



Training packages for health professionals to improve access and quality of health services for migrants and ethnic minorities, including the Roma
MEM-TP

MODULE 4 Knowledge Application

UNIT 5: Community-based approaches, promotion of user and community participation and involvement

Guidelines

PREPARED BY:
Dorota Sienkiewicz
EPHA, European Public Health Alliance, 2015

ADAPTED BY:
Amets Suess
Andalusian School of Public Health, 2015

© European Union, 2015

For any reproduction of textual and multimedia information which are not under the © of the European Union, permission must be sought directly from the copyright holders.

© Cover Illustrations: Observatorio de la Infancia de Andalucía, Escuela Andaluza de Salud Pública. Junta de Andalucía.

Migrants & Ethnic Minorities
Training Packages



JAGIELLONIAN UNIVERSITY
MEDICAL COLLEGE



Funded by the European Union in the framework of the EU Health Programme (2008-2013) in the frame of a service contract with the Consumer, Health, Agriculture and Food Executive Agency (Chafea) acting under the mandate from the European Commission. The content of this report represents the views of the Andalusian School of Public Health (EASP) and is its sole responsibility; it can in no way be taken to reflect the views of the European Commission and/or Chafea or any other body in the European Union. The European Commission and/or Chafea do not guarantee the accuracy of the data included in this report, nor do they accept responsibility for any use made by third parties thereof.

MODULE 4

Knowledge Application

Unit 5: Community-based approaches, promotion of user and community participation and involvement

1. Objectives and Methods

1.1. Objectives

Objectives of the Presentation

- To introduce the topic (community-based approaches, promotion of users, community participation and involvement).
- To introduce fundamentals and definitions of community-based approaches.
- To introduce concepts and relevant aspects related to “involvement” and “participation”.
- To reflect on challenges, limitations and strategies related to community-based approaches.

Objectives of the Activities

- To enhance awareness of the concepts 'community' and 'participation'.
- To reflect on challenges related to being a migrant, ethnic minority, including the Roma in European societies and healthcare system, attitudes and stereotypes.
- To identify levels of involvement and participation of migrants and ethnic minorities in the own professional context, as well as strategies for improving these levels.
- To reflect on power/control relationships and the relativity of choices.

1.2. Methods

The time previewed for Module 4 is 5 hours, approx. 50 min. for each Unit. The training materials of each Unit are composed of presentations, activities, videos and recommended / complementary readings and audiovisual material.

Each Unit includes one or more activities. Due to time limitations, you will not be able to carry out all activities. We recommend you to select the presentation contents and activities you consider most interesting and distribute the time for presentations and activities. We suggest you to leave enough time for activities and discussions, approx. 50% of the session.

Time	Objectives	Activities	Sources
15 min.	<ul style="list-style-type: none"> To enhance awareness of the concepts 'community' and 'participation'. 	<p>Activity 1 "The Own Community"</p> <ul style="list-style-type: none"> Presentation of the methodology In pairs: Description of the own 'perceived' community <p>(Slide 3)</p>	Projector, laptop, screen.
5 min.	<ul style="list-style-type: none"> To introduce the topic (community-based approaches, promotion of users, community participation and involvement). 	<p>Presentation "Community-based approaches, promotion of user and community participation and involvement", part I and questions.</p> <p>(Slide 4)</p>	Projector, laptop, screen. M4_U5_Presentation
15 min.	<ul style="list-style-type: none"> To reflect on challenges related to being a migrant, ethnic minority, including the Roma in European societies and healthcare system, attitudes and stereotypes. 	<p>Activity 2 "Perceptions and Stereotypes"</p> <ul style="list-style-type: none"> Presentation of the methodology In plenary: Brainstorming on common perception of the migrant and ethnic minority individuals and population groups <p>(Slides 5-6)</p>	Projector, laptop, screen. A set of 9 photos, post-its, flip-chart, adhesive (spray).
10 min.	<ul style="list-style-type: none"> To introduce fundamentals and definitions of community-based approaches To introduce the concepts "involvement" and "participation". 	<p>Presentation "Community-based approaches, promotion of user and community participation and involvement", part II and questions.</p> <p>(Slide 7 – 19)</p>	Projector, laptop, screen. M4_U5_Presentation

Time	Objectives	Activities	Sources
20 min	<ul style="list-style-type: none"> To identify levels of involvement and participation of migrants and ethnic minorities in the own professional context, as well as strategies for improving these levels. 	<p>Activity 3 “Levels of Involvement and Participation”.</p> <ul style="list-style-type: none"> Presentation of the methodology. Exchange of experiences in small groups. Summary and discussion in the plenary. <p><i>(Slide 20)</i></p>	<p>Projectos, laptop, screen.</p> <p>M4_U5_Activity3_Template</p>
10 min.	<ul style="list-style-type: none"> To introduce relevant aspects related to “involvement” and “participation”. To reflect on challenges, limitations and strategies related to community-based approaches. 	<p>Presentation</p> <p>“Community-based approaches, promotion of user and community participation and involvement”, part III and questions.</p> <p><i>(Slide 21 – 26)</i></p>	<p>Projector, laptop, screen.</p> <p>M4_U5_Presentation</p>

