



REPORT OF THE TECHNICAL GROUP 6 MEETING
ON INFORMATION, EDUCATION AND COMMUNICATION

Chagas Disease

Kick-off Meeting **2017**

Geneva, Switzerland,
5-6 october 2017



World Health
Organization

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Background

1

Chagas disease (also known as American trypanosomiasis) is caused by the protozoan parasite *Trypanosoma cruzi*. According to the World Health Organization (WHO) between 6 and 7 million people are estimated to be infected, principally in the 21 Latin American continental countries, in the called endemic area. Moreover, it is estimated that >10,000 people die annually due to the disease (1). The infection is mainly transmitted through the faeces/urine of hemaphagous triatomine bugs (vectorial transmission), known as “vinchucas”, “chinchés”, “barbeiros” or “kissing bugs” (among many other names, depending on the geographical area). The infection can also be transmitted by: the ingestion of food contaminated with the faeces/urine of infected insects; infected women during pregnancy or at birth (congenital transmission); blood transfusions or organ transplantation from infected donors; and even through laboratory accidents. Although more than half of people with positive serological results of infection present no symptoms, it is estimated that a third of them develop cardiac, digestive, neurological or mixed clinical manifestations.

Due to its extent and consequences, it has been considered one of the most important public health problems in Latin America. At the same time, the growing population mobility modified the epidemiologic characteristics of this and other diseases (2, 3, 4), and currently it is predominantly an urban problem (two thirds of the infected people live in urban areas) and Chagas disease cases have been found outside Latin America, in Canada, the United States of America, many European and some Western Pacific countries (2).

In that scenario, one of the main challenges for health systems is the large percentage of undiagnosed cases. Worldwide, it is estimated that <10% of people carrying the *T. cruzi* infection know their condition and, consequently, a large number of individuals do not look for adequate healthcare (1, 4).

Alternately to the biomedical denomination of “Chagas disease”, throughout this report we will refer, as well, to “Chagas”, with a broader meaning, to refer, also, to the psychological, legal, socio-economic (etc.) problematic that affects people infected by *T. cruzi* (most of whom will never develop the disease) and their relatives and societies.

(1)WHO, Integrating neglected tropical diseases in global health and development [Internet]. World Health Organization. [Cited 31 January 2018]. Available at: http://www.who.int/neglected_diseases/resources/9789241565448/en/

(2)Coura JR, Vinas PA. Chagas disease: a new worldwide challenge. *Nature* 2010; 465 (n7301_suppl): S6-S7.

(3)Velarde-Rodríguez M, Avaria-Saavedra A, Gómez-i-Prat J, Jackson Y, Oliveira Junior WA, Camps-Carmona B, Albajar-Viñas P. Need of comprehensive health care for *T.cruzi* infected immigrants in Europe. *Revista da Sociedade Brasileira de Medicina Tropical* 2010; 42 (Supl.II): 92-95.

(4)Basile L, Jansà JM, Carlier Y, Salamanca DD, Angheben A, Bartoloni A, Seixas J, Van Gool T, Cañavate C, Flores-Chávez M, Jackson Y, Chiodini PL, Albajar-Viñas P, Working Group on Chagas Disease. Chagas disease in European countries: the challenge of a surveillance system. *Euro Surveill.* 2011; 16(37)

Background

To the frequent recognized barriers to healthcare, three additional challenges are frequently identified: the mobility of the population affected by Chagas disease, mainly by reason of job search; the challenge to recognize, diagnose and take care of infected individuals in places where the disease is not endemic and unknown; the irregular migration condition of the affected people jeopardizing the access to health system.

Due to all factors involved in its existence, the authors defend that speaking about Chagas disease is much more than speaking about a disease. In this regard, the fact of recognizing the biomedical, epidemiologic, sociocultural, political and economic aspects of its complexity, makes necessary approaches of research, prevention, control and treatment that offer comprehensive answers in accordance with the particularities of current scenarios (5), especially in the globalization framework, where population mobility and communication constitute both a reality and a challenge for health teams and services.

The care of affected people ("dentro y fuera" de las llamadas áreas endémicas), therefore, requires a comprehensive and active approach and challenges the health teams and systems, considering not only a biomedical approach, but also others, counting on environmental, housing, psychological, political, social and cultural aspects linked to people lives. It is also essential to pay particular attention to the information flows, the processes of empowerment and participation that today's social and health policies require for their successful implementation. Challenges accentuated in the present context are: eliminar las barreras que impiden el acceso al diagnóstico oportuno y a una atención integral de calidad; to avoid situations and processes in which the disease leads to exclusion and stigmatization; to actively work to demystify the fatalistic disease vision that entails and paralyzes people and health systems (5, 6, 7, 8, 9). It is necessary to promote health rights, so to guarantee access to healthcare and social integration. To advance in the approach of Chagas, it is essential to walk with firm steps in processes of health promotion and social participation, elements that constitute the foundations and sustainability of democratization processes.

In the current scenario, the lack of access to timely, comprehensive and quality care of people who have Chagas, pose an obvious call for attention where international organizations, both those directly related to the health of the population, as others indirectly linked to different aspects of the health of people and their environments, have a key role: beyond all the biomedical aspects that must be reviewed, there are countless elements belonging to other spheres and dimensions that should be taken into account with the same seriousness and rigor (10). Currently, as Ventura-Garcia et al. (11) pose, we find that there is a paradox: although the importance of social and cultural factors is broadly acknowledged, current approaches to neglected tropical diseases (NTDs) almost always neglect aspects of the socio-cultural - biological - environmental triad. This results in a narrower understanding of Chagas disease and hampers sustainable prevention and control.

