



OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance
and people living with NCDs



#NCDvoices

COMMUNITY CONVERSATION **GUIDE**

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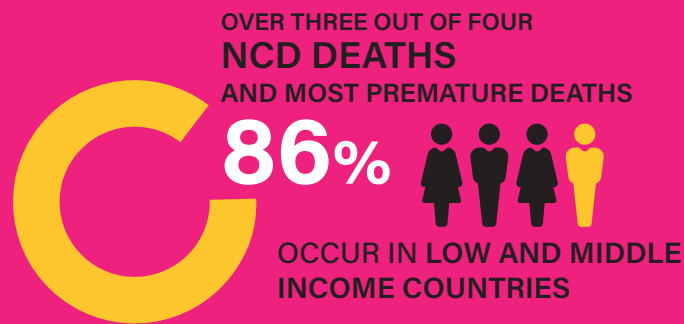
INTRODUCTION

The global importance of Noncommunicable Diseases

Noncommunicable diseases (NCDs) are the most common cause of death and disability worldwide, accounting for 70% of all deaths and more than three out of four years lived with a disability. The main NCDs comprise cancer; cardiovascular disease; chronic respiratory diseases; and diabetes, as well as a range of other diseases and conditions, including mental health disorders; neurological disorders; autoimmune disorders such as psoriasis; bone and joint conditions such as osteoporosis and arthritis; renal, oral, eye and ear diseases; and injuries and disabilities. Historically considered to be diseases of the rich, NCDs are now severely impacting low- and middle-income countries (LMICs).

Many NCDs are linked by four shared major risk factors – tobacco use, unhealthy diet, physical inactivity, and harmful use of alcohol – with additional socio-economic and environmental determinants also increasing the risk for vulnerable people and those living in extreme poverty. NCDs are a major cause of poverty, and a barrier to economic and social development. With the largest NCD burden occurring in LMICs, and leading to and perpetuating poverty, the prevention and control of NCDs is an urgent development issue, as well as a major health issue.

In recent years, NCDs have attracted increased attention from decision makers at global level. This has resulted in several significant global political commitments on NCD prevention and control. The 2018 United Nations High-level Meeting will be an opportunity for leaders to discuss national progress. It is important that the views of people living with NCDs are represented in this process. Our Views, Our Voices is an effort to ensure that this takes place.



We must put people first

People living with NCDs (PLWNCDs) have, for the most part, not been meaningfully involved in global policy discussions. To accelerate progress on NCDs, PLWNCDs must be at the heart of the NCD response, their views and voices considered and listened to – regardless of where they live or how much money they have.

We define people living with NCDs (PLWNCDs) as a broad group of people who are living with an NCD, those who have had an NCD in the past, and those who are closely connected to someone with an NCD – such as relatives, close friends and care partners¹.

¹ Sometimes also referred to as carers or caregivers.



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What is the OUR VIEWS, OUR VOICES initiative?

OUR VIEWS, OUR VOICES is an initiative by the NCD Alliance and PLWNCDs that seeks to invite people from all over the world living with a range of different NCDs to share their views, take action, and drive change.

Among other objectives, the initiative aims to:



CONSULT

Consult a broad cross-section of people living with NCDs (PLWNCDs), in order to understand the common main challenges that they face and how they want to be meaningfully involved in the NCD response.



ADVOCATE

Produce an Advocacy Agenda of People Living with NCDs and promote it through advocacy efforts at global, regional and national levels.



INVOLVE

Ensure the meaningful involvement of PLWNCDs in decision making processes, including the 2018 United Nations High-level Meeting on NCDs, to guarantee outcomes that reflect their needs and views.



AMPLIFY

Amplify the voices and views of PLWNCDs by stimulating public debate, challenging misconceptions surrounding NCDs, and breaking down stigma and discrimination.

Through this work, Our Views, Our Voices seeks to put people first in the NCD response. It aspires to break down stigma and discrimination, equipping people living with NCDs with the skills, knowledge and opportunities to be leaders and active players in the response to these diseases.



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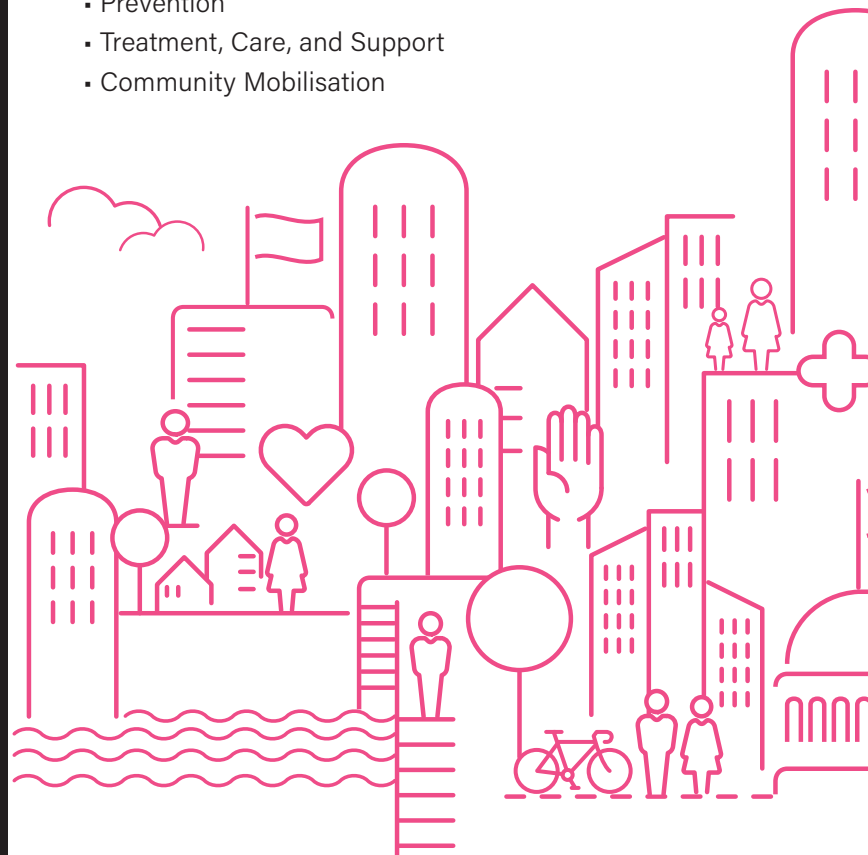
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What is a community conversation?

Community conversations are structured, small group discussions with members of a community, designed to better understand their thoughts and views on particular topics. Our Views, Our Voices is holding a series of in-person community conversations around the world with people living with different NCDs, in order to better understand their needs and challenges, priority “asks”, and how they would like to be involved in a response to NCDs. These conversations will promote thoughtful, constructive, collaborative, empowering dialogue among people living with NCDs.

Community Conversations address the following four themes:

- Social Justice
- Prevention
- Treatment, Care, and Support
- Community Mobilisation



How will the results of the community conversations be used?