Time	Objectives	Activities	Sources
30 min.	<ul style="list-style-type: none"> To reflect on power/control relationships and the relativity of choices. 	<p>Activity 4 “Power / Control Relationships and Relativity”</p> <ul style="list-style-type: none"> Presentation of the methodology Part I (in the plenary): Drawing numbers designing the ‘degree of power’ to be represented, observing the perception of the own ‘degree of power’ in relation to the others. Part II (in the plenary): Drawing characters to be played, relativizing one's perceived position in space in relation to a fixed point of power/control and in relation to other characters. Group discussion. (Slides 27-28) 	<p>Projector, laptop, screen.</p> <p>Box with notes.</p>

2. Presentation

Slide 1: Title page

Slide 2: Outline of the session

This session is based on the assumption that the participants are familiar with the epidemiological profile of migrant and ethnic minority populations in Europe. The aim of the session is to inform and enhance understanding and application of this knowledge, taking into account the specific context of a community, including the participation of its members and their use of health care services.

3. Activity 1: “The Own Community”

Slide 3:

1. Presentation of the methodology
2. In pairs:

Divide the group into pairs of people who do not know each other. Let speak each person for 2-3 minutes to his/her pair about him/herself and the community they live in. Subsequently, each person from a pair presents the other person’s ‘perceived’ community. The first person may correct to give a better/truer representation of the reality. Role change to cover the other person of the pair.

- One person tells the other about the own community, including the following questions:
 - Do communities exist?
 - What does the idea of community evoke?
 - Do you feel belonging to a community?
 - Who / what constitutes your own community?
 - Do you / your health care users belong to a community?
 - Role change.
2. In the plenary
 - Each person from a pair presents the other person’s perceived community.

4. Presentation

Slide 4: Introduction

The approach to health services oriented towards cultural and ethnic diversity is **based on inclusion and multi-dimensionality**, focuses on the **reduction of inequalities in health** in the context of a community, using a **multi-sectoral framework**.

Therefore, health services and health professionals oriented towards cultural and ethnic diversity would be those that consciously and systematically incorporate the **needs of migrants and ethnic minorities, including the Roma**, into and throughout the **entire health design and delivery process**, including health financing, policy, planning, implementation and evaluation – beyond the regular understanding of a health provision-consumption relationship.

A key point is to realise the importance of moving towards a **migrant/ethnic minorities/the Roma-inclusive health system**, rather than one that sets up **parallel specific group-sensitive services** outside the mainstream. This would also ensure that any such work done by NGOs, charities, foundations and philanthropic entities as important as it remains complementary, and does not replace any **rights-based health care service provision** that the government authorities are under obligation to guarantee.

5. Activity 2: “Perceptions and Stereotypes”

Slide 5:

1. Presentation of the methodology

2. Activity *(in the plenary)*

- Look at the photos.
- Which words come to your mind when describing a group / a community of migrants and ethnic minorities, including the Roma?
- Write down the words on post-its and stick them to the wall, next to the photo they refer to.
- Discussion.

The photos are exposed on a paper in the wall. Each participant is given several post-its and a pen. The participants can think for a while about the words they come up with when seeing the photos. Then they are invited to write down the words on post-its and stick them to the wall, next to the photo they refer to. Look out for passive vocabulary used: ‘beneficiaries’, ‘victims’, ‘targets’, ‘recipients’, etc. Even ‘users’ implies a passive attitude. Look out for ‘collective’ descriptive words, not as much as individual traits and characteristics but external perceptions of a group. Invite the group to open a discussion on the perceptions and stereotypes reflected in the post-its.

Slide 6: Photos.

6. Presentation

Slide 7: Fundamentals of community-based approaches.

For the purpose of this session, contents about **community-based approaches** will not be as much about epidemiological profiles and the impact of migration process or ethnic background on health, but rather more about **socio-economic-cultural aspects**, by fully taking into account cultural understanding, diversity and linguistic appropriateness. This does not, however, mean that health professionals representing various health disciplines should not know the basics of community health, and the impact that the migration process and ethnic minorities has on health.

For the purpose of enhancing the ability of health systems and health professionals to deliver **health care oriented towards cultural and ethnic diversity, improve access, utilization and quality of care** several types of services can be introduced. Those include but are not limited to interpretation and translation services, culturally and ethnically informed health care and programmes, and the use of cultural support staff such as intercultural mediators, community health workers, and patient navigators.

