

## User Guide

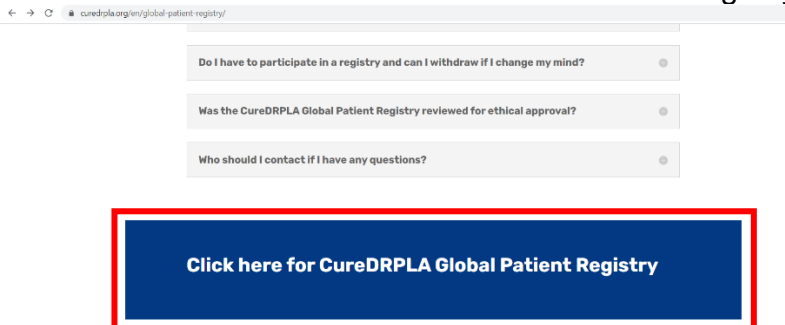
Last updated 17<sup>th</sup> of March 2021.

## Notes

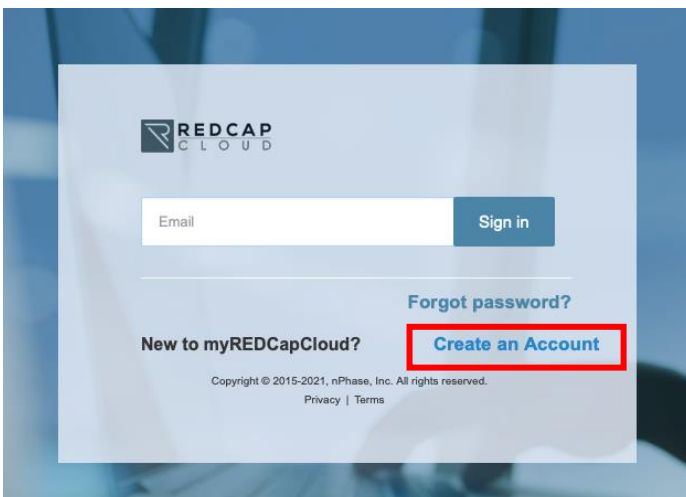
- We recommend using a computer to fill in this Registry. You might experience problems if you use a phone or a tablet to complete the Registry.
- We recommend using Google Chrome for the best user interface experience.
- Once you have created your myRCC account you do not have to complete everything in one go. You can click “Save and Return Later” at the bottom of every form. This will save all your answers. To pick up where you left off use this link: <https://myrcc.redcapcloud.com/>
- This registry is interactive, based on your answers additional questions might appear. Because of this what you see on your screen might be slightly different from the images presented here.
- In the Registry all fields marked with a red asterisk (\*) are required. You will not be able to click “Next/Submit” until these fields have been completed.
- **Each affected family member should create an account.** If you are completing the Registry on behalf of multiple family members please see page 9.