In particular, through the Programme on control of Chagas disease, WHO has evidenced the need to focus the people affected by this disease, underlining the negligence associated to the control and health-care, which implies that affected children, young people, women and men frequently do not have health, work and other conditions of a dignified life, even if >100 years ago the disease was already described and the population continues to be neglected in its basic rights.

Echoing the mentioned call for attention and considering the need of going beyond the biopsychosocial components, the WHO Programme on control of Chagas disease decided to add a sixth, new and particular Technical Group (TG) to the five previously existing (about epidemiological surveillance and information systems, transfusional and organ transplantation transmission, screening and diagnosis, congenital transmission and case management of congenital and paediatric cases and case management of adult cases): the Technical Group No.6 on Information, Education and Communication (TG6-IEC).

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Background

About the Technical Groups:

The Technical Groups (TG) of the Programme on Control of Chagas disease, Innovative and Intensified Disease Management Unit (IDM), Department of Control of Neglected Tropical Diseases (NTD), WHO, were created in 2007/2008 following the recommendations of the WHO meeting "Revisiting Chagas disease: from Latin American Health perspective to Global Health perspective", Geneva, 4 - 6 July, 2007.

For each of the existing Chagas disease challenges different approaches are needed. And each TG was invited to identify, for the very beginning, key actors to be involved (international, national, departmental, municipal, governmental and nongovernmental, public and private, scientific and civilian, institutions, partners, stakeholders...), taking into account their: i) history/background to Chagas disease; ii) explicit and implicit interests; iii) idiosyncratic power/responsibility and natural performance area.

Objectives of the Technical Groups

One of the implicit objectives was to re-enforce links and coordination between key actors to become more efficient and effective. The scientific world seldom has got a political and Public Health vision of health challenges and it does not have a governmental power. On the other hand, governmental authorities seldom have a good and updated knowledge of technical items related to Chagas disease. So, both of them are crucial, and they have different and important roles. At any moment, each TG can invite institutions/partners/stakeholders with the possibility of giving inputs, design, develop and implement projects.

Each TG creates annual objectives and methodology. The planning of the working group can include very different annual goals. For example: a meeting for reaching a methodological consensus on a non-standardized tool; an assessment/consultancy for the use and distribution of an instrument at international level; a WHO official document giving support to international needed control activities in a particular geographical area; among many others.

Finally, TG work closely/synchronously with the national and international governmental meetings ("Initiatives") in order to update and give/receive good technical advice/consultancy (exchange of information) in their annual/biannual meetings, which generate consensus documents to be approved in the regular minister of health meetings.



2

Introduction

The first meeting of the Technical Group No.6 on Information, Education and Communication (TG6-IEC) of the WHO Chagas disease control program was organized by the WHO in Geneva, on October 5-6, 2017.

The goals of the meeting were:

- To configure the fundamental aspects of the TG6 work, such as mission, vision and objectives.
- To identify the principal lines of work and propose the milestones to be developed in the 2018-2020 period.
- To define work strategies, chronogramme and responsibilities.

In his opening remarks, Dr. Pedro Albajar-Vinas, Manager of the Programme on control of Chagas disease, exposed the justification for the proposal to create a new Technical Group, especially the reported difficulty of affected populations to have access to health systems and healthcare and the present underdiagnosis of *T. cruzi* infection (>90%) among those affected. In 2007 five technical groups were created to deal with different biomedical challenges and assess or propose instruments and approaches. Nevertheless, none of them were dedicated to psychological, social, cultural or anthropologic dimensions or focusing information, education and communication (IEC) related to Chagas disease.

Introduction

In 2012 the WHO Roadmap for implementation (Accelerating work to overcome the global impact of neglected tropical diseases) included the objectives of the elimination of transfusional transmission in the Americas, Europe and Western Pacific and the elimination of domiciliary vectorial transmission in Latin America before 2020. On the other hand, additionally to Latin America, Chagas disease cases have been diagnosed in Canada and the USA, 17 European countries and two Western Pacific countries and due to population movements, it is estimated that Chagas disease cases may be found in other continents, including some countries of Africa and Southeast Asia.

In this context, the members of the TG6 were invited to participate because of their knowledge and professional experience, additionally to come from different professional sectors and geographical origins (from different Member States), what brings to the TG their comprehensiveness and internal richness. The active contribution from the TG is needed and its recommendations or conclusions about any topic are achieved through the consensus. This particular TG provides to WHO independent technical support on various aspects related to IEC and recommendations or advice to the WHO Programme at global level or whenever there is the involvement of two or more regions of the planet. Afterwards WHO has to assess the convenience and possibility to implement the recommendations of the TG6. As it is of normal praxis, the members of the TG6 were asked about possible conflicts of interest and none of them referred to have any.

Dr. Jordi Gómez i Prat (Catalonia) was elected as the Chairperson of the meeting, Dr. Andrea Avaria (Chile) as its co-chairman and Dr. Mariana Sanmartino (Argentina) as the Rapporteur. The agenda is included in the Annex 1 and the list of participants in the Annex 2. This report was prepared by Jordi Gómez i Prat, Mariana Sanmartino and Andrea Avaria with the contributions of all participants and the support of the WHO secretariat (Dr. Pedro Albajar Viñas and Ms. Stéphanie Jourdan).