Community conversations will be used to help inform and shape an Advocacy Agenda of People Living with NCDs that articulates the issues of greatest importance to those affected and calls on decision makers to take action. Along with an [online consultation](#) (survey) of PLWNCDs and an in-person workshop to be held in Uruguay in October 2017, Our Views, Our Voices will hold these community conversations, with a view to compiling the perspectives and priorities that emerge into the Advocacy Agenda of People Living with NCDs. The Advocacy Agenda will build on the knowledge and firsthand experiences of PLWNCDs, and will be updated on a regular basis to reflect the evolving needs of the community.

The Advocacy Agenda will be used in advocacy efforts across the world directed at improving the prevention and control of NCDs. It will help support advocacy towards the UN 2018 High-level Meeting on NCDs. This meeting, to be attended by decision makers from across the world, will take stock of progress at global and national levels, commend successes, and redouble efforts where we are collectively falling short.

Promote the Online Consultation survey link with your network!



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What are the **benefits** of hosting a community conversation?

We invite you to join us in exploring what people living with NCDs experience on a daily basis, their main challenges, their key recommendations for decision makers and what support they need to take action. The results of these conversations will feed into the development of the Advocacy Agenda, and they can also be used by organisations to guide programme, strategy and advocacy development at local level.

Community conversation hosts will be acknowledged on the NCD Alliance website through an interactive map that will feature photos or videos of conversations that they submit. A final report summarising the scope, range and findings of the conversations throughout the world will contain a complete list of all host organisations.

What is the **purpose** of this community conversation guide?

This guide provides all the information and materials needed to host a community conversation. It will walk you through the necessary steps to plan, organise, advertise, hold and report on a community conversation with PLWNCDs.

This guide has been developed with the guidance of PLWNCDs members of the Our Views, Our Voices Global Advisory Committee.



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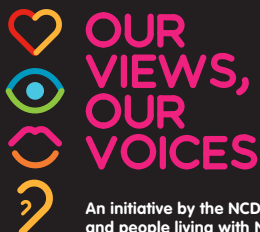
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STEP 1 Logistics

1

SELECT a date, time, and location

Community conversations should be at least 90 minutes long.

Depending on the number of participants, you may wish to increase the allocated time to allow for extensive discussion. The organising team should look to host the event in locations where PLWNCDs in the community would feel comfortable discussing their experiences².

² This guide is for community conversations conducted in person. However, it may be possible to explore online opportunities, such as conducting a community conversation by utilising already established communities of practice and other existing platforms that provide a safe space for discussion among individuals living with a condition or disease.

2

FORM a team of at least two people

Allocate tasks, keeping in mind that people can manage more than one assigned task if your team is small, and agree on who will be:

H1

Providing welcoming and closing remarks

This person will need to review **Handout 1**: 'What to Include in Opening and Closing Remarks'

H2

H3

Facilitating the conversation

This person will need to review **Handout 2**: 'Tips for Facilitators', and to closely study **Handout 3**: 'Community Conversation Discussion Guide for Facilitators'

H4

The conversation note-taker

This person should not be the facilitator, since facilitating and note taking are two separate, important functions. The note-taker will need to review **Handout 4**: 'Tips for Note-Takers'

S1

Registering participants

This person will use a tailored version of **Sample 1**: 'Registration and Consent Form'

H5

Taking photos and/or videos

This person should review **Handout 5**: 'Tips for Collecting Photos'

S2

S3

Advertising and promoting event

This person should review **Sample 2**: 'Community Conversation Flyer' and **Sample 3**: 'Letter of Invitation from the NCD Alliance'

H6

Writing the report

This person will be in charge of submitting the [online Reporting Form](#). For a preview of the information to be reported online, see **Handout 6**.



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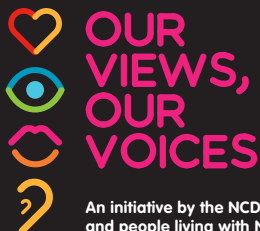
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3

INVITE participants and advertise the event



S2

Create a flyer to advertise the event containing basic information about the purpose, host organisation, date, time, location (see **Sample 2**: 'Community Conversation Flyer'); this can be adapted into targeted emails to specific invitees (e.g., the membership of a host organisation), or posted as a general announcement and open invitation on websites or through social media.

Depending on your setting, you might consider **identifying and recruiting participants** through local hospitals or partner organisations, through trusted health workers in the community or at health facilities, as well as through radio addresses, announcements at community events, targeted telephone calls or other channels, in order to attract people to your event.



S3

You might also consider using **Sample 3**: 'Letter of Invitation from the NCD Alliance' to **help potential hosts or supporters** better understand the purpose of the event and the goals of the NCD Alliance.

Determine whom to invite and how many people you would like to take part in a community conversation. We recommend a maximum of 15 participants to give everyone the chance to speak; if you have organisational capacity and have many participants interested in taking part in a community conversation, you might consider hosting several community conversations.

Note that, in general, community conversations tend to be composed of people living with one particular condition (e.g. people living with diabetes), although it is feasible to host a community conversation among people living with different conditions. In this case, please allow extra time for the ensuing discussion.

Estimate the number of participants through RSVPs.

4

PREPARE the community conversation agenda and handouts

NOTE: In low literacy settings, you should be prepared to share or reiterate written information in person.

Prepare the following:



S1

Registration and Consent Form

(See Sample 1)



S4

NCD Background Information Flyer

(See Sample 4)



S5

Community Conversation Agenda

(See Sample 5)



S6

Evaluation Form

(See Sample 6)

- Organise and order refreshments and snacks (if desired)
- Prepare the event venue.
- Ensure that disability support is provided, including for people with cognitive disabilities, to enable equal participation.



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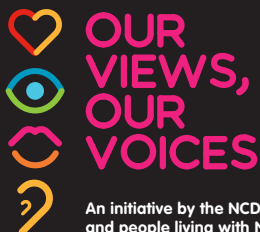
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Holding the community conversation

1

Check in and registration

Register participants, using a Registration and Consent form (see **Sample 1**). You will need to obtain participants' consent in order to use photos, videos or quotes.



S1

2

Welcome and opening remarks

The speaker can be the facilitator or a representative of the organisation that is hosting the community conversation. Welcome participants and thank them for attending. Share more about the host organisation and why it considers NCDs important.



H1



S4

Explain briefly what NCDs are, if needed. Please share why the involvement and contributions of people living with NCDs are important to the host organisation (see **Handout 1** for more tips on opening remarks). Provide handouts on NCDs, if needed (see **Sample 4**).

3

Background information

Provide context for the community conversation

Share more information about the Our Views, Our Voices initiative of the NCD Alliance, explaining how community conversations are taking place around the world and how the results of this community conversation will be shared with the NCD Alliance to inform the Advocacy Agenda of People Living with NCDs. Emphasise that this Advocacy Agenda will be used to reach out to governments and decision makers across the world.