## Step by Step

1. Go to <https://curedrpla.org/en/global-patient-registry/>
2. Click the blue button to be redirected to the Registry.

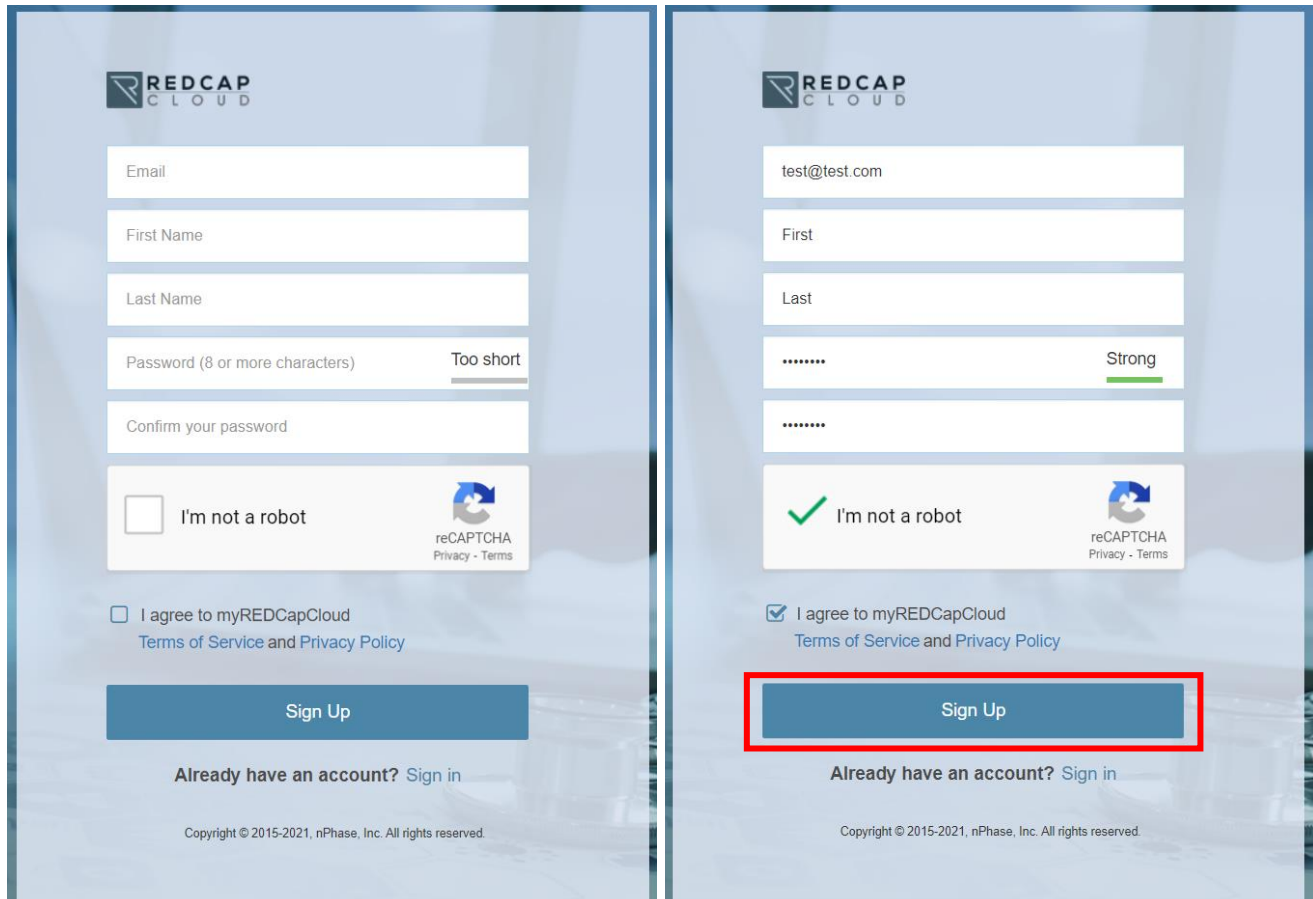


3. Select “Create an Account”.

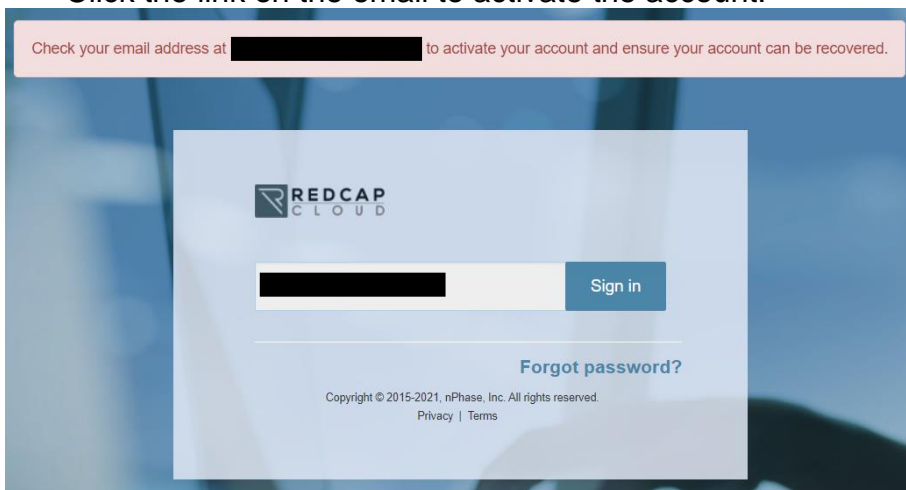


4. Create your myRCC account.  
Type your email address<sup>1</sup>, first and last name, and create a password.  
**Please note that the text fields are case sensitive.**  
Then click “Sign Up”.

