

## Chiari1000: An International Patient Database

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### Purpose

The Chiari1000 is a custom, web accessed, secure database that collected demographic and health related data provided through self-report questionnaires, responses to selected validated scales, and imaging voluntarily provided by Chiari patients. The purpose of the Chiari1000 was to gather the same information from a large, clinically diverse, group of Chiari patients for analysis and research.

### Methods

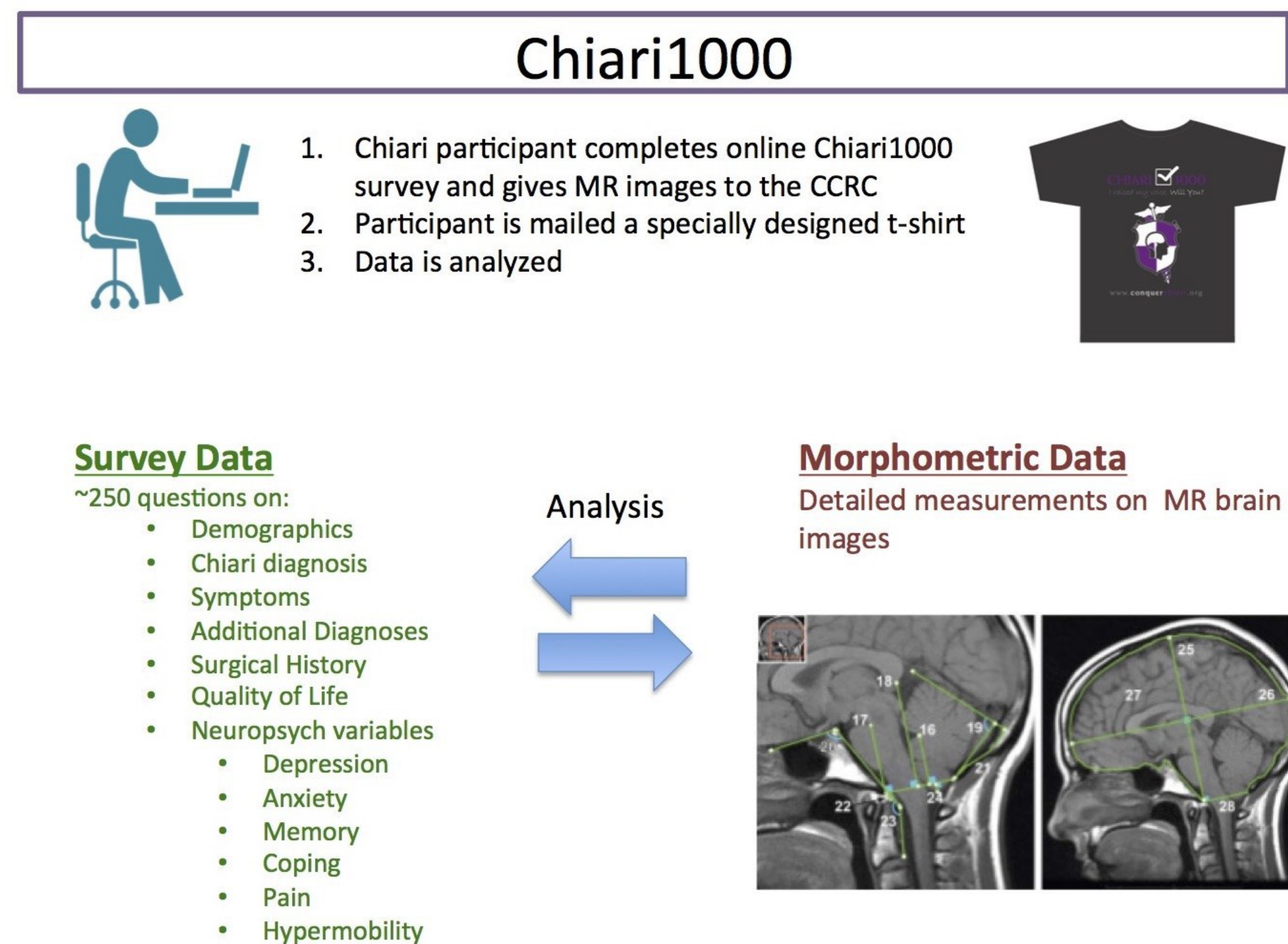
Subjects were recruited through Conquer Chiari's website, social media, and email list. People with a diagnosis of Chiari were asked to register on a secure website; complete online questionnaires on: demographics, symptomatology, diagnostic history, surgical history, additional medical diagnoses of related conditions, and quality of life; respond to 11 standardized assessments: memory, pain, anxiety, depression, coping with, and attitudes towards illness and traumatic life events, loneliness, psychological well-being, and hypermobility; and to share their pre-surgical MRIs via a shared drive, the mail, or by signing a release. Participants were also given the opportunity to indicate if they were interested participating in additional research studies.

### Results

The database is now closed to new participants. In total, 3070 people registered; 1965 people completed all of the self-report questionnaires; 1547 people completed all of the standardized assessments; 787 patients shared their images; and a subset of patients provided biological samples for biomarker and genetic studies. The vast majority of respondents were adult, white women. Geographically, 30 countries are represented as are 49 states in the US, plus Washington DC and Puerto Rico. To date, the Chiari1000 has generated 18 peer-reviewed journal publications on a range of topics. Selected, formatted results are also available for the community to review at: [chiari1000results.info](http://chiari1000results.info)

### Conclusions

The Chiari1000 was a tremendous success thanks to the willing participation of the Chiari community. It represents an incredible resource for researchers, and will continue to produce publishable results for the foreseeable future.



### Chiari1000 Publications by Year (As of 9/22)

2022	2
2021	3
2020	1
2019	7
2018	5
<b>Total</b>	<b>18</b>