BRINGING CANCER PREVENTION CLOSER TO THE MOST VULNERABLE POPULATION

What have we achieved?

The achievements include a high level of inter-sector participation of professionals and social stakeholders (32 women and 27 men), the interconnection of assets for health and the direct involvement of 11 female agents who participate in grassroots community health and who were able to prepare, conduct and evaluate 9 workshops in which 132 persons mostly from North Africa and Spain participated (124 women and 7 men). However, there were difficulties in reaching out to the Roma and Romanian populations.

According to the PRE questionnaire, most of the workshop participants who responded (80.6%) know about existing cancer screening programs and 71% declare that they can prevent it with healthy behaviours.

When comparing the PRE-POST questionnaires completed by participants, the increase in the number of persons who correctly answer the question about the multi-factorial origin of cancer after the workshops is 14.3%. This percentage is even greater (19%) if we include the participants that gave adequate answers to the three questions about information on cancer, which increased from 41.7% in the PRE to 60.5% in the POST. The attitudes towards preventive practices in the POST questionnaire saw an increase of 11% amongst the persons who refer to willingness to participate in early detection programs, and amongst those who acknowledge that their life is not entirely healthy, there was a 9% increase in declared willingness to set about making preventive changes after the workshop.

As regards the qualitative evaluation, the health agents commented that peer relations were established, with mutual aid and social support that had an effect on people's health that goes beyond the workshops.

Selection and participation of community health workers

The selection was made by the technical team of the community health project for highly vulnerable districts operating in the municipalities of Algemesí and Alzira (RIU project) according to a pre-defined profile (democratic leadership, communication skills, interest in health and in offering support), the objectives and activities of the intervention, the responsibilities of the health and their availability.

12 female grassroots community health workers were selected (6 per municipality) one of whom withdrew for health reason. No male or Romanian female health workers could be selected for work reasons. A Romanian women of Roma ethnic background was contacted for the Romanian-Spanish translations during the workshops.

Table 1 shows the socio-demographic data of the eleven female health workers who participated in the project.

Table 1. Socio-demographic data of the 11 female health workers who participated in the project

Age	Number of health workers	Place of residence	Number of health workers
26-35	5	Highly vulnerable districts	7
36-45	2	Rest of municipality	4
46-55	4		
Education		**Country of birth/ethnicity**	
No school certificate	3	Spain	2
With school certificate	3	Spain, Roma ethnicity	3
Secondary school diploma or equivalent	4	Morocco	5
BA or equivalent	1	Algeria	1
Social class			
VI	11		

Professionals participating in the project

Given that cancer prevention does not depend solely on the health sector (public health and healthcare), it was decided to apply an inter-sector approach to the intervention. Partnerships were established between professionals from different sectors in order to include a focus on health and equality in their work and also to generate experiences in collaborative work. Joint working dynamics were also promoted between professionals and citizens (represented by the health workers) in designing, organising, preparing, conducting and evaluating the activities. 59 professionals and social stakeholders (32 women and 27 men) from politics, health, social welfare, the environment, sports, education, media and the social fabric participated in the intervention. Table 2 shows the persons responsible in politics, services management, professionals and social stakeholders who participated.

Table 2. Professionals and social agents who participated in the project

Sector	Service	Professional profile	Gender		Project stage
			Female	Male	
Local politics	Social Welfare Health	Departments	2	1	organisation coordination
Health	FISABIO (research foundation)	Psychology Sociology Socio-cultural activities	1 1 0	0 0 1	coordination design execution dissemination evaluation
	Public Health Centre	Management Medicine Nursing	0 1 0	1 1 1	organisation execution dissemination evaluation
	Hospital	Preventive Medicine	1	0	design execution evaluation
	General Directorate of Public Health	Assistant director	0	1	organisation
Social welfare	Social services	Head office Social education Social work	0 2 1	1 1 1	organisation design execution dissemination evaluation
	Equality, town hall	Psychology	1	0	dissemination
Environment	Town hall	Architecture	0	1	execution
Sports	Town hall	Sports and physical activities	0	1	execution
Education	Schools	Management, teaching staff	3	1	dissemination
Social fabric (groups, associations, platforms)	Neighbourhood associations	Chairperson	0	3	dissemination
	Falla and fiestas	Chairperson	1	1	dissemination
	Social associations	Technicians, managers	5	0	dissemination
	Religious bodies	Persons responsible for worship	0	4	dissemination
	Senior citizens	Chairperson	1	0	dissemination
	Citizens' platforms: District community board and community board of fight against poverty	Different profiles	11	5	dissemination
Media	Radio stations	Journalism	1	2	dissemination
TOTAL 8 sectors			32	27	