In the next slides, various **examples for community-based approaches** will be shown, including health mediation programmes, HIV/STI prevention projects, harm reduction approaches and mobile health services.

Slide 8: As an example for **intercultural mediation**, the Roma Health Mediators Programme developed by IOM, International Organization for Migration, can be mentioned.

Research shows that language and cultural barriers have a negative effect on access to care and prevention services, adherence to treatment plans, timely follow-up, and appropriate use of emergency departments. Roma Health Mediators, working both inside health organisations and in the community, can play a wide range of roles (interpreter, patient advocate, and health educator) and offer the added bonus of facilitating social integration for both the services and those they serve.

Video “Roma Health Mediation in Europe”, IOM, International Organization for Migration, 2014 (6:31 min).

<https://www.youtube.com/watch?v=EarpvGr6n5k>

Slide 9: In an Evaluation Report of an Experimental Health Mediation Programme (*Programme experimental de mediation sanitaire*), publicado por AŞAV, Association pour l'accueil des voyageurs¹, the following success factors of the health mediation programme are identified:

- Institutionalization of the programme.
- Involvement of local communities.
- Focus on preventive health care.
- Adapted messaging.
- Unintended consequences of positive gender roles.
- Female employment.
- Improved daily living conditions.

In relation to the cost-effectiveness of the health mediation programmes, the following aspects are mentioned:

- Improved access to existing services / facilities.
- More frequent and adequate use of existing health services.
- Better adherence to treatment.
- Significant increase in vaccination rates (from 15% to 68% of children <6 years vaccinated against hepB).
- Improvement in the use of contraception methods (after the programme, the majority of women knew where to receive contraception and about approximately half of the women effectively used it).

Slide 10: ECDC, European Centre for Disease Prevention and Control², presents as a Best Practice example for HIV/STI community prevention the Naz Project in London. The project is described as follows:

The Naz Project works in partnership with the Chelsea and Westminster Hospital in London to promote community point-of-care testing to black and minority ethnic groups where late diagnosis is common. The project promotes testing for HIV and other STI in the community, encourages people to come to their centre and provides translation and pre- and post-test information. The appointments are made by outreach community workers. Walk-in services are not provided, as many cases require a translator and these need to be

¹ AŞAV, Association pour l'accueil des voyageurs. Programme experimental de mediation sanitaire. En direction des femmes et jeunes enfants rom. Rapport final d'évaluation, 2013. <http://www.mediation-sanitaire.org/wp-content/uploads/2012/08/rapport-final-d%C3%A9valuation-2011-2012-du-programme-exp%C3%A9rimental-de-m%C3%A9diation-sanitaire.pdf> (retrieved: March 5, 2015).

² ECDC, European Centre for Disease Prevention and Control, Noori T. Technical Report. Migrant health: HIV testing and counselling in migrant populations and ethnic minorities in EU/EEA/EFTA Member States. Stockholm: ECDC, 2011. http://www.ecdc.europa.eu/en/publications/Publications/1108_TER_HIV_in_migrants.pdf (retrieved: March 5, 2015).

planned for in advance. The centre runs a weekly clinic in the afternoon and evening so that people can come after work. Hospital nursing staff comes to the centre to carry out rapid HIV testing, as well as tests for other STIs. People who test positive are immediately referred for confirmatory testing and clinical follow up. Most clients are from black and ethnic minority communities, around 50% are heterosexual women, 25% are heterosexual men and 25% are men who have sex with men. The main challenge has been insurance, as policies require community sites to provide services that are consistent with those in a hospital setting. To overcome this, Naz staff have been given honorary National Health Service contracts.

(ECDC 2011: 14)

Slide 11: Community Projects: Harm Reduction Approaches and Mobile Services:

As examples for further community projects, the following approaches can be mentioned:

- Médecins du Monde (MdM) presents a **harm reduction approach** for drug users and sex workers, including HIV/STI prevention, diagnosis and treatment, socio-economic reintegration, protection of Human Rights, vaccination and mental health services. See video: Médecins du Monde, La Réduction des Risques, 2011: https://www.youtube.com/watch?v=J-HJ_LVnWs0&authuser=0 (8 :35 min, in French).

