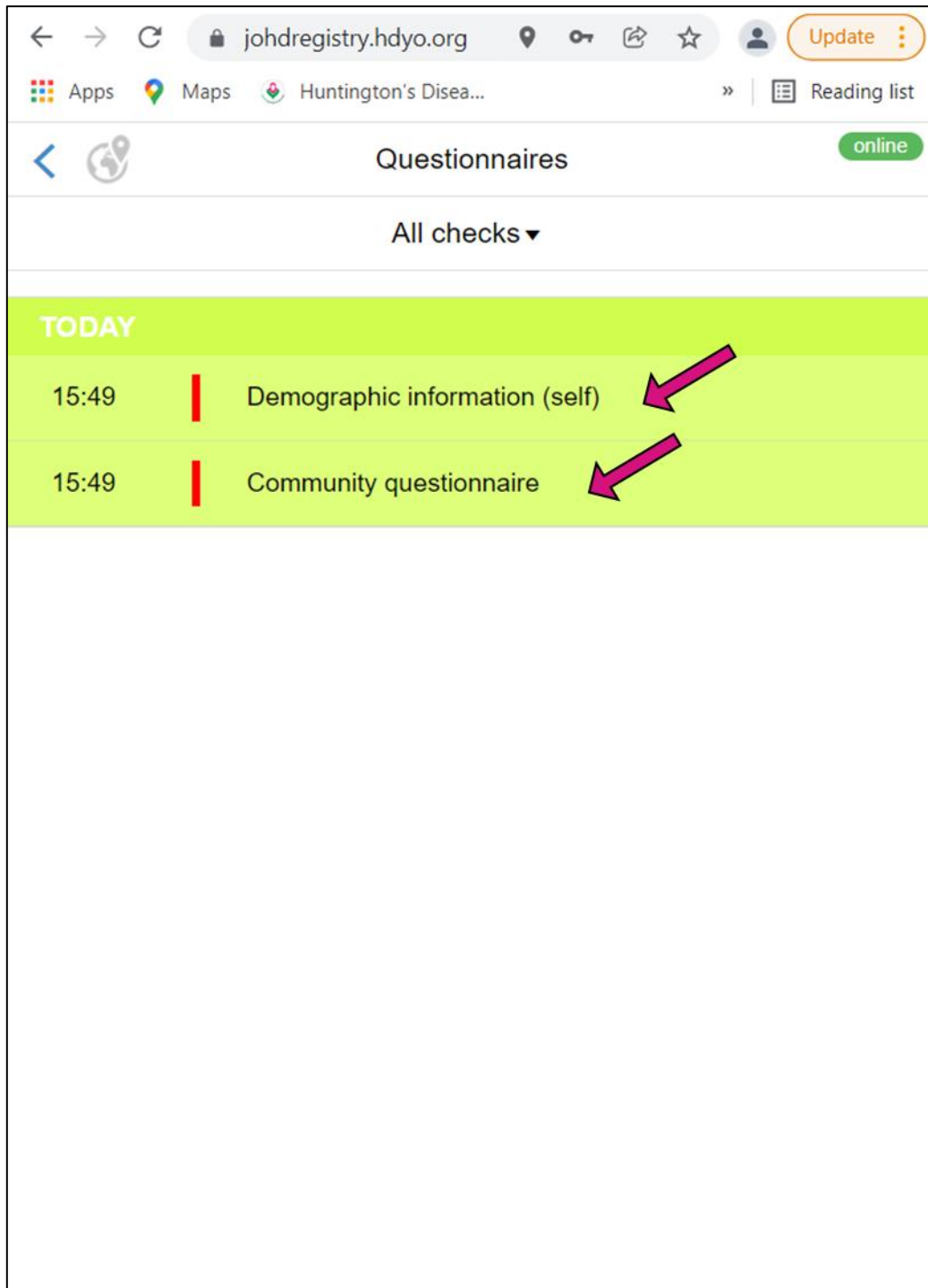


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In the Questionnaires section you will see any surveys ready for you to complete. To access a survey, click on its name.



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