Participants in the workshops

The workshops were attended by 132 participants (124 women and 7 men) in both municipalities. The gender roles (caring for health is associated with women in different cultures) and the type of activity go to explain the low attendance rate of men.

The ethnic make up of the female participants was 58.87% women from North Africa (especially Morocco and to a lesser extent from Algeria), 29.03% Spaniards and 10.48% Spaniards of Roma ethnic background. Table 3 shows the data of the population that attended the workshop with the information divided by municipalities, gender and country of birth and ethnic background.

As the table shows, the populations mostly reached out to were the North African and Spanish populations. Work could be done on the information about the risk factors and cancer prevention, and on the screening programs and the barriers that prevent the North African population from participating in them. The dissemination work carried out by the health agents amongst the North African population was effective, especially the work done in workshops with already established groups that met to carry out other activities (e.g. learning the Spanish language). Another important factor that enabled some women to go to the workshops and make maximum use of them was having a babysitting service (carried out by community health agents) for minors.

However, the participation of the Roma population was very low. The reasons explaining this fact are the beliefs and attitudes they hold with regard to cancer and the idea of death and non-healing, fear of the diagnosis and the consequences of the disease and treatments and avoiding talking about cancer and the risk and/or prevention factors. The concepts of health/disease and prevention held by the Roma population are other factors that played a part.

Neither was it possible to conduct the workshop provided in Alzira with Romanian persons due to a lack of attendance. We believe that the information about the activity did not reach the target population. It was not possible to collaborate in the project with one of the education centres that has a large proportion of Romanian persons and Romanians of Roma ethnic background.

Finally, it should be pointed out that the age of the persons participating in the workshops was very diverse and did not always fit in with the ages planned for in the breast and bowel cancer screening programs. Some of the persons who attended the workshops were 40 and over 65 years of age.

Table 3. Population attending the workshops, according to country of birth, ethnicity and gender

Country of birth and ethnic background	Alzira		Algemesí		Both municipalities		
	Women	Men	Women	Men	Women	Men	Total
Spain	28 (50.91%)	5 (83.33%)	8 (11.59%)	1 (50%)	36 (29.03%)	6 (75%)	42 (31.82%)
Spain with Roma ethnic background	0	0	13 (18.84%)	0	13 (10.48%)	0	13 (9.85%)
Romania with Roma ethnic background	0	0	1 (1.45%)	0	1 (0.81%)	0	1 (0.76%)
North Africa (Morocco, Algeria)	26 (47.27%)	1 (16.67%)	47 (68.12%)	1 (50%)	73 (58.87%)	2 (25%)	75 (56.82%)
Senegal	1 (1.82%)	0	0	0	1 (0.81%)	0	1 (0.76%)
Total	55	6	69	2	124 (93.94%)	8 (6.06%)	132

Connections between assets for health

The organisation and dissemination of the workshops was carried out by connecting different types of assets for health (persons, groups and associations, services and institutions, physical spaces and infrastructures and resources related to the local economy) in order to reach out to populations in fragile situations. Tables 4 and 5 show the connections between the assets for health that were established in each municipality.

The largest number of connected assets for health are the ones corresponding to the "persons" category. It should be pointed out that they are not exclusively professionals of services and institutions but rather the citizens themselves (community health agents, local residents, representatives of associations, owners of small businesses, etc.), considered to be key players for community intervention.