The content of the sections that follow is the product of the consensual work and result of the discussion at the meeting based on the objectives that guided the two days of work. Accordingly, we need to clarify which part of the concepts expressed in this document will be revised subsequently, based on the agreed work plan, understanding that they could later be modified, expanded and enriched, and considering that theoretical revision will be carried out as one of the main tasks agreed by the members of the TG6 during the meeting.



Profile of **TG6IEC**

3.1. Who we are

The Technical Group 6 (TG6-IEC) is convened by the Programme on Control of Chagas Disease, Department of Control of Neglected Tropical Diseases (NTD), WHO to make technical contributions in the areas of Information, Education and Communication (IEC) around to problem of Chagas . It is composed of a group of people, professionals from different disciplines and geographical origins, with wide and varied experience in the subject. Without conflicts of interest and with independence, it is expected that the group will meet periodically to collectively evaluate the diversity of realities where Chagas exists, evaluate instruments and define strategies and methodological proposals to address in a contextualized manner each of the three areas: Information, Education and Communication (IEC) in relation to Chagas.

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3.2. Membership

This group does not speak on behalf of WHO and is not representative of its Member States. However, it is responsible for advising WHO, with evaluations and technical contributions for the agency, with the aim of collaborating globally in the incidence of the problem of Chagas, within the framework of the United Nations.

IEC strategies require a multidisciplinary team so as to be able to carry out tasks in an interdisciplinary and intersectoral manner. For this reason, it was deemed appropriate that the TG6-IEC should be configured with a very particular profile of professionals with the aim of covering the multiple disciplines necessary for IEC work, not only from these three specific components, but also from community work, social mobilization, management, and other areas.

For this reason, the TG is made up of people with shared and intersecting paths and recognized experiences in different fundamental areas to carry out the actions of the group in a simultaneously rigorous, committed and creative way. The members of the TG6-IEC are specialists in education, anthropology and social and community mobilization; specialists in public and community health; members of associations of people affected by Chagas disease; and art and health experts.

The current members of the TG6-IEC are:

Ana Maria de Arruda Camargo

Assistente Social. Mestre em Serviço Social pela Pontifícia Universidade Católica de São Paulo- Brasil. Doutoranda em Gerontologia - Faculdade de Ciências Médicas –FCM- Universidade Estadual de Campinas-UNICAMP/Brasil.

Temas estudados, investigados, publicados: Controle Social e participação social de usuários no Hospital de Clínicas-UNICAMP. Atenção e cuidado à pessoa idosa na atenção básica de Saúde em Campinas. Chagas e Trabalho no Meio Urbano. Associações Cívicas e garantias dos direitos de saúde: experiência de um grupo de portadores de doença de Chagas. Desafios e perspectivas na organização do cuidado à saúde da população idosa na atenção básica – uma revisão bibliográfica.

Exerce a atividade profissional no Hospital de Clínicas-HC/UNICAMP na atenção aos usuários atendidos no ambulatório de Doença de Chagas. Integra o Grupo de Estudos em Doença de Chagas-GedoCh/UNICAMP. É membro do Conselho Científico da Associação de Portadores de Doença de Chagas de Campinas e Região-ACCAMP e do Conselho Consultivo da Federação Internacional de Associações de pessoas afetadas pela doença de Chagas-FINDECHAGAS. É responsável pelo atendimento social, integrando a equipe de saúde, aos usuários do ambulatório de Geriatria. Coordena o Grupo de Educação em Saúde “Flor da Terceira Idade”. É supervisora titular do Programa de Aprimoramento em “Serviço Social, Saúde e Envelhecimento” da FCM/UNICAMP. Exerceu a tutoria do Curso de Educação a Distância –EAD “Saúde e Envelhecimento da Pessoa Idosa” da Fundação Osvaldo Cruz-FIOCRUZ. Ministrou aula em Faculdades de Serviço Social: Faculdade Santa Lucia em Mogi Mirim, Faculdade Salesiana Dom Bosco em Americana e Pontifícia Universidade Católica de Campinas. Elabora e contribui na organização de material de cunho educativo e informativo: folhetos, vídeos, jornais, etc... relacionados a doença de Chagas, Doenças Negligenciadas, Direitos à saúde e Envelhecimento. Participa, organiza e coordena eventos, fóruns de discussão, seminários relacionados a estes temas. Desenvolve abordagens sobre estes temas em oficinas, aulas, rodas de conversa. Contribui para o fortalecimento do controle social por parte da sociedade civil organizada, como as associações de pessoas vivendo com doença de Chagas para conquista de legislação como as Leis Municipais aprovadas em três municípios da região instituindo o Dia Municipal da Pessoa Vivendo com Doença de Chagas, a Semana Municipal de Conscientização sobre as Doenças Negligenciadas e o Projeto de Lei Nacional sobre Doenças Negligenciadas.

Andrea Avaria

PhD in Advanced Studies in Social Anthropology, from the University of Barcelona. Master in Anthropology and Development from the University of Chile, Social Worker from the Universidad de la Frontera in Chile.