Reiterate that these conversations offer a safe, supportive space for PLWNCDs to share their ideas with each other. Mention that the NCD Alliance will produce an interactive online map of the locations of all of the community conversations held all over the world and that this conversation will be included. Indicate that pictures, videos, and quotes recorded from the event may also be featured on this webpage (and, if appropriate, used by the organisation hosting the conversation).





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4

Participant introductions

Invite participants to briefly introduce themselves (share their name, where they are from, occupation) and what motivates them to participate in this community conversation.

5

Facilitate the discussion



Using the 'Community Conversation Discussion Guide for Facilitators' (**Handout 3**), the facilitator should lead the participants in conversation, while the note-taker captures the relevant information.



H2 NOTE: See 'Tips for Facilitators' (**Handout 2**) with instructions for the facilitator, and 'Tips for Note-Takers' (**Handout 4**) with instructions for the note-taker. Please note that conversations can be facilitated and held in local languages as long as the online report submitted to the NCD Alliance is written in English, Spanish or French.



H4

6

Closing remarks

Thank participants, and highlight two to three recurring themes that emerged during the community conversation. Offer to share your community conversation report with the participants, should they wish to receive it. Offer any other follow-up, as needed. If participants know other PLWNCDs who may be interested in sharing their experiences and views, please refer them to the Our Views, Our Voices **online consultation** (survey) of PLWNCDs that will also be informing the Advocacy Agenda. Finally, you may mention that the World Health Organisation has a website called NCDs and me where people can share their personal story, in case participants are interested.

7

Group photo and statement recordings

Reserve some time to:



Take a group photo



Record responses, either as video (maximum 30 seconds) or written statements accompanied by an optional photo, to the following prompt: 'Tell us the most important thing governments should know about NCDs'

8

Collect evaluation forms



Ask participants to fill out an Evaluation Form (see Sample 6: 'Evaluation Form' below).

NOTE: For settings in which participants have low literacy, consider offering quick exit meetings with participants before they leave, in order to administer the Evaluation Form verbally. These insights will prove particularly useful for improving the event format if you intend to host a series of community conversations.



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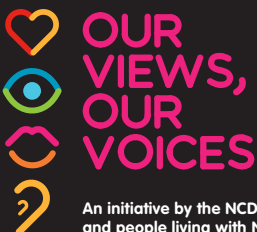
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STEP 3 Reporting back

After hosting your community conversation, it is important to report back to the NCD Alliance by the 31st of August 2017 so that we can use your findings to inform the development of an Advocacy Agenda that reflects the needs and demands of people living with NCDs.

COMPLETE ONLINE REPORTING FORM HERE BY AUGUST 31ST, 2017

For a preview of the questions asked in the online Reporting Form, please refer to Handout 6

H6

The online Reporting Form involves four sections:

1

Provide information on event basics

You are asked to share event basics. For a preview of this section of the [online Reporting Form](#), please see

H6.1

2

Send a complete set of minutes

You are asked to upload the comprehensive minutes of the community conversation in either English, Spanish or French.

The minutes should be as complete and accurate as possible, capturing as many participant quotes as possible. For a preview of this section of the [online Reporting Form](#), please see

H6.2

3

Provide a Summary

You are asked to summarise the community conversation, providing participant quotes and main themes, challenges, and recommendations discussed.

For a preview of this section, and the exact questions asked in the [online Reporting Form](#), please see

H6.3

4

Share photos and other multimedia

The NCD Alliance will feature photos and short videos (*maximum of two minutes*) of community conversations around the world on its [website](#).

Please upload photos and videos taken at the event to the [online Reporting Form](#).

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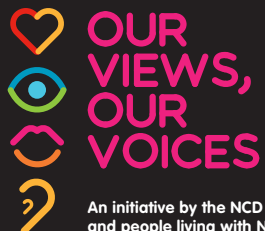
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Handout 1



What to include in opening and closing remarks

H2

Handout 2



Tips for facilitators

H3

Handout 3



Community conversation discussion guide for facilitators

H4

Handout 4



Tips for note-takers

H5

Handout 5



Tips for collecting photos

H6

Handout 6



Preview of Online Reporting Form

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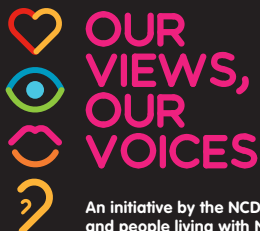
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Handout 1

What to include in opening and closing remarks

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OPENING REMARKS

- **Welcome participants** and thank them for attending.
- **Introduce your host organisation** and explain why it considers NCDs important.
- If necessary, **explain briefly what NCDs** are and why they are of global importance. Provide handout on NCDs, if needed.
- **Share why the involvement and contributions** of people living with NCDs are important to the host organisation.
- **Provide context** to the community conversation by sharing information about the Our Views, Our Voices initiative of the NCD Alliance.
- **Explain how community conversations** are taking place around the world and that the results of this community conversation will be shared with the NCD Alliance to inform the Advocacy Agenda of People Living with NCDs. Emphasise that this Advocacy Agenda will be used to reach out to governments and decision makers across the world.
- Let participants know that the NCD Alliance is also conducting an [online consultation](#) (survey) of people living with NCDs, for those that cannot attend a community conversation.
- **Explain that the NCD Alliance** will produce an online world map and that the location of this community conversation will be noted. Photos and videos recorded from the event may also be featured on this webpage.
- **Remind all participants** or latecomers that they must sign the consent form to allow this material to be published.
- **Explain that the community conversations** are a supportive space for PLWNCDS to share their experiences, and that all perspectives should be heard and respected. Participants should be encouraged to share as much or as little as they would like, as the discussion evolves.
- Go around the room and ask participants to briefly **introduce themselves** (name, where they are from, occupation) and describe what motivates them to participate in this conversation.
- **Introduce the facilitator(s)** and note-taker(s) so that they can begin the community conversation.



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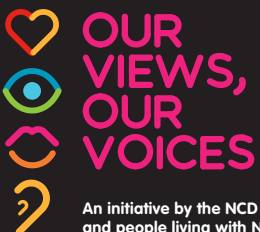
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Handout 1

What to include in opening and closing remarks

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CLOSING REMARKS

- **Thank participants for participating** and helping to shape the Advocacy Agenda of People Living with NCDs.
 - **Highlight two to three recurring themes** that emerged during the community conversation.
 - **Provide information on next steps.** Indicate that the notes of this community conversation will be put into a report and shared with the NCD Alliance. Mention that the NCD Alliance will feature an online world map on its website and the location of this community conversation will be noted.
 - **Offer to share your community conversation** report with the participants, should they like to receive it.
 - Offer any other follow-up, as needed.
-  Ask participants to fill out an **Evaluation Form (see Sample 6)** or to respond to the evaluation questions verbally if needed in low literacy settings, and collect the forms.
 - **Encourage participants to promote the Our Views, Our Voices [online consultation](#)** (survey) with other PLWNCDs they know who may be interested in sharing their views.
 - **Ask participants that if they would like** to share their personal story online, they can do so at a [World Health Organisation's website](#) called NCDs and me.