Synopsis: This video explains MdM's approach to harm reduction as a global medical-psychological-social exercise that puts every individual's personal circumstances at the centre. It is a pragmatic effort that does not seek to change people (e.g. drug users, prostitutes) but to offer them a better quality of life. It lets individuals choose for themselves the tool(s) that might help them reduce their risks of getting infected or infecting others. Harm reduction thus includes 'all policies and practices in relation to reduction of harm caused by psychoactive substances and risky sexual behaviours'. At the same time, this approach seeks to achieve social change, especially in countries where health budgets are low and this type of prevention can increase cost effectiveness (and thus also effect change at political level, e.g. Afghanistan). The actual work undertaken by MdM is very varied and might include free screening (HIV, TB, hepatitis), methadone clinics (including in mobile health units), provision of condoms and sexual advice, always adapted to the individual's circumstances. One slide shows 12 different activities which are part of this approach (1. Information, education, communication; 2. HIV/Aids detection and counselling; 3. Condon distribution and needle exchange programme; 4. Prevention and treatment of sexually transmissible diseases; 5. vaccination, detección and treatment of viral hepatitis, 6. Prevention, diagnostic and treatment of tuberculosis; 7. HIV/Aids diagnosis and antiviral treatment; 8. Socio-economic reintegration; 9. Human Rights defense and fight against criminalization; 10. Mental health; 11. Opiate substitution treatment for drug user; 12. Overdosis prevention and management for drug users). In Europe, MdM's first needle exchange programme was introduced (illegally) in Paris in 1989, and the first international programme in St Petersburg in 1997.

- In another video, Médecins du Monde (MdM) describes the work of **mobile clinics / health units** which provide services for Roma populations in Bordeaux, France. See video: Médecins du Monde, Mission Rroms Bordeaux, 2011. <https://www.youtube.com/watch?v=GEr70CkIM3s> (12.36 min, in French).

Synopsis: This video illustrates how the work of MdM doctors goes beyond providing health care when it comes to vulnerable Roma populations living in Bordeaux's squats. The Bordeaux Roma mission was established in 2007 in response to a demand by the

local Roma community when two squatters asked for help. Since then they visit the squats once a week and provide regular health check-ups - taking temperatures, measuring blood pressure, writing prescriptions to people qualifying for state health services - but also lots of social and legal advice. It is thus a multifaceted role that attempts to create social links with the community in order to better understand the particular problems faced by the Roma in Bordeaux. One of the doctors underlines that the Roma do not arrive sick in France, but they become sick as a result of insalubrious living conditions, precarity and massive social inequalities, which in turn has an impact on health and on lifestyle choices. It remains difficult for many Roma to access healthcare in France and MdM's work thus fills the prevention gap, as otherwise nobody would take care of them which could have significant negative consequences for the French healthcare system one day. MdM deplore that the government relies on them and yet does not change its policies pertaining to the Roma.

Slide 12: Community Projects: Health Prevention and Reduction of Health Disparities

- As an example of an **intercultural community health prevention project**, MiMi, Mit Migranten für Migranten³, organized by Ethno-Medizinisches Zentrum e.V. in Alemania y Austria, can be mentioned. MiMi organizes **training in health mediation and information activities**, with the objective of health prevention, integration of migrants and reduction of health disparities.
- In the Dutch context, Pharos, Expertisecentrum Gezondheidsverschillen⁴ provides **training, conferences, patient panels, school programmes and support activities**, with the objective of reducing health disparities and improving quality, effectiveness and accessibility of health care for people with limited health literacy and migrants, reinforcing prevention and self-management.

Slide 13: Definition of community development

United Nations⁵ defines **community development** as follows:

The term community development has come into international usage to connote the processes by which the efforts of the people themselves are united with those of governmental authorities to improve the economic, social, and cultural conditions of communities, to integrate these communities into the life of the nation, and to enable them to contribute fully to national progress.

This complex of processes is, therefore, made up of two essential elements:

- the participation by; the people themselves in efforts to improve their level of living, with as much reliance as possible on their own initiative; and
- the provision of technical and other services in ways which encourage initiative, self-help and mutual help and make these more effective.

(UN 1956, in UNESCO 1956: 9).

Slide 14: Definition of a Community-Based Approach

Working with people from a community requires us to already have an idea of what constitutes a community and how it works.

³ Ethno-Medizinisches Zentrum e.V. MiMi, Mit Migranten für Migranten, 2009. http://www.ethno-medizinisches-zentrum.de/index.php?option=com_content&view=article&id=28&Itemid=34 (retrieved: March 5, 2015).

⁴ Pharos, Expertisecentrum Gezondheidsverschillen. About Us, 2015. <http://www.pharos.nl/information-in-english/about-us> (retrieved: March 5, 2015).

⁵ United Nations. Fourth Report of the Working Group on Community Development to the Administrative Committee on Co-ordination MES/23/56. In: UNESCO. United Nations Educational Scientific and Cultural Organization Working Paper on Fundamental Education. Paris: UNESCO, 1956, p. 9. <http://unesdoc.unesco.org/images/0014/001448/144817eb.pdf> (retrieved: March 5, 2015).

The definitions are, however, quite complex, time-sensitive, vary from one school of thought to the next, and from one researcher to another.