In Barcelona she carried out an applied investigation with Bolivian people affected by Chagas disease, which allowed to know the ways in which people are affected by Chagas in the framework of migration and to understand, the mechanisms through which the team intervened in a non-endemic disease. Her research contributed to lay the foundations of community and social intervention, in relation to Chagas disease in Unitat de Medicina Internacional Drassanes at Barcelona. She currently works in teaching and research at the Autonomous University of Chile and the Alberto Hurtado University. Develop social research in health. Currently thanks to a Postdoctoral Fondecyt (3160106) she develops the line of reproductive health and migrations. She has researched and published in areas of health and migration.

Her interests in both intervention and research, has conjugated with other interest as photography, watercolor, elements that interact creatively, both in her intellectual work, as in working with groups and community intervention, as well as in the development of intervention strategies with people affected by Chagas disease.

She has laid the foundations of community work with the Bolivian population in the Unit of Tropical Medicine and International health Drassanes of the Catalan Institute of Health, has been a founding member of the Association of people affected by Chagas disease and is member of the Advisory Board of the International Federation of Associations of People Affected by Chagas Disease (FINDE-CHAGAS).

Arturo Solari

Fine Arts artist, Expressive Arts Therapist (ISPA Institute, Barcelona, Spain), Educational Expressive Arts Facilitator (Salve Regina University, RI, USA) and Social Educator (UNED University, Spain). Born in Mexico City (Mexico), he developed as a Fine Arts artist at various art institutes in Mexico and Catalonia (Spain), as well as at different artists' studios and ateliers, some of them in Italy. He has presented more than a hundred solo and group exhibitions in numerous countries. His artistic work relates to the intention of Art as an instrument of transformation of consciousness and society. He has coordinated several public pictorial projects, murals and artistic works.

He has worked with expressive arts for a wide range of groups: inmates in penitentiary centres-centers, substance abusers, HIV-AIDS affected people, migrants, illiterate adults, women victims of violence, elderly, children and teenagers with personality disorders, Chagas disease affected people, etc.

Between 2009 and 2017 he was part of the chore educational staff at the Expressive Arts Therapy Master Degree at ISPA and IATBA Institutes (Barcelona).

As an expressive arts therapist, he consults privately in Girona (Spain). He also offers professional supervision on the same field.

Since 2006 he has participated in several artistic, educational, therapeutic and healthcare programs for a variety of people related to Chagas in different areas, all driven at the Drassanes-Vall d'Hebron Unit of Tropical Diseases and International Medicine (Barcelona).

Profile of TG6

Cristina Carrazzone

Degree in Medicine and Specialist in Hematology at the University of Pernambuco-UPE / Brazil. Master in Public Health, by the Ministry of Health / Oswaldo Cruz (Brazil).

Foundation / Aggeu Magalhães-FIOCRUZ Research Center. Medicine Member of the Reference Service in Chagas Disease of the State of Pernambuco-PROCAPE / UPE.

Collaborator in various research projects and publications in Chagas' disease. Her research line involves the social, cultural and artistic area for patients people with Chagas disease, Coordinator of CorArte Project: Heart with Art, developed with patients in service in the Reference Service. Adviser and Member of the "Pernambuco Association of Patients with Chagas Disease" (APDCIM), the first association of people affected by Chagas disease in the world, created in 1987. Member of the Advisory Board of the International Federation of Associations of People Affected by Chagas Disease (FINDECHAGAS).

Isabel Claveria Guiu

Diploma in nursing. Master in International Health and Tropical Medicine. Post degree in Health Promotion and Health Education (University of Barcelona).

Author of the pedagogical guide of the Program of the expert patient Catalonia® in chronic phase of Chagas disease of the Catalan Institute of Health. Trainer of expert patients and coordinator of patient groups. Author of various educational materials: "Saber o no saber. Me siento bien, dicen que tengo la enfermedad de Chagas" (informative and documentary film about Chagas disease in an european context), "Around me" (educational game about the determinants of health), among others.

Principal investigator of the research module project for primary care professionals Barcelona. XB 2012 Plan of the Institut Català de la Salut. Research: "Knowledge regarding Chagas disease in patients and health professionals, in a non-endemic environment: are there differences?" Founding member of the Association Friends of the People affected by Chagas disease (ASAPECHA) where continues to be an active member. Organizing member of the 2nd FINDECHAGAS Assemblé, held in Barcelona in 2012.

She works as a nurse in the Health Unit of International Drassanes-Vall d'Hebron of Barcelona since 1999, serving people affected by Chagas disease and working with their communities.

Jordi Gómez i Prat

Degree in Medicine and Surgery, Universitat de Barcelona. Specialist in Clinical Infectology and Parasitology, Fundação Medicina Tropical, Manaus, Brasil. Master Science in Public Health, "Escola Nacional de Saúde Pública/Fundação Oswaldo Cruz". Rio de Janeiro, Brazil.

Currently, he is a consultant physician at the Infectology Department-International Health Drassanes Unit, Hospital, Hospital Universitari Vall d'Hebron, Collaborator in various research projects and publications in the field of international health (community health approach in Sexual Affective Health, Tuberculosis and Chagas disease and in the Health Determinants). Previously collaborator in research and public health projects in the field of malaria and public health in the Amazon basin, Brazil.

Artist, mainly in the fields of drawing, painting and writing. Both disciplines, medicine and art, are used in his career for the creation of Health Education tools (www.espictools.cat), in different formats (games, songs, documental, animations, etc), specific in the field of International Health. Foundational Member of the "Asociación de Personas Afectadas por la Enfermedad de Chagas de Barcelona" (ASAPECHA). Member of the Advisory Board of the International Federation of Associations of People Affected by Chagas Disease (FINDECHAGAS).