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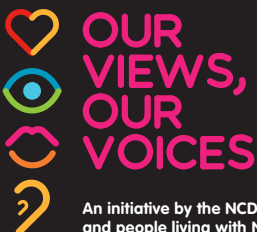
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Tips for facilitators

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- **Welcome everyone**
- **Explain that you will be facilitating the discussion.** Be impartial; the facilitator's opinions are not part of the discussion.
- Make sure everyone has a chance to speak if they want to.
- The facilitator should create a safe environment where each participant feels comfortable expressing ideas and responding to those of others.
- **The facilitator** does not have to "teach" but should be there to **guide the process**.
- **Be prepared.** Make sure you are familiar with the discussion materials, and think ahead of time about the directions in which the discussion might go.
- **Set a relaxed and open tone.** Welcome everyone and create a friendly and comfortable atmosphere.
- **Monitor and assist the group process.** Keep track of how the group members are participating – who has and has not spoken. Don't let anyone dominate; try to involve everyone.
- **Allow for pauses and silence.** People need time to react and respond. Avoid speaking after each comment or answering every question, and allow participants to respond directly to each other. When deciding whether to intervene, lean toward nonintervention in the discussion.
- Help group members **identify areas of agreement** and disagreement.
- Focus and help to **clarify the discussion**.
- **Summarise key points** in the discussion or ask others to do so.
- **Be aware of group dynamics**, particularly in groups where participants are living with different NCDs or have different socioeconomic or cultural backgrounds. Conversations typically occur among participants living with the same NCD, but when there is a diverse group, the facilitator may need to spend extra time inviting the group to identify commonalities and that the ensuing discussion may require more time than a group centered on one NCD.



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Handout 3 Community conversation discussion guide for facilitators

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1

How do people living with your disease or condition define themselves?

FACILITATOR NOTES

This question explores the topic of personal identity. You may wish to prompt further by asking:

- How (if at all) does your disease or condition form part of your identity?
- How has your condition changed you? What have you learned?
- Which words do you prefer to describe yourself and why? (i.e., patient/survivor/person living with your disease or condition/ other)
- Would you describe yourself as a 'patient'?
- Are there any words that you object to being used and if so, why?

Once you have explored the question above, ask the group:

- What recommendations for improvement would you give to those planning environments that promote and protect health and trying to reduce people's exposure to risk factors?

2

What are the main challenges you, and others living with your disease or condition, experience with regards to treatment, care and support?

FACILITATOR NOTES

You may wish to prompt further by asking:

- Do you feel respected by your healthcare service providers: doctors, nurses, community health workers, etc.?
- What kind of experiences have you had with care partners throughout the duration of your illness?

Once you have explored the question above, ask the group:

- **Have you ever experienced challenges with the healthcare system, in accessing affordable early diagnosis and treatment, in accessing psychosocial care, palliative care, or in accessing information and education about managing your disease or condition? If so, what was the challenge and how was it resolved?**
- What recommendations for improvement would you give to those planning treatment, care and support services?



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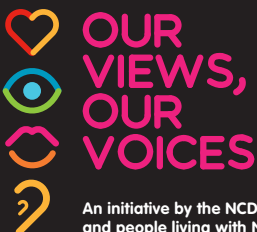
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Handout 3

Community conversation discussion guide for facilitators

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3

Prevention, or reducing risk, is an important area of addressing (insert disease or condition) and other NCDs. How easy would you say it is for people in your local community to lead healthy lives?

FACILITATOR NOTES

This question explores prevention and promoting health. You may wish to prompt further by asking:

- How easy is it to exercise? How easy is it to have a healthy diet? How easy is it to not become a smoker? How readily available is alcohol?
- What types of information and educational campaigns about healthy living are available in your community? About your disease or condition?
- What role do you think people living with your disease or condition or other noncommunicable diseases can play to help ensure environments that promote and protect health?

Once you have explored the question above, ask the group:

- What are the other social, economic, or environmental challenges or risk factors in your community or environment that negatively influence people's health?
- What recommendations for improvement would you give to those planning environments that promote and protect health and trying to reduce people's exposure to risk factors?

4

How (if at all) have you experienced discrimination or stigma in your community, workplace or health care system because of your disease or condition?

FACILITATOR NOTES

This question explores participants' experiences with stigma and discrimination and with the intersection of health and human rights. You may want to prompt further by asking:

- How has living with your disease or condition impacted on your employment/financial/insurance/social/relationships/psychological status?
- Have you ever felt like you were not able to manage your condition or access care because of who you are, where you live, or how much money you have?

Once you have explored the question above, ask the group:

- What would you say are the biggest challenges that people living with your disease or condition face in terms of stigma and discrimination?
- What recommendations would you give to governments and society to address, confront and mitigate discrimination and stigma, and to protect the human rights of those living with your disease or condition?



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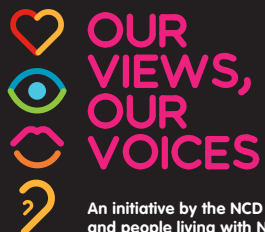
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5

How would you like to be involved and play an active part in helping address your disease or condition and other noncommunicable diseases?

FACILITATOR NOTES

This question aims to explore the meaningful involvement of people living with NCDs and how we can best mobilise communities. It seeks to identify how people living with NCDs would like to be an active part in improving NCD prevention and control. You may prompt further by asking:

- Do you think that people living with different NCDs, e.g. cancer, diabetes, cancer, cardiovascular disease, chronic respiratory disease, etc. face similar challenges and should come together to improve their rights as a group?
- What are some concrete and different ways people living with your disease or condition have been successfully empowered?

Recommendations

What would you need in order to play a more active part to reduce the impact of (your condition/disease/other NCDs) in your community? Stronger community organisations? Networks of people living NCDs? Opportunities to speak up and share your experience? Other?

6

Is there anything else that you think would be important to discuss as part of this conversation?



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OUR VIEWS, OUR VOICES



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Handout 4 Tips for note-takers

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Be comprehensive

Your goal is to create a comprehensive set of minutes that accurately captures the community conversation and serves as a complete record of what was said. Familiarise yourself with **Handout 6** where you can see a preview of what you are expected to report back from your community conversation.



Be accurate

Make note of any information that you did not understand or hear clearly. Consult with the facilitator after the conversation to correct any errors or to confirm that you accurately captured what was said.



Get quotes from participants

Be sure to **capture distinct quotes** from participants that can later be highlighted as representative of the tone and content of the conversation.



Type final minutes

The final minutes should be typed and shared as part of the [online Reporting Form](#). If you take notes by hand during the conversation, type them up as quickly as you can after the conversation to more accurately capture what was said before too much time passes.