As working definitions, we can use the following conceptualizations:

- **Community** refers to a population whose members share **some common interests, needs, demands, geographic areas, traits, values, cultures, and possibly religions.**
- **Community-based approach** or action aimed at improving access and quality of health services for populations of migrant and ethnic minorities' would refer to **collective but local efforts by those communities which are directed towards increasing community control over the (local) determinants of health.**

Slide 15: Community-Based Approaches: Bottom-Up Approaches

In comparison to a usually pursued approach to the public health/population-wide action, a **community-based approach** starts at the **bottom** with assessing the given population group's **situation and needs**, proceeds to drafting certain proposals with the group, negotiates the objectives and necessary actions by the population themselves, and aims to incorporate and respond to the dynamics of the local development and what's understood and possible in the field of health promotion and health education.

Health literacy can be identified as an important aspect for putting community-based approaches into practice, including the ability to access, understand and act on the health-relevant information. **Digital tools** (ehealth and mhealth) can support the communication process (translation, tracking devices).

Slide 16: Community-Based approaches: Relevant aspects

Community-based approaches rely on the dynamics of open, two-way dialogue, intersectoriality and participation.

Working with communities is more complex than it appears. The participation of a person in collective action does not happen naturally but rather by gradual construction, through awareness of belonging to a group.

Mediation can help communities and their members in the process of learning how to integrate healthier lifestyles into their routines, how to access health care and utilize it. Health professionals and policy makers can learn from mediators how to lower the threshold to facilitate access to services.

Slide 17: Concept of "Involvement" and "Participation"

In the Alma-Ata Declaration⁶, WHO defines **community participation** as a means for achieving better organization of health services and a condition for improving the health of the population. Primary Health Care is identified as the basis of the health system, relying on community participation as a relevant element.

Primary health care: (...)

5. requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care,

⁶ WHO, World Health Conference. Declaration of Alma-Ata. International Conference on Primary Health Care, Alma-Ata, USSR, 6-7 September 1978, p. 2. http://www.who.int/publications/almaata_declaration_en.pdf (retrieved: March 5, 2015).

making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;

The participation of groups in the resolution of health issues (eg. unequal access, lower quality or insufficient resources) is one of the elements of the Ottawa Charter for Health Promotion (1986). It assumes the possibility and will of individuals to become involved in debate and joint actions with people affected by the same issues.

Médecins du Monde⁷ defines participation of the population as follows:

[T]he population's involvement helps not only to improve the quality of programmes, by providing a more precise analysis of the situation and context, but also recognises the right of these populations to self-determination. Participatory actions are therefore part of defending patients' rights and access for all to social rights.

Slide 18: Levels of Involvement and Participation

As mentioned in Module 4, Unit 1, Arnstein⁸ developed in 1969 a ladder of citizen participation that serves as a reference point for further participation models⁹. Arnstein distinguishes between degrees of non-participation (manipulation and therapy), degrees of tokenism (information, consultation, placation), as well as degrees of citizen power (partnership, delegated power, citizen control). Applying the model to migrants' and ethnic minorities' participation in health care policies, examples for the different levels of participation can be identified, including "*Informing*" (e.g. health promotion and prevention campaigns, information on legal changes), "*Consultation*" (e.g. surveys on health related issues); "*Partnership*" (Participatory Action Research, participation in health related projects), "*Delegated power*" (e.g. participation in project design, development and assessment), as well as "*Citizen control*" (e.g. participation in health policies decision making).

Slide 19:

Other authors¹⁰ distinguish between the following levels of involvement and participation:

- **Full control:** Service users control decision making by community-run committees or groups.
- **Sharing power:** Shared decisions and responsibility, inclusive governance level. Service users can influence by 'tailored' staff recruitment or supported volunteering.
- **Participation:** Encouraging people to take part in shaping services, policies or perceptions. Service users can make suggestions and influence outcomes by focus groups, participatory appraisal, stakeholder events, peer research or education.
- **Consultation** - asking people what they think of a service or policy. Service users have limited influence by questionnaires, interviews, focus groups or suggestion boxes.

⁷ Médecins du Monde. Working with Communities, 2012.

http://www.medecinsdumonde.org/content/download/13648/163222/file/MdM_Working+with+Communities_2012.pdf (retrieved: March 5, 2015).

⁸ Arnstein SR. A Ladder of Citizen Participation. JAIP 1969;35(4):216 – 224.

⁹ Cornwall, A. (2008). Unpacking 'Participation': modes, meanings and practices. Community Development Journal 43(3):269-283.

¹⁰ FEANTSA, European Federatio of National Organisations Working with the Homeless. Participation Toolkit – Get a different result... get people participating 2013.

