



## Minimal Data Set – Swiss Rare Disease Registry (SRDR)

	Variable	Description	Mandatory
<b>Patient Information</b>			
<i>1. Personal Information</i>			
	Patient ID	Clinic-specific code in Switzerland	X
	Year of Birth	yyyy	X
	Sex	-Female -Male -Other -Unknown	X
<i>2. Informed Consent</i>			
	Information date	Date on which patient has been informed by the e.g., the clinic	X
	Consent status	-Consent signed -Consent refused -No signature/no refusal within 6 weeks -Consent withdrawn	X
	Date of signature/ refusal/ withdrawal	dd.mm.yyyy	X
	Level of withdrawal	-stop medical data collection -stop being contacted for questionnaire surveys or nested studies -keep minimal data set only -unknown	
<i>3. Patient Status</i>			
	Vital status	-Alive -Dead -Lost to follow-up -Unknown	
	Year of death	yyyy	
<b>Clinical Information</b>			
<i>1. Classification</i>			
	ORPHAcode		X

	<b>Variable</b>	<b>Description</b>	<b>Mandatory</b>
	Name of diagnosis	Information is automatically fetched from Orphanet	
	ORPHA-Link	Information is automatically fetched from Orphanet	
	ORPHAcodes status	Information is automatically fetched from Orphanet	
	Classification level	Information is automatically fetched from Orphanet	
	Type of disorder	Information is automatically fetched from Orphanet	
<i>2. Diagnosis Information</i>			
	Year of diagnosis	-yyyy -unknown	X