Submit online Reporting Form in English, Spanish or French

Even if the conversation was held in another language, **all reporting done through the [online Reporting Form](#), including the minutes, must be in one of these three languages.**



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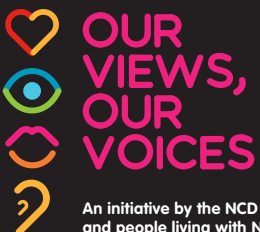
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Handout 5

Tips for collecting photos and videos

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• NCD Alliance welcomes your photos

The NCD Alliance will feature photos from community conversations around the world on its [website](#). Any photos and videos that you share may be displayed in a photo gallery on our global map of community conversations. We encourage you to send photos and short videos from your community conversation for inclusion. You can share these with us through **Section 4** of the [online Reporting Form](#) (see **Handout 6**).



• Remember to collect participants' consent forms

As mentioned in 'What to Include in Opening and Closing Remarks' (**Handout 1**), ensure that all participants understand that they must provide consent through the Registration and Consent Form (see **Sample 1**) in order for the NCD Alliance and the organisation hosting the conversation to publish photos, videos, and statements online and other communications outlets. If there are participants who do not wish to be featured, ensure that they do not appear in material reported back to the NCD Alliance.



• Reserve time for photos and videos

Particularly if you intend to take videos, make your plan in advance. Decide when to shoot, what equipment you will use, and where to capture the best quality footage.

• Choose a quiet and visually calm area

Select an area of the meeting space that is free of visual distractions so that the video will highlight the subject and not the surrounding objects. If it is a sunny day, you might consider shooting outdoors to take advantage of natural light.

• Position interviewees for the best natural light

Note that if windows are behind the subject, you might see unwanted reflections of lights and camera equipment.

• Send us your group photo and "action" shots

In addition to a group photo, we recommend taking "action" photos of participants speaking and engaged in conversation rather than posed shots of participants lined up together.

• Capture short video clips of people speaking from the heart

The agenda includes a suggested 'prompt' to pose to participants for a brief recorded response (maximum 30 seconds). Give participants a few minutes to think of what they would like to say before recording, and allow time for a few takes.

Maximum size: **2 MB**

Formats accepted: **GIF | JPG | PNG | PDF**

See **Handout 6** for details on how to publish videos to Vimeo.



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Handout 6 Preview of Online Reporting Form

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Instructions

For a preview of what is asked in the online Reporting Form please see:

H6.1

Section 1
Event Basics

H6.2

Section 2
Complete Minutes

H6.3

Section 3
Conversation Report

H6.4

Section 4
Multimedia

[Click here to complete the online Reporting Form by August 31st, 2017](#)



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Preview of Section 1 Event Basics

To be completed in the [online Reporting Form](#) here

DATE _____

Location (*city*) _____

Host or Hosts (*organisations*) _____

CONTACT PERSON

Name _____

Email _____

Job Title _____

Organisation _____

PARTICIPANTS

Number of participants Male ____ Female ____ Other ____

Ages represented

(*number of participants in each bracket*)

0-12: _____ 13-19: _____ 20-30: _____

31-40: _____ 41-50: _____ 51-60: _____

61-70: _____ 71-80: _____ >80: _____

Primary Relationship to NCDs

(*number of participants in each category*)

People who have or have had an NCD: _____

Care partner: _____ Relative: _____ Friend: _____

Diseases or conditions represented

(*number of participants in each category*)

Diabetes: _____ Cancer: _____ CVD: _____

Chronic respiratory disease: _____

Mental health disorder: _____ Neurological disorder: _____

Autoimmune disorder (*such as psoriasis*): _____

Bone or joint conditions (*such as osteoporosis and arthritis*): _____

Renal, oral, eye, or ear conditions: _____

Other (*please list*): _____

Nationalities represented

(*please list*)

Details of participants who opted to be kept informed by the NCD Alliance on opportunities for meaningful involvement

Name _____

Email _____

Occupation _____

Organisation _____

Did any participant(s) NOT provide permission for their statements, photos, or videos to be shared?*

YES, one or more participants did not provide sharing permissions: _____

NO, all participants provided sharing permissions: _____

* If you answered YES to the above question, please ensure that the individuals involved are not directly featured in the photos shared, videos captured, or quotes reported below.

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Preview of Section 2 Complete Minutes

The [online Reporting Form](#) will ask you to upload a document with complete conversation minutes.

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Preview of Section 3 Conversation Report

To be completed in the [online Reporting Form](#) here

QUESTION 1

How do people living with your disease or condition define themselves?

LIST 2-3 participant quotes related to this question:

Quote 1: _____

Quote 2: _____

Quote 3: _____

LIST 2-3 recurring themes that emerged during discussion of this question:

Theme 1: _____

Theme 2: _____

Theme 3: _____

QUESTION 2

What are the main challenges you, and others living with your disease or condition, experience with regards to treatment, care and support?

LIST 2-3 participant quotes related to this question:

Quote 1: _____

Quote 2: _____

Quote 3: _____

LIST 2-3 main challenges that emerged during discussion of this question:

Challenge 1: _____

Challenge 2: _____

Challenge 3: _____

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LIST 2-3 main recommendations that emerged during discussion of this question:

Recommendation 1: _____

Recommendation 2: _____

Recommendation 3: _____

QUESTION 3

Prevention, or reducing risk, is an important area of addressing (insert disease or condition) and other noncommunicable diseases. How easy would you say it is for people in your community to lead healthy lives?

LIST 2-3 participant quotes related to this question:

Quote 1: _____

Quote 2: _____

Quote 3: _____

LIST 2-3 main challenges that emerged during discussion of this question:

Challenge 1: _____

Challenge 2: _____

Challenge 3: _____

LIST 2-3 main recommendations that emerged during discussion of this question:

Recommendation 1: _____

Recommendation 2: _____

Recommendation 3: _____



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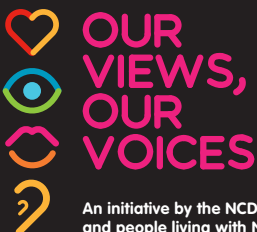
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Section 3: Conversation Report

QUESTION 4

How (if at all) have you experienced discrimination or stigma in your community, workplace or health care system because you are living with your disease or condition?

LIST 2-3 participant quotes related to this question:

Quote 1: _____

Quote 2: _____

Quote 3: _____

LIST 2-3 main recommendations that emerged during discussion of this question:

Challenge 1: _____

Challenge 2: _____

Challenge 3: _____

LIST 2-3 main recommendations that emerged during discussion of this question:

Recommendation 1: _____

Recommendation 2: _____

Recommendation 3: _____

QUESTION 5

How would you like to be involved and take an active role in helping to address your disease or condition and other noncommunicable diseases?

LIST 2-3 participant quotes related to this question:

Quote 1: _____

Quote 2: _____

Quote 3: _____

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LIST 2-3 recurring themes that emerged during discussion of this question:

Theme 1: _____

Theme 2: _____

Theme 3: _____

LIST 2-3 main recommendations that emerged during discussion of this question:

Recommendation 1: _____

Recommendation 2: _____

Recommendation 3: _____

QUESTION 6

Is there anything else that you think would be important to discuss as part of this conversation?