<http://www.feantsa.org/spip.php?article122> (retrieved: March 5, 2015).

- **Information:** Telling people about a service or policy, by means of newsletters, leaflets, notice boards or digital information. Service users have no influence.

7. Activity 3: “Levels of Involvement and Participation”

Slide 20:

1. **Presentation of the methodology**
2. **In small groups**
 - The participants are invited to choose a spokesperson in charge of taking notes (M4_U5_Activity3_Template) and presenting the results of the group discussion in the plenary.
 - The participants of each small group are invited to exchange experiences in relation to the following questions:
 - Which level of involvement and participation exists in your professional context for migrants and ethnic minorities (in relation to the levels information / consultation / participation / sharing power / full control)?
 - Which strategies can you identify to increase the level of involvement and participation?
3. **In the plenary:** Summary and discussion

8. Presentation

Slide 21: Relevant aspects related to Involvement and Participaton:

As important aspects for participation processes, the relevance of a **deliberate, systematic inclusion of individuals, families and communities** as active players in the improvement of their own health and the services they use can be highlighted.

Participation processes require **trust, a sense of belonging and mutual respect** in order to understand and manage the expectations and goals of various parties.

Through a **progressive empowerment** model, communities and their representatives are engaged to a greater or lesser extent in one or several aspects of the process of health service functioning: diagnosis, planning, programming, implementation, oversight and evaluation.

Communities representatives can be directly involved in bridging the gap between their communities and health services by participating as **interpreters, mediators** and **educators** in outreach programmes, and those with health professional qualifications from abroad can be supported to re-qualify and enter practice.

“Participation” and **“involvement”** are often used interchangeably. As the community-based approach is not a static construct, **populations can be “involved” or made to “participate” in actions at various levels.**

For some “participation” is crucial, for others it is “a bonus” while, for others, it is either an added value/advantage or a complete waste of time.

Slide 22: Relevant Aspects related to involvement and participation

Furthermore, the following relevant aspects of involvement and participation can be underlined:

- **Consider time:**
 - Different time availability: The community often has more time than health professionals.
 - Different evaluation of the time employed in involvement / participation: While for many, working with communities is an important component of their contribution to improving access to and quality of health services, for others, this work may be seen as slowing down and holding back the “effectiveness” of interventions.
 - From the community’s perspective, the haste of outside actors is often seen as a problem.
 - In order to ensure regular contact, more time needs to be allocated for people who move around (migrants, Roma, travellers) than for sedentary people.
- **Consider proximity:** being as close as possible to the people (also shortens time and “supply chain” needed).
- Consider **hetero- vs homogeneity of the groups** (heterogeneity both within migrant and ethnic minority communities).
- Consider **power relationships** – certain people in a community can be identified as representatives, capable of speaking for the whole community. Sometimes however, these representatives may be from dominant classes or with dominant status and their interests may be more specific or differ from the collective interest or that of the most vulnerable populations. It is important to understand conflicts of positions and interests.
- Taking into account, not stifling, **local initiatives and collective dynamics** – work with what already exists (does it exist to begin with?). Undermining the legitimacy of local actions can only harm community health.

Slide 23: Challenges and Limitations of Community-Based Approaches:

The following challenges and limitations of community-based approaches can be identified:

- **Challenge of efficiency / effectiveness at the local level**
 - How to improve accessibility and quality.
 - How to adapt to the real needs of populations and their circumstances and avoid the ethnocentric position often unconsciously adopted by professionals from “high-above, detached” positions.
- **Challenge of proximity, simplicity and time**
 - How to reduce obstacles for accessing health care and facilitating administrative, economic and geographic access to prevention and treatment.
 - ⇒ Take services and workers closer to the places where the populations live (e.g. Médecins du Monde Mobile Clinics¹¹, mHealth technologies, mobile phones, smart phones, SMS, Skype translators).

¹¹ Médecins du Monde. Médecins du Monde proches de vous, 2013.
<https://www.youtube.com/watch?v=azcOwfsg5vo> (retrieved: March 5, 2015).

- **Challenge of socio-cultural adaptation and involvement¹²**
 - Socio-cultural adaptation of procedures, languages, standards, values and interpersonal skills as crucial determinants of the output of the health care process.
 - Trust in health workers (e.g. Sexual and Reproductive Health, mental health): Are people in the community reluctant or not to meet health workers?
 - Health literacy: Do they understand the prescription?
 - ⇒ Multilingual information material.
- **Challenge of apprehension and comprehension of needs**
 - Needs are not always perceived adequately by health professionals and migrant and ethnic minority health care users.
 - Health professionals can have a pre-conception of the most 'typical' problems or illnesses those individuals may have, and therefore anything that comes as unexpected, different, 'not fitting in' might get ignored.
- **Ethical challenges and lack of acceptance**
 - ⇒ Respecting people's dignity, recognizing their rights, skills and potentials, treating them less as "victims" or "targets" and more like true "stakeholders".
 - ⇒ Consider issues for continuity, acceptance, sustainability, and trust.
- **Challenge of reconciling different types of knowledge:**
 - Constant tension between so-called lay or traditional knowledge (folk medicine, herbalists) and so-called scientific knowledge.