It should also be mentioned that the groups and associations category also stands out, where alongside the associations that work on social inclusion, there were neighbourhood, religious, Roma, migrant and other associations.

Therefore the protagonists in this community intervention are persons (especially grassroots community health workers), who are key players in health promotion activities since they have skills that can be used to make further progress in community empowerment processes (skills in observation analysis, reflection, decision making and action). Other developments include peer relations, mutual aid and social support that impact people's health and welfare and that spread beyond the context of the workshops (guidance and advice in the neighbourhood,

accompaniment when going to health services, etc.) as the health agents have indicated in the evaluation sessions.

On the other hand, collaborative relationships have been established between professionals from different services that initially seemed far distant from being able to make any contributions towards preventing cancer in the most fragile population.

Connections have also been established between more or less homogeneous groups of the population (Roma people's association, residents' and senior citizens' groups, etc.) and health agents from different cultures, thus promoting spaces for rapprochement and dialogue between cultures. These are windows of opportunity for generating trust, understanding and for deconstructing prejudices and stereotypes.

This same situation has arisen by promoting working relations between persons in fragile situations and professionals in services. These are the first steps in laying foundations for more horizontal relations that shall have future repercussions not only amongst citizens but also on the working procedures of technical personnel and service organisations.

Finally, it should be pointed out that the connection between assets located in the most vulnerable districts and those identified in other zones of the municipalities, as shown in the tables, has contributed towards breaking the isolation of groups of the population and the segregation of more fragile environments.

Ultimately, building networks and relations between citizens, representatives of community groups and associations, professionals and service managers has an effect on generating bridging social capital[1] (generating relations between heterogeneous members that belong to different socio-cultural groups) and linking social capital (connections between the members of local communities and institutions) to create good community health.

[1]Villalonga-Olives E, Kawachi I. The measurement of social capital. Gac Sanit. 2015;29(1):62-4.[Consulted 13/05/2017]. Available at: http://gacetasanitaria.elsevier.es/es/the-measurement-socialcapital/articulo/S0213911114002416/

Table 4. Connected assets for health in Algemesí for workshops and their dissemination

Types of connected assets	Territorial location	
	Highly vulnerable district of Algemesí	**Other areas of Algemesí**
Persons	Community health workers of the RIU project Female neighbours of community health workers Roma neighbours Parents of education centres Management of education centres Technical staff of RIU project Owner of newspaper kiosk Roma matriarch Pastor of the evangelical church Pharmacist	Community health workers of the RIU project Female neighbours of the community health workers Monitors of socio-cultural centre Members of neighbourhood association Volunteer workers of NGO Caritas Agricultural cooperative workers Equality agent of the town hall Health centre midwives Management of education centres Social service personnel Imam of Islamic centre
Groups or associations	Group of male bowls players Roma association	Red Cross (social inclusion association) Caritas (social inclusion association) Amics Providència (inclusion association) L'Eixam (gender equality association) Tolerancia (Islamic association Tyrius (housewives' association)
Services and institutions	Pre-school and primary education centre Pharmacy Evangelical church	Pre-school and primary education centre Secondary Schools Public Adult Education Centre Social services Public Health Centre Socio-cultural centre Town Hall Local radio stations
Physical spaces and infrastructures	Activities centre	Casino (bar for cultural activities)
Local Economy	Grocer's shop Kiosk Bars	Agricultural cooperative and bar Market

