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Sanofi epilepsy program (FAST – Fight Against STigma) – Bolivia

Sanofi

Submitted as part of Access Accelerated

Access Observatory

Contents

Program Description

Program Overview

1 **Program Name**

Community-based epilepsy awareness and training program in rural Bolivia

2 **Diseases program aims to address**

- Mental & Neurological Disorders: Epilepsy

3 **Beneficiary population**

- Gender: All genders
- Ages: All ages
- Special populations: Rural populations

4 **Countries**

- Bolivia

5 **Program start date**

January 1, 2016

6 **Anticipated program completion date**

March 31, 2021

7 **Contact person**

[No response provided]

8 **Program summary**

The main objective of this project is to assess the impact of knowledge-improving strategies to reduce epilepsy treatment gap through training sessions for healthcare workers and awareness raising activities for the community in rural areas of Santa Cruz Department in the Cordillera Province in Bolivia.

Three target groups have been identified within the study area:

A. Community healthcare personnel including general practitioners (GPs), nurses, community health workers (CHWs)

B. People with epilepsy (PWE)

C. Community members

The program is organized into the following 4 phases:

1. Training sessions on epilepsy directed to rural healthcare providers (GPs, nurses, CHWs), including baseline and endline evaluation of knowledge, attitudes and practices regarding epilepsy among health care personnel,

2. Identification of PWE and assessment of treatment gap, conducted by trained CHWs and nurses through door- to-door face-to-face interviews with validated screening questionnaire.

3. Community awareness campaign starting with a baseline assessment of epilepsy related knowledge, attitudes and practices among community members of rural communities, evaluation of stigma-related to epilepsy among PWE, rural health care personnel, teachers and community members, and evaluation of quality of life among PWE. A series of awareness and education activities will be conducted within the communites.

4. Treatment gap will be re-evaluated, 6 months after the second training course for CHWs and nurses, as well as knowledge, attitudes and practices of community members, epilepsy-related stigma among PWE, rural health care personnel, teachers and community members, and quality of life among PWE

This program designed by the University of Catania (Department "G.F. Ingrassia", section of Neurosciences), involves Sanofi as well as local partners such as the Bolivian Society of Neurology and Servicio departamental de Salud de Camiri in the Santa Cruz region.

Program Strategies & Activities

9 Strategies and activities

Strategy 1: Community Awareness and Linkage to Care

ACTIVITY	DESCRIPTION
Communication	An awareness and educational program aimed at improving knowledge, attitudes and practices regarding epilepsy for PWEs, their families and community members has been developed, with the support of a local anthropologist. Communication materials have been developed in guarani language with local artist illustrations. Various activities and meetings are organized and promoted through the participation of community leaders and local school teachers. Meetings are advertised via local radio. Local healthcare personnel is also actively involved in the organization of these events.

Strategy 2: Health Service Strengthening

ACTIVITY	DESCRIPTION
Training	Module 1. Training for GPs This course has a duration of two subsequent days and is delivered to about 7 people at a time. The main purpose is to provide information on the management of PWE, including the following aspects: - Epidemiology; - Public health aspects; - Causes; - Diagnosis of epilepsy; - Differential diagnosis; - Prevention measures for preventable factors - Drug treatment; - First aid; - Prevention of the secondary forms of epilepsy (infectious disease, head trauma, perinatal care); -Psycho-social aspects (social difficulties, prejudice and stigma) and strategies to deal with them. Module 2. Training for CHW and Nurses CHWs and nurses closely collaborate within the communities. This course has a duration of one day and includes two modules six months apart from each other. It is delivered to about 30 people at a time. The main purpose is to provide information on PWE identification and referral and on promotion and dissemination of correct information within the communities: - Main causes of epilepsy; - Diagnostic work-up for epilepsy confirmation; - Treatments available;

Program Strategies & Activities

9 Strategies and activities, cont.

Strategy 3: Health Service Delivery

ACTIVITY	DESCRIPTION
Screening	Screening phase and treatment gap assessment. In order to estimate the prevalence of epilepsy in the study area, and the treatement gap, and to refer suspected cases to GPs for diagnosis, all CHWs and nurses participating to the first training course will screen, through face-to-face interviews with householders, all the population of their communities through the use of a Spanish language questionnaire for convulsive seizures validated in the Gran Chaco area. The screening is done after the first training session.

10 Strategy by country

STRATEGY	COUNTRY
Community Awareness and Linkage to Care	Bolivia
Health Service Strengthening	Bolivia
Health Service Delivery	Bolivia

Companies, Partners & Stakeholders

11 Company roles

COMPANY	ROLE
Sanofi	To provide funding to the University of Catania for the purposes of implementing the program. To monitor the implementation of the program.