Slide 24: Strategies for community-based approaches

The following dynamics are **recommended to be avoided** in community-based approaches:

- **Tokenism:** Usually felt around activities such as when a service user is nominated (or self-nominated) to represent others in groups, meetings, committees or boards. Participation gives those facilitating it evidence that all sides are considered, but makes it possible that only some of those sides benefit. Also, avoid the creation of 'apparent' participation without permitting a 'real participation' of the community members.
- **Consultation fatigue:** Can result from a person's experience of being asked their opinion about things, then not hearing what the outcome of their participation has been or what arguments were used. Feeding back is very important, even if it seems that people will not like the feedback or that (final) results cannot yet be presented;
- **Lack of appreciation:** Ensure that there is an incentive available for participants; service users are volunteering their time and should be rewarded and valued for their effort. Incentives can include cash, vouchers or hospitality. As a minimum, service users should never be 'out of pocket' as a result of participating;
- **Creating fears:** some representatives of the community who would probably benefit the most from greater involvement and improved access to health services may experience fear of being put under a spotlight, held accountable for the inputs and outcomes, or even in the case of unclear/conditioned legal status and psychological vulnerability fearing being deported or 'punished' for complaining about the system etc.

¹² Ethno Medizinisches Zentrum e.V. Publikationen Wegweiser Schutzimpfungen in 16 Sprachen erhältlich, 2015. http://www.ethno-medizinisches-zentrum.de/index.php?option=com_content&view=article&id=37&Itemid=40 (retrieved: March 5, 2015).

- **Reinforcing stigmatization:** Working with marginalised communities can carry the risk of reinforcing the stigmatisation of these people by identifying or categorizing them.

How to promote changes in the community?

The community must be encouraged to choose the model that is consistent with its prevailing values and attitudes. Any health care system/service that aims to involve and encourage users' and community participation should not underestimate the changes that external intervention imposes on the community value system. Values change as community models evolve, but this change cannot be accelerated or guided by an external influence or conscious manipulation.

Slide 25: Benefits of User and Community Involvement and Participation

There are many reasons for pursuing a participatory approach in community-based health service delivery. The benefits can be far reaching for:

- **For the person being involved:** An individual receives personal gain or empowerment from being involved, for example through increased confidence, knowledge, skills or awareness. This is separate from gains that may be made in the longer term, for example from improved policy or practice.
- **For the communities:** The community receives gains from raising awareness, improving perceptions of migrants and ethnic minorities, including the Roma, correcting images and dispelling myths and stereotypes. This is separate from gains that may be made in the longer term, for example from improved policy or practice.

Slide 26: Benefits of User and Community Involvement and Participation

Furthermore, the following benefits can be identified:

- **For the organisation:** Participation is most regularly used as a tool by services to consult with their service users to better identify aspirations, and adjust practice in response. This is used most widely as change can be facilitated relatively easily, so both the person and the service can reap immediate rewards.
- **For planners and policy-makers:** Often this is done when expected outcomes of participation are thought to be politically timely or relevant. Unavoidable time lapses between the participation and any resultant change at policy level make it challenging to ensure that participation is empowering and interesting for service users. People should be aware that any changes might not be tangible in the short term.

9. Activity 4: “Power / Control Relationships and Relativity”

Slide 27:

The activity consists of 4 parts:

1. Presentation of the methodology

Due to time limits, we suggest you to select part I or part II of the activity.

Activity “Power / Control Relationships and Relativity” (Part I) *(in the plenary)*

- Each person in the group draws a number from a secrete name box (1-10, 1: the least power, 10: the most power).
- Without revealing their number, each person has to walk around in the room together with outer participants, representing a role of the imagined ‘degree of power’.
- Each person has to observe others in order to identify in the end the number they were supposed to be playing.

Activity “Power / Control Relationships and Relativity” (Part II) *(in the plenary)*

- Each person in the group draws a character from a secrete name box *(among them characters such as: hospital manager, community pharmacist, private practice dentist, Eastern European migrant mother with 2 young kids, elderly North-African migrant living in Western European country for the last 35 years, newly arrived Sub-Saharan young men, mother of the Roma community with 3 kids, Chinese female exchange student, local grocery storekeeper of North-African origin, community worker with migrant background, local priest, local police agent, communal school teacher, migrant male construction worker, general practitioner).*
- Each character has to place him/herself in relation to a ‘point of power’ identified in the center of the room, as well as to other characters according to the perceived control they hold in terms of 1. their own health, 2. the health of the health care users, 3. the health of other people in the local community.