LIST 2-3 participant quotes related to this question:

Quote 1: _____

Quote 2: _____

Quote 3: _____

LIST 2-3 recurring themes that emerged during discussion of this question:

Theme 1: _____

Theme 2: _____

Theme 3: _____



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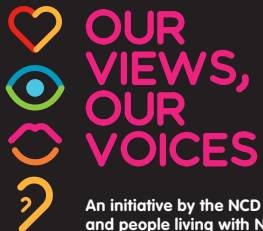
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Preview of Section 4 Multimedia



The final section of the [online Reporting Form](#) will allow you to upload multimedia files from your conversations in the following formats:

<https://vimeo.com>

Use the following ID and password to upload your videos:

User ID: info@ncdalliance.org

Password: 12345678

Click on the link below to access to basic information to upload videos:

<https://help.vimeo.com/hc/en-us/categories/201496018-Uploading-to-Vimeo>

Click on the link below to access to Vimeo Guidelines:

Vimeo Guidelines <https://vimeo.com/help/guidelines>



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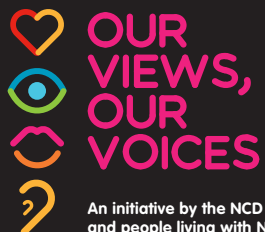
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Sample 1
S1 Registration and consent form



Sample 2
S2 Community conversation flyer



Sample 3
S3 Letter of invitation from the NCD Alliance



Sample 4
S4 NCD Background information flyer



Sample 5
S5 Community conversation agenda



Sample 6
S6 Evaluation form



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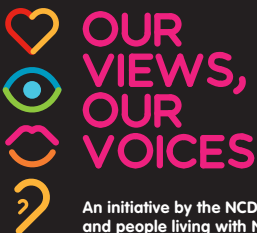
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Sample 1 Registration and consent form

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GENDER: Male Female Other AGE _____

In what way are you affected by noncommunicable diseases? (please select the most relevant option below)

I have/had a noncommunicable disease myself Care partner (sometimes referred to as carer or caregiver)

Relative of someone who has or has had a noncommunicable disease

Friend of someone who has or has had a noncommunicable disease

Disease/condition (select all that apply)

Diabetes Cancer Cardiovascular disease Chronic respiratory disease

Mental health disorder Neurological disorder Autoimmune disorder (such as psoriasis)

Bone or joint conditions (such as osteoporosis and arthritis) Renal, oral, eye, or ear condition

Other (please specify) _____

I would like to be kept informed by the NCD Alliance on the initiative Our Views, Our Voices and opportunities for meaningful involvement.

Yes No

Nationality _____ Name (optional) _____ Email (optional) _____

Occupation (optional) _____

Organisational affiliation (optional) _____

I authorise the NCD Alliance, and the organization hosting this community conversation, to use my statements, photos and videos collected during this event on its website and other communication platforms.

Yes No



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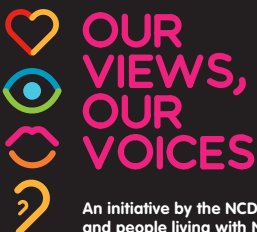
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Sample 2 Community conversation flyer

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WORD



DATE AND TIME
[INSERT DATE AND TIME]

LOCATION
[INSERT VENUE ADDRESS]

A Community Conversation with People Living with [NCDs OR INSERT NAME OF DISEASE/CONDITION]

[HOST] (on behalf of the Our Views, Our Voices initiative of the NCD Alliance)

Are you or is someone you care for living with [NCDs OR INSERT NAME OF DISEASE/CONDITION]?

[INSERT NAME OF DISEASE/CONDITION AND EDIT PARAGRAPH ACCORDINGLY] is one of the main groups of diseases and conditions known collectively as noncommunicable diseases (NCDs). In addition to [INSERT NAME OF DISEASE/CONDITION], the main NCDs comprise cancer; cardiovascular disease; chronic respiratory diseases; and diabetes, as well as a range of other diseases and conditions, including mental health disorders; neurological disorders; autoimmune disorders such as psoriasis; bone and joint conditions such as osteoporosis and arthritis; renal, oral, eye and ear diseases; and injuries and disabilities. NCDs are the most common cause of death and disability worldwide.

[INSERT NAME OF YOUR ORGANISATION], in partnership with Our Views, Our Voices, an initiative by the NCD Alliance and people living with NCDs, would like to invite you to

participate in our community conversation for people living with [NCDs OR INSERT NAME OF DISEASE/CONDITION].

Our Views, Our Voices is holding these conversations all over the world for people living with [INSERT NAME OF DISEASE/CONDITION] and other NCDs, in order to better understand their needs and challenges, and their recommendations for addressing these. The results of these conversations will be used to produce an Advocacy Agenda of People Living with NCDs that can be used at global and local levels to bring greater attention to the needs and priorities of people living with NCDs (PLWNCDs).

This is your chance to contribute to an advocacy agenda of people living with NCDs! Community conversations with people living with NCDs are an excellent way to inform and shape advocacy efforts. If you are living with [INSERT NAME OF DISEASE/CONDITION] or another NCD and cannot participate in the community conversation and you would like to share your views, please go to: <http://bit.ly/2slCW1L>. Get involved!

Insert your organisation's logo

Click [here](#) for more information



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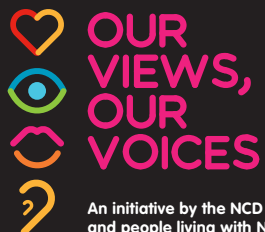
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Sample 3 Letter of invitation from the NCD Alliance

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Dear colleague:

The NCD Alliance unites 2,000 civil society organisations in more than 170 countries, dedicated to improving noncommunicable disease (NCD) prevention and control worldwide.

Noncommunicable diseases (NCDs) are the most common cause of death and disability worldwide, accounting for two out of every three deaths, and for two out of every three years lived with a disability. The main NCDs comprise cancer; cardiovascular disease; chronic respiratory diseases; and diabetes, as well as a range of other diseases and conditions, including mental health disorders; neurological disorders; autoimmune disorders such as psoriasis; bone and joint conditions such as osteoporosis and arthritis; renal, oral, eye and ear diseases; and injuries and disabilities

Through the initiative Our Views, Our Voices, the NCD Alliance and its partners around the world are hosting community conversations to identify common issues faced by people living with NCDs, to receive their main recommendations, and to understand how they would like to be involved in a global response to NCDs.

The results of these conversations will be used to produce an Advocacy Agenda of People Living with NCDs that can be used at global and local levels to bring greater attention to the needs and priorities of people living with NCDs (PLWNCDs). These community conversations will promote thoughtful, constructive, collaborative and empowering dialogue among people living with, and affected by NCDs.