12 Funding and implementing partners

PARTNER	ROLE/URL	SECTOR
University of Catania	To develop, plan, implement, monitor and evaluate the program in collaboration with other partners. To develop/adapt training materials. To develop/adapt materials to raise awareness among the public, educate patients and families. To ensure timely implementation of activities (training, screening, awareness activities etc...). To provide regular activity and financial reports. https://www.unict.it/en/	Public

13 Funding and implementing partners by country

PARTNER	COUNTRY
University of Catania	Bolivia

14 Stakeholders

STAKEHOLDER	DESCRIPTION OF ENGAGEMENT	REQUESTED OR RECEIVED FROM STAKEHOLD-
Government	The University of Catania has involved the Servicio departamental de Salud in Santa Cruz, and in particular Dr Elizabeth Crespo Gòmez, neurologist.	Infrastructure: No Human Resources: Yes Funding: No Monitoring or Oversight: No Other resource: No
Faith Based organization	The University of Catania is working very closely with Convenio de Salud, Obra social de la Iglesia Catolica, Camiri. They are in charge of identifying and recruiting local stakeholders to participate in the program (CHWs, nurses,GPs et...) and of implementing local activities (training, screening, awareness activities...).	Infrastructure: No Human Resources: Yes Funding: No Monitoring or Oversight: No Other resource: Yes

Local Context, Equity & Sustainability

15 Local health needs addressed by program

More than 450 million people worldwide suffer from mental disorders and in low and Epilepsy is one of the most prevalent non communicable neurologic diseases, with an estimated aggregate burden of around 0.7% of the total global disease burden[1]. It affects approximately 70 million people worldwide[2] and at least 5 million people in Latin American Countries (LAC)[3], representing a considerable and often untreated health problem. In this region the median lifetime epilepsy (LTE) prevalence is 15.8/1,000 (95% CI 13.5-18.3), and the median active epilepsy (AE) prevalence is 10.7/1,000 (95% CI 8.4-13.2)[4] .

In Bolivia, a LTE prevalence of 12.3/1,000, an AE prevalence of 11.1/1,000 and a treatment gap (TG) of 90% were estimated in 1994, during a population-based survey performed in rural communities located in the southwestern section of Santa Cruz Department[5], a region called Gran Chaco. In this area, epilepsy associated with convulsive seizures (EACS) was the most frequent type (>60%) and was also associated with a high mortality[6] and with stigma[7,8]. Neurocysticercosis is considered one of the main causes of epilepsy and it is responsible for about 30% of seizure disorders in endemic regions[9].

In Bolivia a strong association of epilepsy and neurocysticercosis (NCC) was found and about 30% of cases identified during the prevalence survey were due to NCC[6,10,11,12].

The reduction of epilepsy TG in the area of Gran Chaco has been the main aim of the projects carried-out for more than 20 years in this area. This objective goes through the reinforcement of the primary care setting by implementing an action-plan aimed at preventing, treating and managing epilepsy at a community level.

Inadequate skilled manpower, cost of treatment, unavailability of drugs, cultural beliefs about the causation, use of traditional medicine, and distance from a health-care facility are considered the main causes of the epilepsy TG in developing countries[13]. All of these causes can be addressed with appropriate interventions, although some, such as cultural beliefs and use of traditional medicine, are more challenging to change.

In developing countries, general physicians and nurses play a major role in providing medical care and social support to PWE. Nurses and non-medical health workers are often the only health staff available to diagnose epilepsy. In countries where there are no specific programs on epilepsy, little data is available on the specific knowledge the health staff from different settings or specialties have. The poor knowledge of health staff has been suggested as a contributing cause to the epilepsy TG.

Furthermore epilepsy, like mental health disorders, is often associated with substantial stigma, particularly in poor areas. The identification of the main determinants that contribute to the stigmatization process is essential to establish the awareness and educational campaigns should have to overcome stigma and facilitate the development of biomedical programs aimed at treating epilepsy.

In order to manage people with epilepsy at a primary care level, knowledge about epilepsy needs to be enhanced among health professionals and communities awareness needs to be promoted. However, focused educational interventions and models should be developed considering the different backgrounds and the different roles of the health professional figures involved in the provision of care. This, associated with education for community members, people with epilepsy (PWE) and their family, could result in the reduction of some of the most important determinants of epilepsy TG.

a How needs were assessed

Thorough literature review as well as prevalence surveys were conducted to assess the unmet needs in terms of epilepsy in rural Bolivia. The University of Catania has had over 20 years of experience in this area. This was also complemented by discussions with local neurologists and healthcare professionals.

b Formal needs assessment conducted

Yes

Local Context, Equity & Sustainability

(16) Social inequity addressed

The Plurinational State of Bolivia is a low-income country where almost 4 million people live under the "poverty line"[14], especially in rural areas, and where access to the health system is still difficult, since the country has the lowest ratio of health workers per person of all the American countries, as low as 14.1 per 10,000 inhabitants[15]. This program is being conducted in three departments of Bolivia: the department of Santa Cruz, municipalities of Lagunillas (5366 inhabitants) and Gutierrez (12,273 inhabitants); the department of Chuquisaca, municipalities of Huacaya (2426 inhabitants) and Machareti (7062 inhabitants); and the department of Tarija, municipality of Villamontes (9572 inhabitants). These three departments are part of the Chaco region, which is a subtropical area of lowforests and savannas, inhabited by indigenous Guaraní people. They live in communities that often lack basic services such as running water or electricity, basing their economy on animal husbandry and agriculture.

(17) Local policies, practices, and laws considered during program design

POLICY, PRACTICE, LAW	APPLICABLE TO PROGRAM	DESCRIPTION OF HOW IT WAS TAKEN INTO CONSIDERATION
National regulations	No	N/A
Procurement procedures	No	N/A
Standard treatment guidelines	Yes	In line with local recommendations from the Bolivian Neurological Society
Quality and safety requirements	No	
Remuneration scales and hiring practices	Yes	Rely on local partners
Other	Yes	All training materialw, screening questionnaires as well as awareness materials have been reviewed and validated and/or approved locally. Awareness materials in particular adapted to local Guarani culture and representations and have benefited from the input of a local anthropologist.