Table 5. Connected assets for health in Alzira for workshops and dissemination

Types of connected assets	Territorial location	
	Highly vulnerable district of Alzira	**Other areas of Alzira**
Persons	Community health workers of the RIU project Female neighbours of comunity health workers Neighbours Social service personnel Technical staff of RIU project Cepaim (social inclusion association) Management of education centres Headmistress of pre-school centre Caritas (social inclusion association) Pharmacist Owner of newspaper kiosk Members of neighbourhood association Parents of education centres Chairperson of local festival committee	Community health workers of the RIU project Social service personnel
Groups or associations	Caritas (social inclusion association) Neighbourhood association *Falla* (local festival) Festival committee Community Round Table Centre for the elderly	Red Cross Caritas-food bank (social inclusion) Grup Debat per la Igualtat (gender) Plataforma Lucha contra la pobreza (fight against poverty)
Services and institutions	Pre-school and primary education centre Pharmacy Christian church	Libraries Casa de la Cultura (cultural association) Health centres Public Health Centre Public Adult Education Centre Town Hall Mosque Evangelical church Local radio stations
Physical spaces and infrastructures	Social services office	Parks Swimming pool Sports centres
Local Economy	Grocer's shop Baker's Kiosk Tobacconist's	Print shop

Impact of the workshops on the knowledge and attitudes of the participating population towards cancer prevention

Table 6 shows the differences in percentages of the persons participating in the workshops who correctly answered the questions about information and their attitudes regarding preventive practices in the PRE and POST questionnaires.

Table 6. PRE-POST differences of participants in the workshops who correctly answered the questions in the questionnaire

Item	Percentage of participants who gave correct answers in the PRE questionnaire (%)	Percentage of participants who gave correct answers in the POST questionnaire (%)	Difference in percentage of participants who answered correctly in the POST compared to the PRE (%)
1. Multifactorial etiology of cancer	75.8	90.1	+14.3
2. Ability of each person to prevent cancer with healthy behaviours	71.0	71.6	+0.6
3. Knowledge about the three existing cancer screening programs	80.6	87.3	+6.7
4. Total number of correct answers to the 3 items above about information: 1, 2 and 3	41.7	60.5	+19
5. Willingness to participate in screening programs in future	54.9	65.9	+11
6. Willingness to make changes for a healthier lifestyle amongst those who acknowledge that they do not have one	8.8	18.6	+9.8

The greatest increase in the percentage of persons who gave correct answers in the POST questionnaire in comparison to the PRE after participating in the workshops can be seen in the item relating to information about the multifactorial origins of cancer (14.3%) and in the willingness to participate in early detection programs (11%).

This percentage is even greater if we include only the participants who all together correctly answered the three questions about information on cancer, which increases the percentage from 41.7% in the PRE to 60.5% in the POST questionnaire.

If we consider this variable (level of information about cancer) as a quantitative one, the value of which oscillates between 0 and 3 (0=none of the three questions about information correctly answered, 1=1 question correctly answered; 2=2 questions correctly answered; and 3=3 questions correctly answered), the average obtained in the PRE questionnaires is 2.13 (SD 0.934) and the obtained in the POST is 2.36 (SD 0.919) making the difference between both averages statistically significant when applying the T-Test.

Evaluation of the project

Table 7 shows who participated in the evaluation session.

Table 7. Participants in the community intervention evaluation

Service Sector	Professional profile	Algemesí		Alzira	
		Women	Men	Women	Men
Citizens	Community health worker	5	0	6	0
Public health	Medicine	0	1	0	0
Cancer Prevention Unit	Nursing	0	0	0	1
Health Promotion Unit					
Public Health	Psychology	1	0	1	0
FISABIO	Sociology	0	0	1	0
	Socio-cultural animation	0	1	0	0
Social welfare	Social work	1	0	0	0
Social services	Social education	1	0	1	0

Organisation and coordination of the intervention

Coordinating and organising the large number of activities required a major effort from the promoter group, which had to conduct the intervention in just three months and organise the activities around their habitual work load. The proposal was made to distribute the tasks of coordination and organisation amongst different participants and to define the responsibilities and functions at the start of the intervention.

> *"Organisation could be better" … "I think it worked well thanks to the detailed planning but there are a lot of tasks and more people could have done them" (Alzira)*

> *"Improve coordination from start to finish. Specify responsibilities" (Algemesí)*

> *"There are a lot of activities and that meant a large work load. It would be better if the tasks were distributed amongst more people" (Algemesí)*

Another aspect requiring improvement was the need to transfer more information to the public health staff who collaborated in the additional training sessions on each sequential phase of the intervention (design, planning and completion of the workshops).