Maria Cristina Parada

A Spanish national, born in Bolivia. She graduated in Biochemistry and Pharmacy, from the Universidad Real and Pontifical University of San Francisco Xavier de Chuquisaca, Bolivia. Specialist in Microbiology and Bacteriology, Gabriel René Moreno University, Santa Cruz, Bolivia. She completed a Diploma in advanced studies and research, University of Valencia - Spain; Master in Tropical Medicine, University of Valencia-Spain and Master in International Health, University of Alicante – Spain. She has completed the Active Chronic Patient Leader Course, Ministry of Health of the Valencian Community, Spain.

She is a founding member of ASAPECHAVAE (Association of people affected by Chagas disease, volunteers and friends) Valencia - Spain, July 2009, and a founding member of FINDECHAGAS (October 2010). She is also a founding partner of ACHACOVA (Association of Chagas disease in the Valencian Community). Member of the Advisory Board of the International Federation of Associations of People Affected by Chagas Disease (FINDECHAGAS).

She is the author of a number of publications on the subject of Chagas. Throughout her professional career she has carried out various activities related to people affected by Chagas: Workshops, lectures and talks on pathology, groups from endemic areas, indigenous people and health, in addition to screening campaigns. People who test positive for the disease are referred to health services for possible treatment and subsequent follow-up. Psychological care for carriers, family and social environment. Meetings of Mutual Aid and Self Help.

Mariana Sanmartino

She was born in the city of Córdoba (Argentina). Biologist (Universidad Nacional de Córdoba, Argentina), Specialist in Social Sciences, with mention in Hhealth (Facultad Latinoamericana de Ciencias Sociales), Specialist in Epistemologies of the South (Consejo Latinoamericano de Ciencias Sociales) and PhD in Education Sciences (Université de Geneve, Suisse).

The guiding thread of her career is the search for elements that make it possible to understand the problem of Chagas from an integral perspective and, at the same time, highlight the role of education and communication as key tools to address this complex and current issue.

Independent researcher of the National Board of Scientific and Technical Research (Consejo Nacional de Investigaciones Científicas y Técnicas, CONICET). Her current research subject is "Analysis and development of didactic strategies and resources to deal with Chagas disease in different educational contexts." Her work is being developed in the "Grupo Didáctica de las Ciencias" (La Plata, Argentina), through research activities, teaching, communication and extension.

She is founder and coordinator of the group ¿De qué hablamos cuando hablamos de Chagas? (www.hablamosedechagas.com), whose main objective consists of promoting an approach of Chagas from an integrated and innovative perspective in different educational contexts, employing various languages to communicate understandings of the subject. Linking multiple voices, diverse artistic expressions and unconventional spaces, the group seeks to install the Chagas theme in different scenarios, aiming to strengthen the role of education and communication in the public treatment of this problem.

She is member of the Advisory Board of the International Federation of Associations of People Affected by Chagas Disease (FINDECHAGAS).

Profile of TG6

Mariella Anselmi

Graduated in Medicine and Surgery at the University of Padua (Italy); PhD in Tropical Diseases from "La Sapienza" University (Rome, Italy).

Since 1979 volunteer in Ecuador, Esmeraldas province, in Primary Health Care interventions with a focus on community epidemiology and community control of prevalent health problems (malaria, yaws, onchocerciasis).

From 1998 to 2010 coordinator of the Chagas intervention at the Tropical Medicine Centre of the Sacro Cuore-Don Calabria de Negrar Hospital (Verona, Italy).

She is the author and co-author of various publications on Chagas disease and community participation in the control of prevalent health problems.

She is also responsible for the intervention for community control of Chagas in Awa indigenous communities in the province of Esmeraldas (Ecuador).

She is also President of the Centre for Community Epidemiology and Tropical Medicine (Cecomet) of Esmeraldas (Ecuador), founding member of the Ailmac (Associazione italiana di lotta alla malattia di Chagas) and member of the Advisory Board of the International Federation of Associations of People Affected by Chagas Disease (FINDECHAGAS).

Wilson Oliveira Jr.

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Master in Tropical Medicine, Federal University of Pernambuco, Brazil.

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Vision, mission, general objective of TG6-IEC

4.1. Vision

In line with the principles of the WHO Constitution, the vision of the TG6-IEC is that - in those parts of the world where Chagas exists - people, families and communities can: enjoy a healthy life, live in healthy environments, enjoy access to comprehensive care to address the problem of Chagas, exercise their right to health, have access to appropriately trained teams, and enjoy universal and holistic access to health care. Society as a whole will ensure a social and legal structure that protects the rights of people, with institutions and structures that respect and strengthen these rights (health, labour, social), empower their autonomy, self-management and organization, in the framework of a healthy life.

4.2. Mission

The TG6-IEC is a multidisciplinary group convened to make scientific-technical contributions to the WHO Chagas Disease Control Programme. From an interdisciplinary / intersectorial approach to public health, the TG6-IEC contributes to the achievement of the objectives of the programme, taking into account geographical, historical, cultural, political, social, etc. characteristics of the contexts where the problem of Chagas exists. Considering all the social stakeholders involved, through Information, Education and Communication (IEC), the TG6 enhances the exercise of health rights, the treatment of people affected by the disease, their families and communities, seeking to eliminate or remove the social, structural, subjective and objective barriers that prevent, hinder or exclude them from the development of a healthy life.