(18) How diversion of resources from other public health priorities is avoided

[No response provided]

(23) Sustainability plan

There are potential plans to accredit the training courses as part of continuous professional development programs for General Practitioners and nurses.

Local Context, Equity & Sustainability

19 Program provides health technologies (medical devices, medicines, and vaccines)

No

20 Health technologies are part of local standard treatment guidelines

N/A

21 Health technologies are covered by local health insurance schemes

N/A

22 Program provides medicines listed on the National Essential Medicines List

N/A

23 Sustainability plan

No dedicated transition plan has been designed at this stage, however, capacity building and awareness activities have been previously proven to have a long lasting impact in this region. Moreover, this program is leveraging existing healthcare resources. Based on the results of the evaluation of this program, the plan is to demonstrate the cost-effectiveness of training and awareness activities and advocate for the authorities to roll-out similar activities in other rural areas.

Additional Program Information

24 Additional program information

[No response provided]

a Potential conflict of interest discussed with government entity

[No response provided]

25 Access Accelerated Initiative participant

Yes

26 International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) membership

Yes

Resources

1.   Murray CJ, Vos T, Lozano R, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet 2012;380:2197-2223

2.   Ngugi AK, Bottomley C, Kleinschmidt I, et al. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. Epilepsia 2010;51:883-890

3.   Declaration of Santiago on epilepsy in Latin America (2002) Epilepsia 43: 42

4.   Bruno E, Bartoloni A, Zammarchi L, Strohmeyer M, Bartalesi F, Bustos JA, Santivañez S, García HH, Nicoletti A; COHEMI Project Study Group. Epilepsy and neurocysticercosis in Latin America: a systematic review and meta-analysis.PLoSNegl Trop Dis. 2013 Oct 31;7(10):e2480

5.   Nicoletti A, Reggio A, Bartoloni A, Failla G, Sofia V, Bartalesi F, Roselli M, Gamboa H, Salazar E, Osinaga R, Paradisi F, Tempera G, Dumas M, Hall AJ (1999) Prevalence of epilepsy in rural Bolivia. a door-to-door survey. Neurology 53: 2064-2069

6.   Nicoletti A, Sofia V, Vitale G, Bonelli SI, Bejarano V, Bartalesi F, Tran DS, Preux PM, Zappia M, Bartoloni A (2009) Natural history and mortality of chronic epilepsy in an untreated population of rural Bolivia: a follow-up after 10 years. Epilepsia Oct;50(10):2199-206

7.   Bruno E, Bartoloni A, Sofia V, Rafael F, Magnelli D, Ortiz E, Padilla S, Quattrocchi G, Bartalesi F, Segundo H, Zappia M, Preux PM, Nicoletti A (2011) Sociocultural dimension of epilepsy: an anthropological study among Guaraní communities in Bolivia-an International League Against Epilepsy/International Bureau for Epilepsy/World Health Organization Global Campaign against Epilepsy regional project. Epilepsy Behav Oct;22(2):346-51

8.   Bruno E, Bartoloni A, Sofia V, Rafael F, Magnelli D, Padilla S, Quattrocchi G, Bartalesi F, Segundo H, Zappia M, Preux PM, Nicoletti A (2012) Epilepsy-associated stigma in Bolivia: A community-based study among the Guarani population: An International League Against Epilepsy/International Bureau for Epilepsy/World Health Organization Global Campaign Against Epilepsy Regional Project. Epilepsy Behav Aug 20

9.   Newton CR, Garcia HH. Epilepsy in poor regions of the world.Lancet. 2012 Sep 29;380(9848)

10. Nicoletti A, Reggio A, Bartoloni A, Failla G, Bartalesi F, Roselli M, Gamboa H, Salazar E, Paradisi F, Tempera G, Hall A (1998) A Neuroepidemiological survey in Rural Bolivia: Background and methods. Neuroepidemiology 17:273-280

11. Nicoletti A, Bartoloni A, Reggio A, Bartalesi F, Roselli M, Sofia V, Rosado J, Gamboa H, Paradisi F; Cancrini G, Tsang VCW, Hall AJ (2002) Epilepsy, cysticercosis and toxocariasis: a population based case-control study in rural Bolivia Neurology 58:1256-61

12. Nicoletti A, Bartoloni A, Sofia V, Bartalesi F, Rosado Chavez J, Osinaga R, Paradisi F, Dumas JL, Tsang VCW, Reggio A, Hall AJ (2005) Epilepsy and neurocysticercosis in rural Bolivia: a population based survey. Epilepsia 46: 1127-1132

13. CR Newton, HH Garcia (2012)Epilepsy in poor regions of the world. The Lancet 29;380(9848):1193-201

14. Poverty & equity data | Bolivia | TheWorld Bank. http://povertydata.worldbank.org/poverty/country/BOL, Accessed date: 13 January 2017.