> *"More communication between the technical staff of the training sessions in the first phase and the development of the health workers' workshops …" (Alzira)*

Although the intervention was driven by the two local administrations in collaboration with public health, some local government departments did not perceive it as something belonging to them and therefore their involvement in the intervention was lower (e.g. the environment or economic intervention departments).

> *"They weren't sure who the project belonged to at Town Hall. At Intervention, it was a disaster" (Algemesí)*

> *"I miss the participation of the technicians from Environment, Pablo and Juan and the fact that Quique from Culture couldn't get in touch with us" (Algemesí)*

More time is needed for dissemination and coordination with associations and services needs to be reinforced to make them interested and transfer the information to the target population.

The objectives

Spaces have been promoted where information about cancer prevention and screening programs has been made available to the most vulnerable population and to those of different cultures (especially Spanish and North African, and to a lesser extent to the Spanish Roma population).

> *"I think it reached North African persons and also Roma, but especially it got through to women" (Algemesí)*

> *"Knowing about cancer prevention and screening programs, especially amongst the Spanish and North African populations, but we weren't able to reach out to the Roma and Romanians." (Alzira)*

Thanks to these activities it was possible to reach out to women. Conducting the workshops during school hours, in frequently used facilities and having a babysitting service made it easier for them to attend.

The scarce participation of men seems to be related to existing gender concerning caring for health, which are habitually assigned to women. This is a recurring issue in other health promotion and education activities and is not specific to the vulnerable population.

> *"More effort and energy is needed to reach out to men. Even so, it's been a tremendous effort" (Algemesí)*

Neither was it possible to reach out to the Romanian population because of difficulties with dissemination and the Spanish Roma because of their beliefs and attitudes towards cancer, and their concepts of health/disease and prevention.

The proposal was made to improve dissemination and facilitate incentives to improve the attendance of the target population at the workshops.

The community health workers showed a high level of involvement in developing the intervention and in carrying out their functions effectively.

The content

The evaluation of the contents and of the technical personnel who participated in the training was highly satisfactory. The information was adequate and was transferred to the population in situations of high vulnerability (to the community health workers and workshop participants) thanks to the cultural adaptation of the activities, contents and materials. An outstanding feature was the usefulness of the information in reducing the barriers impeding people from participating in the programs and in particular, the fear of a possible positive outcome in the tests.

> *"I think they were very suitable because a lot of information was lacking and we could see that when the workshops were being conducted" (Algemesí)*

> *"Very good, Good level and amount of information. Excellent work too on adapting materials when you take into account how diverse the population was" (Alzira)*

The methodology used

The participative methodology used was very positively assessed. Including the perspective of positive health and not just the lack of it, of the problems and risks of cancer in the workshops was very relevant.

The maps of the assets for health worked very well in the design and planning of the workshops. It was very helpful to have printed and plastic-coated maps to give a graphic view of the different connections between assets in the work sessions.

> *"I'd highlight how the assets map streamlined planning for the workshops" (Algemesí)*

> *"The methodology used was excellent. The asset maps worked very well in designing the actions in large plastic-coated posters" (Alzira)*

The group techniques were very useful for working on the contents. Giving more time to case stories used to identify and overcome barriers to access for screening programs.

The materials used in the workshops were very suitable. Some adaptations were made to ease understanding (include drawings in the recommendations in the European Code Against Cancer, use a non-sexist language and translate it to Arabic).

"Important to work on the European Code and highlight prevention" (Alzira)

The use of audiovisual media and computer resources to reinforce workshop content is recommended, along with improvements to the air-conditioning systems of the premises where the interventions take place.

"Computer and audiovisual resources are needed to back up the workshops" (Algemesí)

Posters are necessary for dissemination but they are not effective in motivating people to attend. Organising the workshops with groups that periodically meet for other activities worked very well (e.g. literacy , Spanish literacy groups for North African women).

"Dissemination of workshops: works very well in already functioning groups. Dissemination with posters is not effective" (Algemesí)

<u>Working documents</u>

The working documents were positively assessed by the health workers. They considered that they were well organised, with precise information, well explained and with instructions to enable them to answer whatever questions might arise.

