Summary of the principal FSHD registries features-updated to 2021							
Registry Country	**Italy**	**UK**	**China**	**US**	**France**	**Germany**	**Netherlands**
Registry name	Italian National Registry for FSHD (INRF)	UK FSHD Patient Registry	Chinese Clinical Trial Registry: Registration study of FSHD	National Registry of Myotonic Dystrophy and FSHD Patients and Family Members	The French National Registry of Facioscapulohumeral Dystrophy	German National FSHD Registry	FSHD registratie
Scale of the registry	National	National	Regional	National	National	National	National
Date of establishment	2007	2013	2020	2000	2013	2017	2015
Total of FSHD Patients	***2.169****	***1.035***	***998***	***975***	***930***	***630***	***384***
Country population	***59.258.000***	***68.168.033***	***1.443.615.491***	***332.915.073***	***65.426.176***	***83.995.966***	***17. 550.654***
Recruiting power	***1:27.000***	***1:65.862***	***1: 1.446.508***	***1:341.451***	***1:70.000***	***1:133.326***	***1:45.704***
Data collection	Clinical assessment, patient reported, genetic tests, family histories, Clinical categorization based on phenotypic scores and features developed by the Italian Clinical Network for FSHD	Patient reported (online), genetic tests, family histories, motor function assessment	Clinical assessment, patient reported, genetic tests, family histories, motor function assessment	Patient reported (online), genetic tests, family histories, motor function assessment	Clinical assessment, patient reported, genetic tests, family histories,	Clinical assessment, patient reported, genetic tests, family histories,	Clinical assessment, patient reported, genetic tests, family histories,
FSHD-Specific tool for clinical evaluation	Yes Comprehensive Clinical Evaluation Form (CCEF)	Yes FSHD Pain questionnaire	No	No	Yes Clinical Evaluation Form (CEF)	No	No
Longitudinal studies	Yes	Yes	No	Yes	Yes	Yes	Yes
Genetic diagnosis required	***Yes***	***No***	***Yes***	***No***	***Yes***	***No***	***No***
Participants with genetic diagnosis	***100%***	***50%***	***100%***	***57%***	***96%***	***51%***	***100%***
Data reports from	***Clinicians***	***Patients***	***Clinicians and Patients***	***Clinicians and Patients***	***Clinicians and Patients***	***Patients***	***Patients***
Access to data	Yes upon request No fee	Yes upon request Usage Fee	Yes upon request No fee	Yes upon request No fee	Yes upon request Usage Fee	Yes Upon request No fee	Yes upon request No fee
Feedback to Patients-Divulgative	Yes FSHD day on a yearly basis. Webinar on specific topics	No	No	Sporadic newsletters	Sporadic newsletters	Sporadic newsletters	No
Founds	Non-profit grants	Non-profit grants form patients association	Non-profit grants	Non-profit grants	Non-profit grants	Non-profit grants	Non-profit grants
**Data updated to august 2021*							

Additional File 2