15. segunda_medicion_metas_bol.pdf n.d

Program Indicators

Community-based epilepsy awareness and training program in rural Bolivia

27 List of indicator data to be reported into Access Observatory database

INDICATOR	TYPE	STRATEGY	2016	2017	2018	2019
1 Staff time	Input	All program strategies	83:832 hours	83:832 hours	83:832 hours	83:832 hours
2 Value of resources	Input	All program stragegies	$ 30,192	$ 25,827	$ 59,000	$ 25, 827
3 Communication materials in use	Output	Community Awareness and Linkage to Care	530 materials	0 materials	---	530 materials
4 Population exposed to oral communication activities	Output	Community Awareness and Linkage to Care	0 people	0 people	0 people	0 people
5 Knowledge Attitudes & Practices (KAP) of community members	Outcome	Community Awareness and Linkage to Care	---	---	---	---
6 Change in stigma related to epilepsy	Outcome	Community Awareness and Linkage to Care	---	---	---	---
7 GPs' Knowledge Attitudes & Practices (KAP)	Outcome	Health Service Strengthening	---	---	---	---
8 CHWs/nurses' Knowledge & Attitudes	Outcome	Health Service Strengthening	---	---	---	---
9 Number of people trained	Output	Health Service Strength-	169 people	0 people	29 people	0 people
10 Population screened	Output	Health Service Delivery	0 people	0 people	0 people	0 people
11 Number of patients diagnosed	Output	Health Service Delivery	0 people	0 people	0 people	0 people
12 Number of patients on treatment	Outcome	Health Service Strengthening	0 people	0 people	0 people	0 people
13 Communication materials developed	Output	Community Awareness and Linkage to Care	5 materials	0 materials	0 materials	1 material87

ITEM	DESCRIPTION
Definition	The ratio of the total number of paid hours during a year by the number of working hours in that period. This indicator excludes the time of volunteers or staff time for external partners.
Method of measurement	The ratio is also called Full Time Equivalent (FTE) Calculation: Sum of the number of paid hours per year Total number of working hours per year
28 Data source	Routine program data
29 Frequency of reporting	Once per year

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Company: Sanofi	Various Sanofi employees involved n the management and monitoring of this project track the number of hours they spend working on the project.	Ongoing
31 Data processing	Company: Sanofi	Time spent on the program by company staff is evaluated on a quarterly basis, so that data can be consolidated and annual Full Time Equivalent (FTE) estimated.	Every three months
32 Data validation		We do not conduct any further validation of our internal human resources records.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
1 Staff time	83:832 hours	83:832 hours	83:832 hours	83:832 hours

Comments:
2016, 2017, 2018, 2019: Numerator: 166, denominator: 1664. Unit for the numerator is "Hours worked" and the Unit for the denominator is "Total Hours in one Annual Full-Time Equivalent".

ITEM	DESCRIPTION
Definition	Total expenditure by company to operate program, including all expenditures that can reasonably be defined as necessary to operate the program.
Method of measurement	Program administrative records or accounting or tax records provide details in the expenditures on the program in a defined period of time. Calculation: Sum of expenditures (e.g., staff, materials) on program in US$
28 Data source	Routine program data
29 Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	The local project team (implementing partner) collects al the invoices to be paid. Finance makes the payments and keeps records of payments.	Ongoing
31	Data processing	Implementing partner: University of Catania	A member of the project team produces a financial report based on the program administrative and accounting records. The expenses for the year are summed at the end of the year.	Once per year
32	Data validation		Random audits of invoices might be conducted to validate financial records.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
2 Value of resources	$ 30,192	$ 25,827	$ 59,000	$ 25, 827

Comments: N/A.

Communication materials in use

STRATEGY   COMMUNITY AWARENESS AND LINKAGE TO CARE

ITEM		DESCRIPTION
	Definition	Number of communication materials introduced and in use by the program
	Method of measurement	Counting the number of communication materials created and in use by the program Calculation: Sum of communication materials created by the program
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	A member of the local team (implementing partner) will record every time a communication / awarenss activity takes place the number of materials distributed.	Ongoing
31	Data processing	Implementing partner: University of Catania	A member of the local team (implementing partner) sums the data.	Once per year
32	Data validation		We do not conduct any further validation of these data.	

33   Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR		2016	2017	2018	2019
3	Communication materials in use	530 materials	0 materials	---	250 materials

Comments:

2016: 400 leaflets + 100 copies of Poster + 30 copies of Flip chart + Radio information campaign.

2019: 250 comic books were distributed to 22 students to perform KAP study .

Population exposed to oral communication activities

4

	ITEM	DESCRIPTION
	Definition	Number of communication materials introduced and in use by the program
	Method of measurement	Counting of participants that attend campaign meetings Calculation: Number of people/participants in the target audience segment that participated/attended the community awareness campaign recorded in a given period of time
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	A member of the local team (implementing partner) will record every time an awareness activity takes place and will detail the date, location, province, and number of attendees.	Ongoing
31	Data processing	Implementing partner: University of Catania	A member of the local team (implementing partner) sums the data.	Once per year
32	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
4 Population exposed to oral communication activities	0 people	0 people	0 people	0 people

Comments:

2016, 2017: Awareness activities have not started yet in the new areas.

2018, 2019: Awareness activities of the 2nd phase of the program have not started yet in the new areas.