4.3. General objective

The TG6-IEC aims to promote a comprehensive approach to the problem of Chagas - from a technical-scientific and humanistic approach- through the development and dissemination of resources and strategies of Information, Education and Communication (IEC), in line with the objectives of the WHO Chagas Disease Control Programme.

Below are the objectives that will guide the work of the TG6, which we consider to be one of the main results of the discussions held at the meeting. From them, a series of strategic proposals are presented that are also presented in this section, which constitute a first approximation to the work that we will develop in these first years. Therefore, it should be clarified that they will be adjusted, updated and rethought, based on the progress made in the work of the TG6.

5.1. Specific and strategic objectives

Specific objective 1. Influence the generation, discussion and updating of information, to adequately communicate the multiplicity of aspects related to the problem of Chagas.

Strategies for the achievement of specific objective 1.

1. Validation of training strategies (individual and collective) for free access to information on Chagas, oriented to health teams, the educational system, diverse institutions, the media, etc.
2. Development of impact assessment instruments and relevance of information strategies about the problem of Chagas implemented in various contexts.



Specific objectives and areas of work

Specific objective 2. Disseminate resources and strategies in the areas of information, education and communication through the identification, systematization, development and dissemination of relevant and contextualized proposals, within the framework of respect for the rights of people, as well as in coordination with different stakeholders and institutions.

Specific objective 3. Contribute with guidelines and proposals that allow the different social stakeholders (communities, health teams, educational stakeholders, social communicators, etc.) to increase information, education and communication strategies aimed at a healthy life for persons affected by Chagas and their families and communities.

Strategies for the achievement of specific objectives 2 and 3.

1. Systematization of communication and education strategies on the Chagas problem implemented worldwide.
2. Construction of a bank of information and freely available materials bringing together various Chagas-related education initiatives developed around the world.
3. Development of communication models and education initiatives and strategies, with free access oriented to the education of health teams, institutions, teachers and communicators, individuals and communities.

5.2. Areas of work and activities

During the meeting, a series of activities were agreed upon, based on proposals that were prioritized as soon as we recognized the possibility of initiating - through specific actions - the path that will lay the foundations for the group's work.

By way of synthesis, the group's activities are based on the following considerations:

1. The group will work on projects and specific activities based on the various components and scope of IEC.
2. The group is multidisciplinary in nature.
3. We propose a group that creates, constructs, distributes, discusses and shares what it produces.
4. We propose the construction, production, organization, dissemination of a critical-humanist stance that involves knowledge in a broad sense linked to the problem of Chagas.
5. We recognize the need to develop and promote an approach to the problem of Chagas that involves a transformation of subjects and reality.

6. It is proposed to seek / generate / disseminate approaches (recommendations, actions, resources, etc.) to bridge the big gap between knowledge produced in laboratories and academic settings and the daily reality of people and communities affected, to organized groups of civil society around the problem of Chagas and the population in general.

7. It is considered urgent and inescapable to take on a commitment to promote the leading role of communities in addressing the Chagas problem.

Among the main lines of work agreed, it was proposed to start with the following:

1) Definition of basic concepts: review and update of concepts linked to the information, education and communication areas; construction of a glossary linked to the three particular areas approaching the topic "Chagas" in general; preparation of a manual of good practices. To this end it is also necessary to identify the language and ways in which knowledge about Chagas is produced and communicated worldwide.

2) Preparation of comprehensive training proposals focused on: professionals and technicians; teachers, communicators and facilitators; persons affected, relatives and the "general public", i.e. propose online training spaces to facilitate access to material and exchange of reflections and experiences, and encourage an updated and critical approach to the subject that complements and promotes the work of people associated in some way with the problem of Chagas.

3) Create a database of IEC strategies and informative and educational resources in different languages: both from the survey and analysis of experiences and materials produced in different parts of the world; as well as the creation and dissemination of new resources and initiatives. We propose the possibility of using the BEATCHAGAS platform (<http://beatchagas.org>) created at the request of previous contacts between TG6 members.

4) Build strategies that facilitate, through the use of ICTs (Information and Communication Technologies), actions around incidence / surveillance, not only at an epidemiological but also at a social level, i.e. the ability to detect social situations of exclusion, vulnerability, stigmatization, discrimination, etc. that make it possible to lay the groundwork for the development of specific actions (political action, intervention, communication, education, etc.).

5) Responsibilities of WHO.

As a result of the discussion, in the light of the diversity in the language around Chagas, its use and the particularities of the variety of contexts, it was decided as a priority - and as a preliminary work of the group - to carry out the following activities:

- a. Carry out an exhaustive bibliographical review in relation to the terminology related to "Information", "Education" and "Communication", in general and specifically around the topic "Chagas".
- b. Develop and edit a (working) glossary of the terminology related to information, education and communication in Chagas and underlying and central aspects of the problem.



Concepts of Information, Education and Communication

6

In accordance with the agreed lines of work and the challenges we decided to address, and as discussed in the previous section, the unquestionable starting point should be a clear update and positioning in relation to certain concepts linked to the sphere of action of TG6. For this reason, and also bearing in mind the diversity found in the literature and the variability of uses and definitions around the three key areas of our task, we believe that the group's research, reflections and output should begin with the concepts of "Information", "Education" and "Communication".

For the time being, recognizing the importance of the challenge outlined here, we wish to share some considerations published by the WHO -aiming to encourage a critical appraisal of them- and a brief summary of the discussions at our own meeting.