<sup>1</sup> Please use an email address that will remain active over time. We will send you yearly reminders to complete the registry once a year.



5. Check your Inbox to activate myRCC account.  
Click the link on the email to activate the account.





**REDCap Cloud** <noreply@redcapcloud.com>  
to [REDACTED]

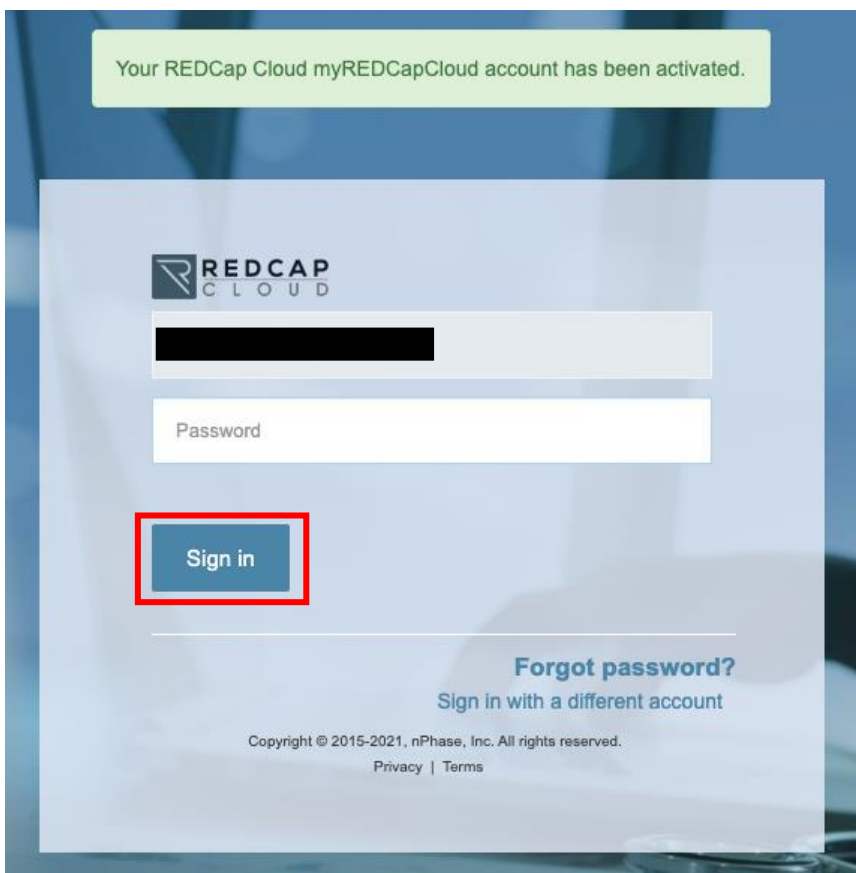
Hello [REDACTED] welcome to myREDCapCloud!

Your username is: [REDACTED]

Please click the link below to activate your account

<https://myrcc.redcapcloud.com/?#signup=898a52344fcd4f33899934eed1db896b&join=0c89dbbbfca447309965a1ef4489ac2a>

6. Log in to myRCC account. Add your password and click “Sign In”.



7. Confirm that you want to participate in the registry (1) and click “Submit” (2).

## CureDRPLA Global Patient Registry

Welcome

# WELCOME to the CureDRPLA Global Patient Registry!

This is your patient portal where you will be completing all of your yearly assessments. Before you begin, you will need to read the Participant Information Form and sign the Informed Consent Agreement. Once you have completed the Informed Consent Agreement, a copy of your signed form will be sent to your email address and the first of your assessments will be made available. **To start please confirm that you are interested in participating in the CureDRPLA Global Patient Registry by checking the box below.**

THANK YOU!