Knowledge Attitudes & Practices (KAP) of community members

STRATEGY   COMMUNITY AWARENESS AND LINKAGE TO CARE

	ITEM	DESCRIPTION
	Definition	Knowledge Attitudes & Practices of community members is evaluated before and after Community Awareness campaigns
	Method of measurement	The evaluation of the Knowledge Attitudes & Practices of community members occurs through the use of a pre-tested adapted KAP questionnaire. The questionnaire includes between 12 questions for which differences between responses before and after the training will be estimated using McNemar test.
28	Data source	Non-routine program data
29	Frequency of reporting	One-time event

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	A member of the local team (implementing partner) will conduct the interview with the KAP questionnaires before and after the communication activty took place.	One-time event
31	Data processing	Implementing partner: University of Catania	Data entry is completed by a member of the local team (implementing partner). Scoring and analysis is conducted by the implementing partner and results are communicated once the statistical analysis is completed.	One-time event
32	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
5 Knowledge Attitudes & Practices (KAP) of community members	---	---	---	---

Comments: The program evaluation (sample size: 216 subjects from 17 rural communities) confirms that continuous educational campaigns lead to a significant change in the social perception and attitudes toward epilepsy. A significant improvement was recorded in knowledge, attitudes, and practices toward epilepsy. For more details, please refer to the article: Giuliano et Al; Knowledge, stigma, and quality of life in epilepsy: Results before and after a community-based epilepsy awareness program in rural Bolivia; Epilepsy & Behavior 92 (2019) 90–97; https://doi.org/10.1016/j.yebeh.2018.11.036;

Change in Stigma related to Epilepsy

STRATEGY   COMMUNITY AWARENESS AND LINKAGE TO CARE

ITEM		DESCRIPTION
	Definition	Difference in the perception of epilepsy related stigma by patients and members from the community between before and after the community awareness activities
	Method of measurement	Epilepsy related stigma is evaluated through the completion of a Stigma Scale of Epilepsy (SSE) questionnaire, a multiple-choice questionnaire containing 24 items grouped in 5 domains. Patients and members of the community will be interviewed with the SSE questionnaire before and after the community awareness activities.The score after the community awareness activities will be compared with the score before the activities
28	Data source	Non-routine program data
29	Frequency of reporting	One-time event

		RESPONSIBLE	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	The validated Stigma Scale of epilepsy (SSE), previously used and adapted to this population is administered to a sample of members from the community. The participants are identified from the census available at the health centers and are selected using a random list generator. Interviews are conducted by members of the implementing partner, before and after the community awareness activities.	One-time event
31	Data processing	Implementing partner: University of Catania	Data entry is conducted by a member of the local team (im-plementing partner). Scoring and analysis is completed by the implementing partner and results are communicated once the statistical analysis is completed.	One-time event
32	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
6 Change in stigma related to Epilepsy	---	---	---	---

Comments: Stigma Scale of Epilepsy (SSE) total score went from 38.3 ± 14.7 to 28.5 ± 12.3; pb 0.01, reflecting a reduction of stigma levels. The SSE total score ranges from zero, which is the lowest level of stigma, to 100, which is the highest stigma level. The study (sample of 216 subjects from the 17 rural communities that have been involved in the program) confirms that continuous educational campaigns lead to a significant change in the social perception and attitudes toward epilepsy. For more details, please refer to the article: Giuliano et Al; Knowledge, stigma, and quality of life in epilepsy: Results before and after a community-based epilepsy awareness program in rural Bolivia; Epilepsy & Behavior 92 (2019) 90–97; https://doi.org/10.1016/j.yebeh.2018.11.036.

INDICATOR **GPs' Knowledge Attitudes & Practices (KAP)**

STRATEGY   HEALTH SERVICE STRENGTHENING

ITEM		DESCRIPTION
	Definition	Knowledge Attitude and Practices is evaluated before and after training sessions
	Method of measurement	Knowledge Attitude and Practices are being evaluated through an adapted and pre-tested question-naire before and after the training sessions.
		Each of the Knowledge Attitude and Practices sections of the questionnaire includes between 5 and 26 questions for which différences between responses before and after the training will be estimated using McNemar test.
28	Data source	Non-routine program data
29	Frequency of reporting	One-time event

		RESPONSIBLE	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	At the beginning of a training session and at the end of it, a member of the local team (implementing partner) asks each participant to fill in a KAP questionnaire.	One-time event
31	Data processing	Implementing partner: University of Catania	Data entry is completed by a member of the local team (im-plementing partner). Scoring and analysis is conducted by the implementing partner and results are communicated once the statistical analysis is completed.	One-time event
32	Data validation		We do not conduct any further validation of these data.	

33   Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR		2016	2017	2018	2019
7	GPs' Knowledge Attitudes & Practices (KAP)	---	---	---	---

Comments: The program evaluation shows a significant impact of specific training programs on epilepsy among GPs. Before the training, most GPs declared a low level of satisfaction about their epilepsy knowledge, which improved after the courses. Also, a change in practic-es was recorded after the training, with an increased confidence to manage antiepileptic treatment. For more details, please refer to the article: Giuliano et Al; Knowledge, attitudes, and practices towards epilepsy among general practitioners in rural Bolivia: Results before and after a training program on epilepsy; Epilepsy & Behavior 83 (2018) 113–118; https://doi.org/10.1016/j.yebeh.2018.02.030.