We invite you to help us with this important initiative by supporting local organisations to host community conversations.

Please consider lending your support by helping to:

- Identify participants;
- Identify or provide appropriate meeting space to hold conversations;
- Advertise conversations through your network; or
- Provide healthy refreshments or other resources.

Thank you for your support.
With warm regards,

Katie Dain
CEO, NCD Alliance



COMMUNITY CONVERSATION GUIDE

If you have questions or require further information, please visit our [website](#)



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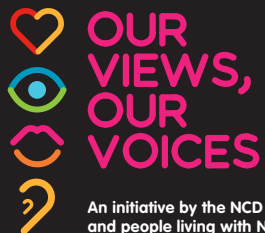
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Sample 4 NCD Background information flyer

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What are NCDs?

The main **NONCOMMUNICABLE DISEASES**, or NCDs, comprise



CANCER



CARDIOVASCULAR DISEASE



CHRONIC RESPIRATORY DISEASES



DIABETES



MENTAL HEALTH DISORDERS

as well as a range of other diseases and conditions, including mental health disorders, neurological disorders, autoimmune disorders such as psoriasis, bone and joint conditions such as osteoporosis and arthritis, renal, oral, eye and ear diseases, and injuries and disabilities.

They are called 'noncommunicable' because they cannot be transmitted from person to person.

Driven largely by four main MODIFIABLE RISK FACTORS



TOBACCO USE



UNHEALTHY DIET



PHYSICAL INACTIVITY



HARMFUL USE OF ALCOHOL

NCDs are a major cause of poverty globally and also act as a barrier to economic and social development.

How many people are impacted?



NCDs kill **39.5** MILLION PEOPLE each year



They are the most common cause of death and disability worldwide, accounting for **70%** of all deaths and more than three out of four years lived with a disability

Historically considered to be diseases of the rich, NCDs are now severely impacting low- and middle-income countries (LMICs), with four out of five people with an NCD living in LMICs, and more than three out of four NCD deaths along with most

With the global burden of NCDs **EXPECTED TO INCREASE** by

17% by 2025

the trend is headed in the wrong direction



86% occurring in LMICs

What is being done to address NCDs?

Premature deaths due to NCDs can be reduced significantly when governments implement effective policies. In recent years, this has attracted increased attention from decision makers at the global level. As a result, several significant global political commitments on NCD prevention and control have been adopted, including commitments to reduce premature mortality caused by these diseases.

In 2018, the UN General Assembly will convene a third high-level meeting to take stock of national progress on NCD prevention and control. This is an excellent opportunity for people living with NCDs to get involved, make their voices heard, and keep their governments accountable to ensure that they live up to their commitments.



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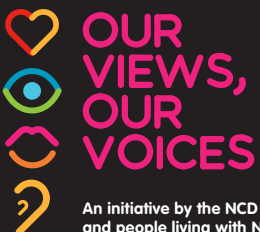
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Sample 5 Community conversation agenda

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ACTIVITY	SUGGESTED DURATION
Registration	15 minutes
Welcome and Opening Remarks	10 minutes
Introductions	10-15 minutes
Facilitated Discussion <ol style="list-style-type: none"> 1. How do people living with your disease or condition define themselves? 2. What are the main challenges you, and others living with your disease or condition, experience with regards to treatment, care and support? 3. Prevention, or reducing risk, is an important area of addressing (<i>insert disease or condition</i>) and other noncommunicable diseases. How easy would you say it is for people in your community to lead healthy lives? 4. How (<i>if at all</i>) have you experienced discrimination or stigma in your community, workplace or health care system because you are living with your disease or condition? 5. How would you like to be involved and be an active part in helping address your disease or condition and other noncommunicable diseases? 6. Is there anything else that you think would be important to discuss as part of this conversation? 	60-90 minutes
Closing Remarks	5 minutes
Group Photo and Statements	5 minutes



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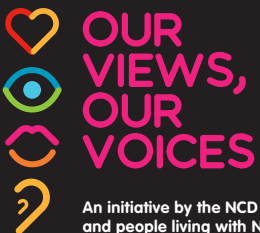
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Sample 6 Evaluation form

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1. What is your overall assessment of the community conversation event in terms of how successful it was in carrying out its goal of exploring the needs and recommendations of people living with NCDs?

(1 = not successful at all - 5 = highly successful)

1 2 3 4 5

2. Which topics or aspects of the community conversation did you find most interesting or useful?

3. How do you think the event could have been made more effective?

4. Please comment on the organisation of the event

(from 1 = insufficient to 5= excellent)

1 2 3 4 5

5. Comments and suggestions

(including conversation topics you think would be useful for future community conversations)

6. Further comments, suggestions or thoughts



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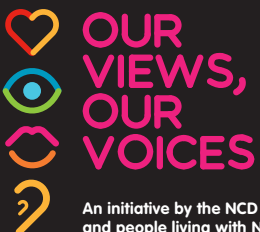
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SOCIAL MEDIA TIPS

Organisers

Primary hashtags:

#NCDVoices

#NCDs

Primary handle:

@ncdalliance

Before sharing community conversation quotes and photos on social media, please be sure to ask participant's consent.



How to get the most out of social media



Use a positive tone

Strive for an approachable, authentic and friendly tone. The essence of Our Views, Our Voices is to explore the views and voices of people living with NCDs. Take the role of an impartial observer that highlights participants' courage and insights.

Give credit where it is due, highlight the relevance of community conversations, and show your appreciation for everyone involved. Include quotes, experiences and insights from your community conversation and those of others during theirs.

Tag and add hashtags

Tag photos and posts with the names of participating organisations and individuals (ensuring that all those tagged have signed consent forms). Tag the Our Views, Our Voices campaign, @ncdalliance, and the [interactive campaign map](#). Prioritise the #NCDVoices hashtag. Add other relevant hashtags for your event, wherever possible.

Connect with the Our Views, Our Voices network

Interact with participants and organisers of other Our Views, Our Voices events by tracking the hashtag #NCDVoices on Twitter. Like and share their posts. Direct them to the Our Views, Our Voices [website](#).



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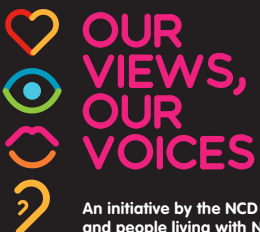
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HOW TO CONDUCT A COMMUNITY CONVERSATION

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An initiative by the NCD Alliance and people living with NCDs

#NCDvoices



Amplify advocacy messages

Proactively follow organisations with whom you align. Amplify advocacy messages to give them greater traction and visibility. This will show potential followers who you are, what you advocate for, and that you are supporting and contributing to a common agenda. Like, share and comment on photos, messages and calls to action that resonate with Our Views, Our Voices and the NCD Alliance network.

Connect and call to action

Encourage comments and feedback on your posts, by inviting followers to comment, or asking a direct question, e.g. "What did you think of...?" "What should be done to...?" "What is most important about...?" Whenever a follower leaves a comment, respond promptly, thanking him/her for their feedback and clearly answering queries.