Would you like to participate in the CureDRPLA Global Patient Registry  
*(Required fields are marked with an asterisk)*

\*  Yes, I confirm that I would like to participate and I want to proceed to the Participant Information Form and Informed Consent Agreement [Reset](#)

2

8. Every time you submit a form this message will appear. Click “Yes” to proceed.

### Confirm

Are you sure you want to submit your form?

9. Welcome to myRCC portal. All the questionnaires will appear here and you will be able to track your progress. Select “Informed Consent and Agreement” to proceed.

PLEASE FILL IN THE FOLLOWING E-CONSENT FORMS		
<a href="#">Welcome!</a>	Mar 3, 2021	<b>Completed</b>
<a href="#">Informed Consent and Agreement</a>	Mar 3, 2021	<b>Not Started</b>

10. Read the Informed Consent and Agreement. When ready click “Next” at the bottom of the page.

## CureDRPLA Global Patient Registry

CureDRPLA

Patient Registry reserves the right to charge third parties (such as pharmaceutical companies) a fee for Registry data in order to cover some of the costs associated with maintenance of the Registry. Data will never be sold for profit.

You will not be paid for being in the CureDRPLA Global Patient Registry.

### Questions

If you have questions, concerns, or complaints, or think you have experienced a research-related problem, contact the Registry Coordinator at the email address listed on the first page of this consent.

This research is being overseen by an Institutional Review Board (IRB). An IRB is a group of people who perform independent review of research studies. You may talk to them at (800) 562-4789, [help@wirb.com](mailto:help@wirb.com) if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research participant.

Once you have read all of the information presented above please indicate whether you accept or decline participation in the CureDRPLA Global Patient Registry. If you tick the agreement in the next page you are agreeing to participate in the Registry and to the information presented above. Once you have agreed you will be taken into the Registry web pages where you will be able to complete the survey. You can only participate in the Registry if you tick this agreement.

Cancel

Save and Return Later

→ Next

11. Select the patient age and the capacity to consent.

What is the patient's age group?\*

- 0 to 11 years old
- 12 years old or over but under the age of consent in the country of residency (i.e. age 18 in most European countries and North America, age 16 in United Kingdom, and age 20 in Japan)
- DRPLA individual has reached the age of consent in the country of residency

[Reset](#)

**Subjects that lack the capacity to consent (e.g. cognitively impaired individuals) will require consent from the legal authorized representative, and the assent of the subject will be obtained to the extent compatible with their capacity.**

Patient Status for Assent\*

- The patient is not cognitively impaired and can complete the study independently.
- I have explained the study to the extent compatible with the patient's capability, and the patient has agreed to be in the study
- The cognitive capability of the patient is so limited that the subject cannot reasonably be consulted to assent

[Reset](#)

12. To participate in the Registry, you must accept all the statements in the consent form.

Please initial the following statements if you agree to them	
1. I confirm that I have read and understand the information for entry to the CureDRPLA Global Patient Registry. I have had the opportunity to consider the information, ask questions, and to have these answered satisfactorily.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
3. I understand that if I withdraw from the CureDRPLA Global Patient Registry I will no longer be contacted by the Registry.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
4. I understand the registry will contact me from time to time to ask me to update or input additional data.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
5. I understand I have the option for the registry to contact me if a suitable clinical trial or clinical study becomes available.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
6. I accept that allowing my data to be stored on this database does not mean that I will automatically be entered into future clinical trials.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
7. I understand that the data that I enter will be stored in the CureDRPLA Global Patient Registry with servers in the United States.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
8. I understand that my data and/or information may be shared with third parties (such as advocacy groups, non-profit organizations, academics, clinicians and drug development companies) who would use such data and/or information for secondary research purposes, but it will only be in an anonymized format where I cannot be identified.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
9. I understand that my data and/or information may be transferred to countries other than my own country, and such other countries may not have the same, or as strict privacy laws as my own country.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
10. I understand that the data I provide may be used to inform and plan future research.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
11. I understand that the results from future research may not have any direct implications for me or my family.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>
12. I understand that I give consent for the storage of data on myself in the CureDRPLA Global Patient Registry.	<input checked="" type="checkbox"/> I ACCEPT <a href="#">Reset</a>

13. (Only applies if assent is needed) If the patient agrees to be in the study select “I agree” (1) and click “Next” (2).