CHWs/nurses' Knoweldge Attitudes & Practices (KAP)

8

STRATEGY   HEALTH SERVICE STRENGTHENING

ITEM	DESCRIPTION
Definition	Knowledge and Attitude before and after training sessions
Method of measurement	Knowledge and Attitudes are being evaluated through an adapted and pre-tested questionnaire before and after the training sessions. The Knowledge section of the questionnaire includes 9 questions and the and Attitude section includes 11 questions. Differences between responses before and after the training will be estimated using McNemar test.
28 Data source	Non-routine program data
29 Frequency of reporting	One-time event

	RESPONSIBLE	DESCRIPTION	FREQUENCY
30 Data collection	Implementing partner: University of Catania	At the beginning of a training session and at the end of it, a member of the local team (implementing partner) asks each participant to fill in a Knowledge & Attitudes questionnaire.	One-time event
31 Data processing	Implementing partner: University of Catania	Data entry is completed by a member of the local team (implementing partner). Scoring and analysis is conducted by the implementing partner and results are communicated once the statistical analysis is completed.	One-time event
32 Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
8 CHWs/nurses' Knoweldge Attitudes & Practices	---	---	---	---

Comments: The program evaluation (sample size: 119 subjects from CHW and nurses) showed good baseline knowledge, attitudes and practices towards epilepsy and no significant change after the training program. This can be explained by the hypothesis that over the last 20 years, many projects have been carried out in the Chaco region, with the main aim of enhancing knowledge about epilepsy and, consequently, reducing the Treatment Gap. Also, unlike the GPs who move every year to different rural areas, non-specialist healthcare providers remain the only persons responsible for providing healthcare to PWE. This evaluation confirms the usefulness of continuous educational campaigns, especially directed to non-specialist healthcare providers of rural communities of LMIC . For more details, please refer to the article: Giuliano et Al; Knowledge and attitudes towards epilepsy among nonmedical health workers in rural Bolivia: Results after a long-term activity in the Chaco region; Epilepsy & Behavior 85 (2018) 58–63; https://doi.org/10.1016/j.yebeh.2018.05.026;

INDICATOR **Number of people trained**

STRATEGY HEALTH SERVICE STRENGTHENING

	ITEM	DESCRIPTION
	Definition	Number of trainees
	Method of measurement	Counting of people who completed all training requirements Calculation: Sum of the number of people trained
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE	DESCRIPTION	FREQUENCY
30	Data collection	[No response provided]	A member of the local team (implementing Partner) asks each GP, nurse and CHW attending a training workshop to sign their name on an attendance form. Data are collected at the time of each training workshop.	Ongoing
31	Data processing	Implementing partner: University of Catania	A member of the local team of the implementing partner reviews the number of attendees per training session and consolidates the data from each session into the total number of people having attended the training for each type of training.	Ongoing
32	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
9 Number of people trained	169 people	0 people	29 people	0 people

Comments:

2016: 50 GPs + 119 Nurses & CHW.

2018: 8 GPs, 16CHWs, 3 Nurses, 2 traditional healers.

ITEM	DESCRIPTION
Definition	Number of individuals screened for disease as a result of the screening test or procedure being provided by the program. Screening activities could include any screening procedures (mammogram, cholesterol measurement, colonoscopy, etc.) delivered directly to a specified population, by the program. Screening activities are often preventive in nature and aim to look for diseases or conditions prior to symptoms developing.
Method of measurement	Counting of people who were screened for disease in the program Calculation: Sum of the number of people screened
28 Data source	Non-routine program data
29 Frequency of reporting	One-time event

	RESPONSIBLE	DESCRIPTION	FREQUENCY
30 Data collection	Implementing partner: University of Catania	A group of nurses and CHWs, previously trained on epilepsy and on the administration of the screening questionniare, screen, through face-to-face interviews with householders, all the population of their communities for the presence of persons with convulsive epilepsy. They use a Spanish language questionnaire for convulsive seizures validated in the Gran Chaco area.	One-time event
31 Data processing	Implementing partner: University of Catania	Data entry is completed by a member of the local team (implementing partner). Data analysis is conducted by the implementing partner and results are communicated once the statistical analysis is completed.	One-time event
Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
10 Population screened	0 people	0 people	0 people	0 people

Comments:

2016, 2017: Screening was not part of the first phase of the program.

2018, 2019: Screening has not started yet.

ITEM	DESCRIPTION
Definition	Number of patients that were diagnosed with disease through the program
Method of measurement	Counting of people who were diagnosed with disease through the program Calculation: Sum of the number of people diagnosed with disease
28 Data source	Non-routine program data
29 Frequency of reporting	One-time event

		RESPONSIBLE	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	People who have screened positive through the epilepsy screening questionnaire see the neurologist to have confirmation of their diagnosis. Data is collected via a questionnaire for each suspected case when they see the neurologist.	One-time event
31	Data processing	Implementing partner: University of Catania	People who have screened positive through the epilepsy screening questionnaire see the neurologist to have confirmation of their diagnosis.	One-time event
	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
11 Number of patients diagnosed	0 people	0 people	0 people	0 people

Comments:

2016, 2017: Patients screening and diagnosis was not part of the first phase of the program

2018, 2019: Patients screening and diagnosis has not started yet.