The health workers stated that the areas of improvement included having the final version of the workshops far enough in advance to effectively prepare them and improve their design to make them more pleasant. They pointed out that the evaluation questionnaire used in the workshops was not worked on by them in the planning sessions and had an effect on the way they were completed.

"Some materials were delivered very late, for example, the evaluation questionnaire was prepared late and was publicised in the first workshop" (Algemesí)

" Just to point out that sometimes final versions were not provided enough in advance. Likewise for the planning of the activities in each workshop. Work on the evaluation questionnaires before since they were delivered on the same day as the first workshop" (Alzira)

The duration of the intervention

The time given over to developing the intervention was one of the main aspects regarded as needing improvement by the community health agents and the technical staff. The conditions of the announcements for grants from public health and the very tight schedules were the main factors in imposing such a short time period to develop the intervention (only three months). The time for dissemination and for completing the workshops (fitted into 3 weeks) was especially brief and made attendance difficult for the target population.

All the above lead us to recommend that the intervention time should be extended and the dissemination activities and the workshops themselves should be more effectively segregated.

> *"Too intense for all the work that was done. The project was developed in 2.5 months. More time would be necessary for the phases of dissemination and for the workshops themselves" (Algemesí)*

> *"The time needed to adequately develop the project was very intense. Especially the hardest part, disseminating the workshops, this part needs to be improved by the staff and by the health workers" (Alzira)*

Level of participation

There was a high level of participation of the stakeholders involved, both the technical staff (social services, public health and RIU project) and the community health workers.

The community health workers showed a high level of involvement in developing the different stages, and worked with great enthusiasm and willingness. The elements to be improved included increasing their skills to better manage the group debates in the workshops and to actively contribute in dissemination. At the same time, the community health workers insisted that it was a sensitive issue for the target population to show interest in attending.

> *"Very good work by the community health workers. They did very well. They dedicated a lot of time to preparing everything and they always did their work with enthusiasm and interest" (Algemesí)*

> *"Generally speaking, a good job by the group of community health workers and the technical staff of social services and public health" (Alzira)*

The collaboration of the technical staff and the collaborative associations was positively evaluated. However, their involvement in dissemination to reach the target population could be improved, especially with the Roma and Romanian ethnic groups.

The high attendance levels of the North African population was a notable point, and a very positive assessment was given to the workshops being given in Arabic for persons with low levels of Spanish.

Most of the persons who went to the workshops actively participated in the dynamics to work on the contents and they gave positive assessments, declaring their wish to attend health promotion workshops on other issues.

However, in one of the workshops organised by Spanish and Roma community health workers where there were only members of the Spanish population, the participants refused to work on one of the case stories whose protagonists were two women, Roma and North African, respectively. This fact highlighted the prejudices that exist in mainstream society towards ethnic minorities, and so it is recommended that the community health workers and technical staff should have intercultural mediation skills to avoid potential conflicts. Finally, in the same workshop, the participants disliked the term “vulnerable”, saying they did not identify with it. We suggest that terms that might generate unpleasant emotions, such as “vulnerability” should not be used, or if they are, then their meaning should be explained with some care.

> *“There was a conflict in the workshop in Carrascalet because the women were "payas" (non-Roma) and they didn't want to work on the story or on the Roma or Arabic woman, they were offended by the term “vulnerable” (Algemesí)*

Level of satisfaction

The stakeholders who participated in the intervention expressed a high level of satisfaction with the project.

> *“Pleased to participate in this project and happy with the response from everyone involved in it” (Alzira)*

Notable elements alongside the ones mentioned in the sections above include greater involvement of certain departments of the local administration, the usefulness and importance of tackling the issue, the high level of participation and degree of satisfaction of the people attending the workshops and those who developed the project, the joint work of the community health agents and professionals, the need to adapt the activities and materials to the languages of the target population, the babysitting service and extending the intervention periods to avoid stress and work overload.