I confirm that I have read and understand the information for entry to the CureDRPLA Global Patient Registry. I have had the opportunity to consider the information, ask questions, and to have these answered satisfactorily. I agree to participate in this research.

I agree  
 I do NOT agree  
[Reset](#)

14. Type your/the patient initials and select the date.  
 To select the date click the calendar icon (1) and pick today’s date. Then click “Submit” (2).  
 When the message appears click “Yes” (3).


**INITIALS**

Subject Initials\*

(- / 5)

Legal Representative Initials (this includes a parent/guardian):\*

(- / 5)

Date of consent:\*   1

### Confirm


Are you sure you want to submit your form?

Yes
No

15. To continue select the form “Who is completing this survey”.

YOU GAVE YOUR CONSENT TO PARTICIPATE IN THIS STUDY.		
Welcome!	Mar 3, 2021	Completed
Informed Consent and Agreement	Mar 3, 2021	Completed
Who is completing this survey	Mar 3, 2021	Not Started

16. Indicate who is completing this survey. Then click “Submit”.  
Once you submit this form you will have completed the enrolment process.

**Assessment Date:**  

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**Survey Completion**  
*\*Required fields*

**Who is completing this survey?\***


- A person who has been diagnosed with Dentatorubral-pallidolusian atrophy (DRPLA)
- The parent or caregiver of someone that has been diagnosed with DRPLA. Completing the survey by asking the questions directly to the patient
- The parent or caregiver of someone that has been diagnosed with DRPLA. Completing this survey taking into account my personal experiences with the person with DRPLA who is either a young child or unable to complete the survey on their own

[Reset](#)

Cancel
Save and Return Later
Submit

17. These are all the Registry questionnaires that we would like you to complete. To complete a form click the form name (e.g. Demographics), answer the questions, and click submit. All fields marked with a red asterisk (\*) are required. You will not be able to click “Next/Submit” until these fields have been completed.

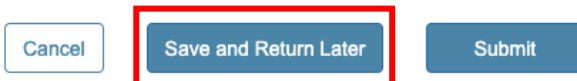
**CureDRPLA Global Patient Registry**  
CureDRPLA



YOU GAVE YOUR CONSENT TO PARTICIPATE IN THIS STUDY.

Welcome!	Mar 3, 2021	Completed
Informed Consent and Agreement	Mar 3, 2021	Completed
Who is completing this survey	Mar 3, 2021	Completed
Demographics	Mar 3, 2021	Not Started
Diagnosis	Mar 3, 2021	Not Started
Medical History	Mar 3, 2021	Not Started
Research	Mar 3, 2021	Not Started
Functional Mobility	Mar 3, 2021	Not Started
Activities of Daily Living	Mar 3, 2021	Not Started
DRPLA Economics	Mar 3, 2021	Not Started

If you have started answering a form but you are unable to finish it at this time select “Save and Return Later” at the end a form. This will save all your answers.