	ITEM	DESCRIPTION
	Definition	Number of people that received treatment through the program
	Method of measurement	Counting of people who received treatment through the program Calculation: Sum of the number of people treated
28	Data source	Non-routine program data
29	Frequency of reporting	One-time event

		RESPONSIBLE	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	A member of the implementing partner will ask each patient identified through the door-to-door screening campaign, and diagnosed with epilepsy by the neurologist, a set of questions about their antiepileptic treatment in order to assess the baseline treatment gap. This will be repeated again 12 months after the initial GP training.	One-time event
31	Data processing	[No response provided]	Data entry is completed by a member of the local team (implementing partner). Data analysis is conducted by the implementing partner and results are communicated once the statistical analysis is completed. Data is collected via a questionnaire for each suspected case when they see the neurologist.	One-time event
	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

[No response provided]

INDICATOR	2016	2017	2018	2019
12 Number of patients on treatment	0 people	0 people	0 people	0 people

Comments:

2016, 2017: Not included in the evaluation of the first phase of the program.

2018, 2019: Not started yet.

ITEM	DESCRIPTION
Definition	Number of materials (e.g., Behavior Change Communication materials, training materials etc...) specifically developed or adapted for and by the program
Method of measurement	Counting the number of different communication materials developed for and by the program Calculation: Sum of number of communication materials developed for and by the program
Data source	Routine program data
Frequency of reporting	One-time event

		RESPONSIBLE	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: University of Catania	A member of the local team (implementing partner) reports on any new Behavior Change Communication or training materials developed for the program, and provides a copy of the final tool.	Ongoing
31	Data processing	Company: Sanofi	A member of my company consolidates the information provided by the implementing partner.	Once per year
	Data validation		We do not conduct any further validation of these data.	

33 Challenges in data collection and steps to address challenges

We do check that the number of tools recorded match the actual number of tools which we have a copy of.

INDICATOR	2016	2017	2018	2019
13 Communication materials in use	5 materials	0 materials	0 materials	1 material

Comments:

2016: 1 educational video+1 flipchart + 1 leaflet + 1 poster + 1 radio message to inform about awareness activities.

2019: 1 comic book.

Program Documents

Program Documents

1. Giuliano, L., Cicero, C.E., Padilla, S., et al. Knowledge, stigma, and quality of life in epilespy: Results before and after a community-based epilepsy awareness program in rural Bolivia. Epilepsy & Behavior 92 (2019) 90-97. https://www.epilepsybehavior.com/article/S1525-5050(18)30776-5/fulltext

2. Giuliano, L., Cicero, C.E., Padilla, S., et al. Knowledge, attitudes, and practices towards epilepsy among general practitioners in rural Bolivia: Results before and after a training program on epilepsy. pilepsy & Behavior 83 (2018) 113-118. https://www.epilepsybehavior.com/article/S1525-5050(18)30004-0/fulltext

3. Giuliano, L., Cicero, C.E., Padilla, S., et al. Knowledge and attitudes towards epilepsy among nonmedical health workers in rural Bolivia: Results after a long-term activity in the Chaco region. Epilepsy & Behavior 85 (2018), 58-63. https://linkinghub.elsevier.com/retrieve/pii/S1525505018302865

Appendix

This program report is based on the information gathered from the Access Observatory questionnaire below.

Program Description

PROGRAM OVERVIEW

1 Program Name

2 Diseases program aims to address:

Please identify the disease(s) that your program aims to address (select all that apply).

3 Beneficiary population

Please identify the beneficiary population of this program (select all that apply).

4 Countries

Please select all countries that this program is being implemented in (select all that apply).

5 Program Start Date

6 Anticipated Program Completion Date

7 Contact person

On the public profile for this program, if you would like to display a contact person for this program, please list the name and email address here (i.e. someone from the public could email with questions about this program profile and data).

8 Program summary

Please provide a brief summary of your program including program objectives (e.g., the intended purposes and expected results of the program; if a pilot program, please note this). Please provide a URL, if available. Please limit replies to 750 words.

PROGRAM STRATEGIES & ACTIVITIES

9 Strategies and activities

Based on the BUSPH Taxonomy of Strategies, which strategy or strategies apply to your program (please select all that apply)?

10 Strategy by country

If you have registered one program for multiple countries, this question allows you to provide a bit more specificity about each country (e.g. some countries have different strategies, diseases, partners, etc.). Please complete these tables as applicable. For each portion you have you selected from above (program strategies), please identify which country/countries these apply.

COMPANIES, PARTNERS AND STAKEHOLDERS

11 Company roles

Please identify all pharmaceutical companies, including yours, who are collaborating on this program:

What role does each company play in the implementation of your program?

12 Funding and implementing partners

Please identify all funding and implementing partners who are supporting the implementation of this program (Implementing partners is defined as either an associate government or non-government entity or agency that supplements the works of a larger organization or agency by helping to carry out institutional arrangements in line with the larger organization's goals and objectives.)

a. What role does each partner play in the implementation of your program? Please give background on the organization and describe the nature of the relationship between the organization and your company. Describe the local team's responsibilities for the program, with reference to the program strategies and activities. (response required for each partner selected).

b. For each partner, please categorize them as either a Public Sector, Private Sector, or Voluntary Sector partner.