6.1. WHO: “Information, education and communication”

What is Information, Education and Communication? Information, education and communication initiatives are grounded in the concepts of prevention and primary health care. Largely concerned with individual behavior change or reinforcement, and/or changes in social or community norms, public health education and communication seek to empower people vis-à-vis their health actions, and to garner social and political support for those actions. IEC can be defined as an approach which attempts to change or reinforce a set of behaviors in a “target audience” regarding a specific problem in a predefined period of time. It is multidisciplinary and client-centred in its approach, drawing from the fields of diffusion theory, social marketing, behavior analysis, anthropology, and instructive design. IEC strategies involve planning, implementation, monitoring and evaluation. When carefully carried out, health communication strategies help to foster positive health practices individually and institutionally, and can contribute to sustainable change toward healthy behavior.

Countries, health services and NGOs often develop posters, flyers, leaflets, brochures, booklets, messages for health education sessions, radio broadcast or TV spots, etc. as a means of promoting desired, positive behaviors in the community. In some cases, these activities are part of a communication plan within a comprehensive strategy, while in many others they are isolated actions. These initiatives are commonly referred to broadly as “Information, education and communication (IEC)” activities.

An operational -and classical- definition of “IEC” refers, as mentioned, to a public health approach aiming at changing or reinforcing health-related behaviors in a target audience, concerning a specific problem and within a pre-defined period of time, through communication methods and principles.

Even considering that it needs to be reviewed critically, this definition helps emphasize the need for IEC initiatives to: have a clear objective; target a specific audience; address a specific problem (rather than attempt to face many problems at the same time); set a timeframe within which the results are expected to occur.

It is obvious that this requires a detailed plan, the implementation of which needs to be monitored closely according to pre-set indicators, and then properly evaluated.

Activities following these principles and meeting the above definition can be considered IEC initiatives, with a higher potential to achieve the stated objective than the others. Thus, for example, the development of a poster without the following elements would not be a structured IEC initiative (audience analysis; testing; a plan with objectives, indicators and targets; a clear target audience; a distribution plan with follow-up; regular feedback through monitoring; and a formal evaluation).

6.2. Discussion within the group

As mentioned, another of the key moments of the meeting consisted of sharing - and at the same time, putting into dialogue - the knowledge and practices of the members of the TG6 around the three basic concepts of the IEC proposals: information, education and communication, separately. Three groups were formed and each element was discussed by each group. At the end the results of the discussions were presented and common points were identified.

The discussion showed the need to take stock, update and review the issues raised. And at the same time it became clear that not all three elements of the triad “IEC” are necessarily involved in each case; the decision to address one, two or all three of them depends on issues such as: the objectives, the topic to be addressed, the stakeholders involved, the participating institutions, the historical context, the geographical context, the budget, etc.

By way of conclusion, we were able to synthesize in a “simple” yet forceful way the central aspects that we identified for each of the three elements in the following way:

Inform= “Make aware”

Information consists of data and knowledge on a specific topic. Its circulation and democratization are fundamental when it comes to promoting knowledge and recognition of knowledge. In other words, it also implies recognizing that in local and cultural contexts, the knowledge thus produced is differentiated and popular knowledge which must be taken into consideration, i.e. it is necessary to recognize that from each subject, and from the place that it occupies in social and health structures, “knowledge” is produced that is put into play in the social sphere: popular knowledge, usually reviled or despised, medical and “scientific” knowledge, generally validated and hegemonic.

2 Many lessons have been learnt over the years in using IEC (information, education and communication) in public health. The document “Information, education and communication – Lessons from the past; perspectives for the future” provides a concise, user-friendly summary of many of them in just a few pages. Prepared for the WHO Department for Reproductive Health and Research, most of the lessons described in the paper are relevant and applicable to any IEC intervention.

The information, by itself, does not guarantee either the appropriation of certain concepts by the “public” or the dialogue of knowledge. Appropriation and production of knowledge and dialogue of knowledge are instances that are sought and promoted through the understanding of phenomena and the transformation of power-knowledge relationships; from discussion, listening, education and communication.

It is essential to recognize that, in any act of informing, we can identify intentionalities that bring into play the decisions about what and how to be informed (hegemonic and institutional knowledge) in certain circumstances or when faced with certain topics or contexts (and therefore, reproduce power relations and hegemonic relations).

Educate= “Transform”

In the group discussions on what is meant by education, a series of points of debate and reflection were reached, unanimously recognizing the importance of educating as a key means of transforming reality.

Education understood as a dialogue of knowledge, as a means that promotes reflection, as opposed to banking education (which poses a unidirectional position that only recognizes the value of one of the stakeholders, and where the learners are conceived as passive entities). Education implies transformation; it also implies teaching skills and capacity for reflection; it involves putting knowledge into action from a critical and contextualized perspective. It means deconstructing, reconstructing and building knowledge, practices and experiences.

The tools brought into play in the act of educating are very important. In addition to “knowing” about the subject in particular, it is essential to know the different kinds of knowledge circulating among the learners in order to start a true dialogue. The interaction of knowledge is a way of aggregating parts and building the whole, it means going from appearances to the essence of a topic, problem, or reality. It means to emerge, to unveil the occult in its concreteness in a relationship from inside to outside and from outside to inside incorporating this process of transformation.

Education also involves exchanging, listening carefully, and collectively constructing new meanings.