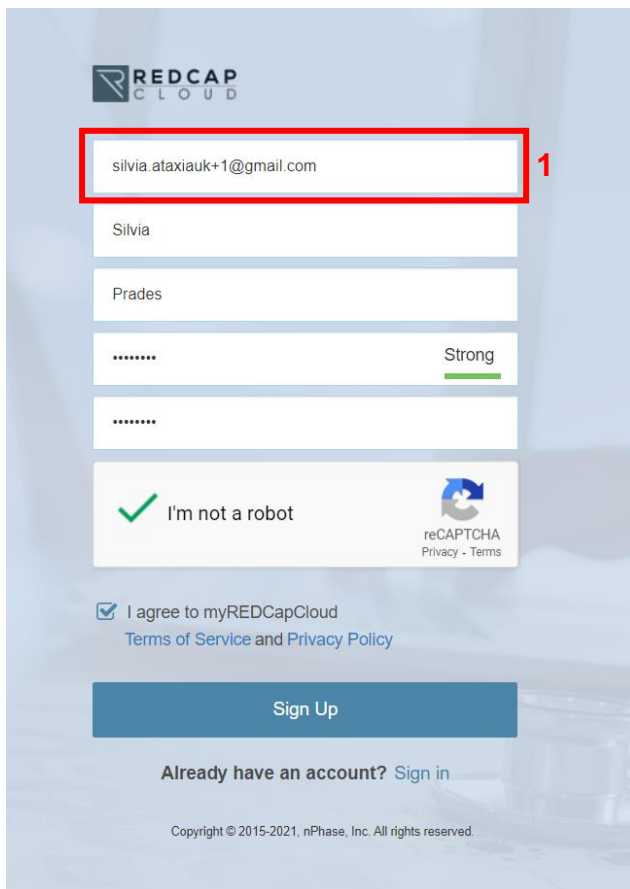
Once you complete this process, you will have received three additional emails from RCC which will address:

- Downloading your e-Consent documents
- A password to use at the secure site to download your Informed Consent and Agreement
- A notification that new forms are available for you to complete.



## How to create multiple myRCC accounts

- Each person with DRPLA should have a myRCC account. For example, if your son and daughter have DRPLA you should to complete the Registry twice.
- To create multiple accounts you can choose to:
  - Use multiple email addresses. However, we always recommend to use accounts that will remain active over time, so we have a way to contact you OR
  - Create multiple myRCC accounts using the same email address by adding “+1, +2, +3, +4, etc.” (1) to your email address. If you use this trick all the emails will go to the same inbox (e.g. silvia.ataxiauk@gmail.com).



REDCAP CLOUD


silvia.ataxiauk+1@gmail.com 1

Silvia

Prades

..... Strong

.....

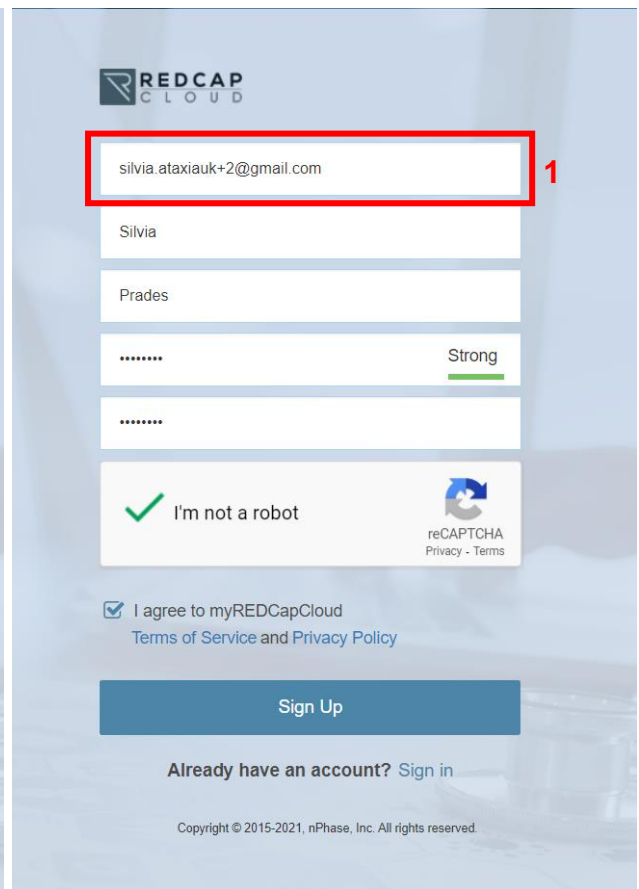
I'm not a robot  reCAPTCHA Privacy - Terms

I agree to myREDCapCloud Terms of Service and Privacy Policy

Sign Up

Already have an account? [Sign in](#)

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silvia.ataxiauk+2@gmail.com 1

Silvia

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.....

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I agree to myREDCapCloud Terms of Service and Privacy Policy

Sign Up

Already have an account? [Sign in](#)

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Every time you have to complete a form you will receive an email with your username (2).