(Public Sector is defined as government; Private Sector is defined as A business unit established, owned, and operated by private individuals for profit, instead of by or for any government or its agencies. Generation and return of profit to its owners or shareholders is emphasized; Voluntary Sector is defined as Organizations whose purpose is to benefit and enrich society, often without profit as a motive and with little or no government intervention. Unlike the private sector where the generation and return of profit to its owners is emphasized, money raised or earned by an organization in the voluntary sector is usually invested back into the community or the organization itself (ex. Charities, foundations, advocacy groups etc.))

c. Please provide the URL to the partner organizations' webpages

13 Funding and implementing partners by country

If you have registered one program for multiple countries, this question allows you to provide a bit more specificity about each country (e.g., some countries have different strategies, diseases, partners, etc.). Please complete these tables as applicable. For each portion you have you selected from above (funding and implementing partners), please identify which country/countries these apply.

14 Stakeholders

Please describe how you have engaged with any of these local stakeholders in the planning and/or implementation of this program. (Stakeholders defined as individuals or entities who are involved in or affected by the execution or outcome of a project and may have influence and authority to dictate whether a project is a success or not (ex. Ministry of Health, NGO, Faith-based organization, etc.). Select all that apply.

• Government, please explain
• Non-Government Organization (NGO), please explain
• Faith-based organization, please explain
• Commercial sector, please explain
• Local hospitals/health facilities, please explain
• Local universities, please explain
• Other, please explain

LOCAL CONTEXT, EQUITY & SUSTAINABILITY

15 Local health needs addressed by program

Please describe how your program is responsive to local health needs and challenges (e.g., how you decided and worked together with local partners to determine that this program was appropriate for this context)?

a How were needs assessed

b Was a formal need assessment conducted

(Yes/No) If yes, please upload file or provide URL.

16 Social inequity addressed

Does your program aim to address social inequity in any way (if yes, please explain). (Inequity is defined as lack of fairness or justice. Sometime 'social disparities,' 'structural barriers' and 'oppression and discrimination' are used to describe the same phenomenon. In social sciences and public health social inequities refer to the systematic lack of fairness or justice related to gender, ethnicity, geographical location and religion. These unequal social relations and structures of power operate to produce experiences of inequitable health outcomes, treatment and access to care. Health and social programs are often designed with the aim to address the lack of fairness and adjust for these systematic failures of systems or policies.*)

*Reference: The definition was adapted from Ingram R et al. Social Inequities and Mental Health: A Scoping Review. Vancouver: Study for Gender Inequities and Mental Health, 2013.

17 Local policies, practices, and laws considered during program design

How have local policies, practices, and laws (e.g., infrastructure development regulations, education requirements, etc.) been taken into consideration when designing the program?

18 How diversion of resources from other public health priorities is avoided

Please explain how the program avoids diverting resources away from other public health priorities? (e.g. local human resources involved in program implementation diverted from other programs or activities).

19 Program provides health technologies

Does your program include health technologies (health technologies include medical devices, medicines, and vaccines developed to solve a health problem and improve quality of lives)? (Yes/No)

20 Health technology(ies) are part of local standard treatment guidelines

Are the health technology(ies) which are part of your program part of local standard treatment guidelines? (Yes/No) If not,

what was the local need for these technologies?

21 Health technologies are covered by local health insurance schemes

Does your program include health technologies that are covered by local health insurance schemes? (Yes/No) If not, what are the local needs for these technologies?

22 Program provides medicines listed on the National Essential Medicines List

Does your program include medicines that are listed on the National Essential Medicines List? (Yes/No) If not, what was the local need for these technologies?

23 Sustainability plan

If applicable, please describe how you have planned for sustainability of the implementation of your program (ex. Creating a transition plan from your company to the local government during the development of the program).

ADDITIONAL PROGRAM INFORMATION

24 Additional program information

Is there any additional information that you would like to add about your program that has not been collected in other sections of the form?

a Potential conflict of interest discussed with government entity

Have you discussed with governmental entity potential conflicts of interest between the social aims of your program and your business activities? (Yes/No) If yes, please provide more details and the name of the government entity.

25 Access Accelerated Initiative participant

Is this program part of the Access Accelerated Initiative? (Yes/No)

26 International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) membership

Is your company a member of the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)? (Yes/No)

Program Indicators

INDICATOR DESCRIPTION

27 List of indicator data to be reported into Access Observatory database

For this program, activities, please select all inputs and impacts for which you plan to collect and report data into this database.

28 Data source

For this indicator, please select the data source(s) you will rely on.

29 Frequency of reporting

Indicate the frequency with which data for this indicator can be submitted to the Observatory.

30 Data collection

a. Responsible party: For this indicator, please indicate the party/parties responsible for data collection.

b. Data collection — Description: Please briefly describe the data source and collection procedure in detail.

c. Data collection — Frequency: For this indicator, please indicate the frequency of data collection.

31 Data processing

a. Responsible party: Please indicate all parties that conduct any processing of this data.

b. Data processing— Description: Please briefly describe all processing procedures the data go through. Be explicit in describing the procedures, who enacts them, and the frequency of processing.

c. Data processing — Frequency: What is the frequency with which this data is processed?

32 Data validation

Description: Describe the process (if any) your company uses to validate the quality of the data sent from the local team.

33 Challenges in data collection and steps to address challenges

Please indicate any challenges that you have in collecting data for this indicator and what you are doing to address those challenges.