Communicate= “Share”

Communication implies a dialogue, and like all dialogues, the most essential elements are the inescapable importance of the listening capacity of the interlocutors, and the need to take account of the diversity of stakeholders and contexts to adapt the instruments of communication to the reality of particular audiences.

We also agree with the diversity of forms of expression and languages that allow communication, beyond words (music, images, gestures, etc.). We also agree that the nonverbal is often undervalued.

For communication to be effective, it is necessary to know about the subject being addressed but also to have common codes that enable one to question and actively involve the different stakeholders since we consider that emitter and receiver interact dynamically and are also roles that continuously interchange.

Current media have accelerated and multiplied the channels of communication in an unusual way and that poses important challenges. We also recognize a great variety in the types of communication: digital / face-to-face, critical / uncritical, unidirectional / bidirectional / multidirectional, etc.

We are in a moment of era transformation where digital communication has taken centre stage. We are faced with a revolution in the forms of communication in the framework of which we can recognize a certain impoverishment or loss of depth of communication in the face of the multiplication and complexification of media.



Conclusions

7

The participants of the meeting concluded that:

1. The Technical Group 6 on Information, Education and Communication to control Chagas disease (TG6-IEC) is a new technical group that will provide technical support to WHO.

2. The TG will be composed of various expert members with particular individual profiles that bring forth richness from diversity (see point 3.2.), but with the following important points in common:

- a. The humility, commitment, quality and warmth of the human group.
- b. A comprehensive and complex view of the Chagas problem.
- c. Close link with communities.
- d. Extensive overview of various aspects of IEC-based components in the approach to Chagas.

3. The targets of the TG are:

- a. To incorporate information, education and communication into the "normal" approach to Chagas..
- b. To incorporate the humanist contribution.
- c. To detect gaps in certain aspects of IEC..
- d. To consider the historical moment: in the twenty-first century context where information and the media have so much presence and power, there is an important challenge to react appropriately.
- e. To detect and define the challenges and opportunities in IEC generated by the change of era.
- f. To evaluate the working methodology: methodologies incorporating a dialogical relationship that transcends the three spheres (information, education and communication). An alternative way to proceed is emerging, suggesting a different methodology which we need to take account of.
- g. To respond to the demands of WHO.

Conclusions

We conclude and emphasize the importance of the historical framework in which this meeting took place. There is a clear demand from the United Nations Sustainable Development Goals, of which Chagas disease forms a part, in addition to a precise and specific demand by WHO in relation to Chagas disease. Taking all this into account, the Chagas programme clearly needs to incorporate the group in order to complement the comprehensive approach to the Chagas problem. It is therefore pertinent to share the words of Dr Daniel Dagne, Coordinator of the WHO Programme on Neglected Tropical Diseases: "Today we prefer to use the term health promotion instead of health education and in that context we really need your group to create education and communication strategies and adapt them to their local contexts. This requires different disciplines and cross-cutting work."

The humanist contribution of the group should help to identify the important gaps in certain aspects of IEC, and to overcome the challenges of the era transformation by providing a new paradigm. It is a slow but feasible process, the important thing is to press ahead in the knowledge that each step leads to better results.

Annex 1. Schedule

Thursday 5 October

Morning (9:00 – 13:00):

Time	Activity
8:30	Arrival at WHO
9:00	Reception by WHO
9:15	Programme on Control of Chagas Disease and technical groups
9:30	Presentation of the agenda. Methodology of the meeting. Drafting the report
9:45	Presentation (5 minutes to prepare and write the response to the fourth question on one side of paper): Where do I come from? Where am I? Where do I think the TG6 will take me/us? What will I bring to the process? (Why was I invited?)
11:00	Break
11:15	Presentations, continued.

Afternoon (14:00 – 18:00)

Time	Activity
14:00	Reading and discussion on vision, mission, general objective
15:00	Operation of Ezcollab and identification of communication and work tools
16:00	Break
16:15	Debate on concepts of Information, Education and Communication in three subgroups. Synthesis of conclusions on each element
17:00	Specific objectives: brief outline with view of discussion on day 2
17:15	Wrap-up Adjustments to agenda for day 2
17:30	Close

Friday 6 October

Morning (9:00 – 13:00)

Time	Activity
8:30	Adjustment and definition of specific objectives
9:00	Work on ideas and proposals: group discussions to categorize and select (initially, 5 minutes of solo work to note down ideas on hand-outs)
10:15	Synthesis and discussion of group work (explanation and consensus-building around inclusion, exclusion and organization criteria)
11:00	Break
11:15	WHO needs
11:45	Update and discussion on future of Beatchagas
12:15	Identification of actions going forward (including group output, future of Beatchagas platform and WHO needs). Relationship between strategies, schedule, point persons, target group(s)

Afternoon (14:00 – 18:00)

Time	Activity
14:00	(Cont.) Identification of actions going forward (including group output, future of Beatchagas platform and WHO needs). Relationship between strategies, schedule, point persons, target group(s)
14:45	First version of strategies, schedule, point persons
15:00	Thought shower on words/elements to be defined, "clearing the ground", etc.
13:30	Solo work on conclusions and recommendations
16:00	Break
16:15	Consensus-building around conclusions and recommendations
17:00	Group wrap-up exercise
18:00	Close

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REPORT OF THE TECHNICAL GROUP 6 MEETING
ON INFORMATION, EDUCATION AND COMMUNICATION

Chagas Disease

Kick-off Meeting

2017