Slide 28:

2. Exchange of experiences and discussion *(in the plenary)*

Lookout for passive vocabulary used: ‘beneficiaries’, ‘victims’, ‘targets’, ‘recipients’. Even ‘users’ implies a passive attitude.

Lookout for ‘collective’ descriptive words, so not as much as individual traits and characteristics but an external perception of a group.

Slide 29: Thank you and questions.

Slide 30-31: References.

Slide 32: European Commission disclaimer.

10. Readings

Recommended readings

ECDC, European Centre for Disease Prevention and Control, WHCA, World Health Communication Associates Ltd. Let's talk about protection: enhancing childhood vaccination uptake. Communication action guide for health care providers. Stockholm: ECDC, 2012.

<http://www.ecdc.europa.eu/en/healthtopics/immunisation/comms-aid/Documents/Vaccine-comms-action-2013.pdf> (retrieved: March 5, 2015).

MdM, Médecins du Monde. Working with communities, 2012.

http://www.medecinsdumonde.org/content/download/13648/163222/file/MdM_Working+with+Communities_2012.pdf (retrieved: March 5, 2015).

National Network of Health Mediators. About Health Mediators, 2015.

http://www.zdravenmediator.net/en/index.php?page_type=text&page_id=60 (retrieved: March 5, 2015).

Open Society Foundations, Public Health Programme. Roma Health Mediators: Successes and Challenges. New York: Open Society Foundations, 2011.

<http://www.opensocietyfoundations.org/sites/default/files/roma-health-mediators-20111022.pdf> (retrieved: March 5, 2015).

WHO Regional Office for Europe (2013). Roma health mediation in Romania. Roma Health – Case Study Series 2013;1.

http://www.euro.who.int/data/assets/pdf_file/0016/235141/e96931.pdf?ua=1 (retrieved: March 5, 2015).

Complementary readings

Arnstein SR. A Ladder of Citizen Participation. JAIP 1969;35(4):216 – 224.

AŞAV, Association pour l'accueil des voyageurs. Programme experimental de mediation sanitaire. En direction des femmes et jeunes enfants rom. Rapport final d'évaluation, 2013. <http://www.mediation-sanitaire.org/wp-content/uploads/2012/08/rapport-final-d%C3%A9valuation-2011-2012-du-programme-exp%C3%A9rimental-de-m%C3%A9diation-sanitaire.pdf> (retrieved: March 5, 2015).

ECDC, European Centre for Disease Prevention and Control, Noori T. Technical Report. Migrant health: HIV testing and counselling in migrant populations and ethnic minorities in EU/EEA/EFTA Member States. Stockholm: ECDC, 2011. http://www.ecdc.europa.eu/en/publications/Publications/1108_TER_HIV_in_migrants.pdf (retrieved: March 5, 2015).

Ethno Medizinisches Zentrume e.V. Publikationen Wegweiser Schutzimpfungen in 16 Sprachen erhältlich, 2015. http://www.ethno-medizinisches-zentrum.de/index.php?option=com_content&view=article&id=37&Itemid=40 (retrieved: March 5, 2015).

Ethno-Medizinisches Zentrum e.V. MiMi, Mit Migranten für Migranten, 2009. http://www.ethno-medizinisches-zentrum.de/index.php?option=com_content&view=article&id=28&Itemid=34 (retrieved: March 5, 2015).

FEANTSA, European Federation of National Organisations Working with the Homeless. Participation Toolkit – Get a different result... get people participating 2013.

<http://www.feantsa.org/spip.php?article122> (retrieved: March 5, 2015).

Médecins du Monde. Médecins du Monde proches de vous, 2013. <https://www.youtube.com/watch?v=azcQwfg5vo> (retrieved: March 5, 2015).

Pharos, Expertisecentrum Gezondheidsverschillen. About Us, 2015. <http://www.pharos.nl/information-in-english/about-us> (retrieved: March 5, 2015).

UN, United Nations. Fourth Report of the Working Group on Community Development to the Administrative Committee on Co-ordination MES/23/56. In: UNESCO. United Nations Educational Scientific and Cultural Organization Working Paper on Fundamental Education. Paris: UNESCO, 1956, p. 9.

<http://unesdoc.unesco.org/images/0014/001448/144817eb.pdf> (retrieved: March 5, 2015).

WHO, World Health Conference. Declaration of Alma-Ata. International Conference on Primary Health Care, Alma-Ata, USSR, 6-7 September 1978, p. 2. http://www.who.int/publications/almaata_declaration_en.pdf (retrieved: March 5, 2015).