A picture is worth a thousand words

Visuals are the most liked and most shareable content on social media. Share pictures of the community conversation with people actively involved in discussion (ensuring you have their consent for sharing). Clear images are more likely to be shared.

Keep it real and real clear

Steer clear of overtly technical, specialised or colloquial terminology. Keep your posts and comments simple, accessible and shareable.

Regular, short posts are more effective than periodical or occasional, longer posts. Spark interest, engage users and maintain momentum by posting regularly.

Consider automated posting tools like HootSuite to pique interest, prevent absence and lagging interest.

Open forum, safe space

Our Views, Our Voices serves a safe space for open discussions. Encourage friends and followers to post and to send private messages, should they feel more comfortable doing so. Endeavour to respond to all messages and posts as swiftly as possible.



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HANDOUTS



SAMPLES



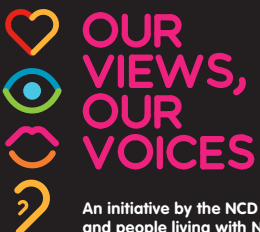
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More info at
<http://bit.ly/2teye9o>

[SHARE] Share your views, take action & drive change. Be part of #NCDVoices @ncdalliance <http://bit.ly/2teye9o>

[SHARE] Are you living with an #NCD? Join Our Views, Our Voices. Take action & drive change #NCDvoices @ncdalliance <http://bit.ly/2teye9o>

[SHARE] #NCDvoices: stimulating public debate & challenging misconceptions @ncdalliance #NCDs <http://bit.ly/2teye9o>

[SHARE] #NCDvoices: breaking down stigma & discrimination @ncdalliance #NCDs @ncdalliance <http://bit.ly/2teye9o>

[SHARE] Tell us the most important thing governments should know about #NCDs #NCDvoices @ncdalliance <http://bit.ly/2teye9o>

[SHARE] What are the main challenges that PLWNCDs face every day? Tell us your story. Join #NCDvoices @ncdalliance <http://bit.ly/2teye9o>

[SHARE] What would you say are the biggest challenges that people living with #NCDs face in terms of stigma & discrimination? Join #NCDvoices @ncdalliance <http://bit.ly/2teye9o>



[SHARE] What recommendations would you give to governments to protect the #humanrights of people living with #NCDs? #NCDvoices @ncdalliance <http://bit.ly/2teye9o>

[SHARE] What are some concrete ways people living with #NCDs have been meaningfully involved in the response? Share your story #NCDvoices @ncdalliance <http://bit.ly/2teye9o>

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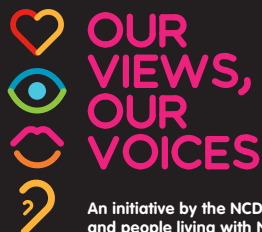
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Our Views, Our Voices is an initiative by @ncdalliance and People Living With NCDs (PLWNCDs) that seeks to invite people from all over the world living with a range of different NCDs to share their views, take action, and drive change. Join us! #NCDvoices <http://bit.ly/2teye9o>

Our Views, Our Voices initiative promotes the vision of PLWNCDs by stimulating public debate, challenging misconceptions surrounding NCDs, and breaking down stigma & discrimination. Be part of the conversation! #NCDvoices <http://bit.ly/2teye9o>

What are the main challenges you, and others living with your condition experience with regards to NCD treatment, care and support? Join the Our Views, Our Voices initiative. Share your ideas and collaborate with PLWNCDs to take action #NCDvoices <http://bit.ly/2teye9o>

What recommendations for improvement would you give to those planning NCD treatment, care and support services? Join the Our Views, Our Voices initiative #NCDvoices <http://bit.ly/2teye9o>

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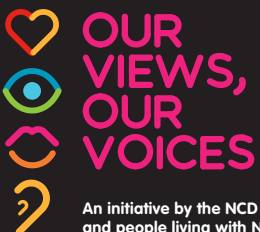
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SOCIAL MEDIA TIPS

Participants

Primary hashtags:

#NCDVoices

#NCDs

Primary handle:

@ncdalliance



When posting on social media, remember to...



Use a positive tone

The essence of Our Views, Our Voices is to explore the views and voices of people living with NCDs.

Tag and add hashtags

Tag photos and posts with the names of the community conversation organiser, participating organisations and individuals (with their permission). Tag the Our Views, Our Voices campaign using the #NCDVoices hashtag and @ncdalliance.

Connect with others

Interact with participants of other Our Views, Our Voices events by tracking the hashtag #NCDVoices. Like and share their posts. Direct them to the Our Views, Our Voices website on the NCD Alliance homepage www.ncdalliance.org) and social media pages.

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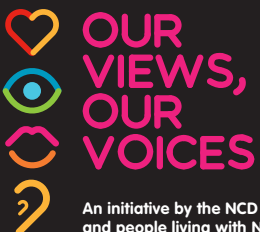
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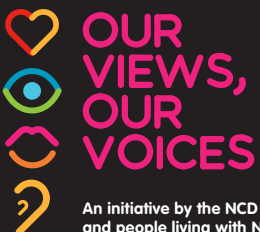
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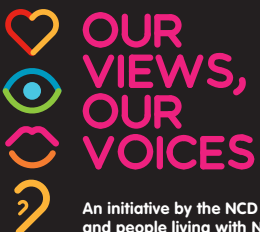
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Community Conversation: A structured, small group discussion open to members of a community, in order to better understand their thoughts and views on particular topics.

HLM: United Nations High-level Meeting on Noncommunicable Diseases (NCDs). The next HLM will be held in 2018.

NCDs: Noncommunicable diseases. The main NCDs comprise cancer; cardiovascular disease; chronic respiratory diseases; and diabetes, as well as a range of other diseases and conditions, including mental health disorders; neurological disorders; autoimmune disorders such as psoriasis; bone and joint conditions such as osteoporosis and arthritis; renal, oral, eye and ear diseases; and injuries and disabilities.

NCDA: The NCD Alliance.

PLWNCDs: People living with NCDs.





OUR VIEWS, OUR VOICES

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and people living with NCDs



"I am not just my disease. I like to play soccer. I have a family, friends, etc. Nobody would want to be reduced to a condition. We are here to work for people, not for a disease."

NCD Alliance Community Conversation participant, World Congress of Cardiology & Cardiovascular Health, Mexico, June 2016

#NCDvoices

OUR VIEWS, OUR VOICES is an initiative by the NCD Alliance and PLWNCDs that seeks to invite people from all over the world living with a range of different NCDs to share their views, take action, and drive change. This guide provides all the information and materials needed to host a community conversation.

This community conversation guide has been possible thanks to the partnership with Medtronic Philanthropy as part of the programme *"Expanding Access to Care, Supporting Global, Regional and Country level NCD Action"*.



The NCD Alliance is a unique civil society network, uniting 2,000 organisations in more than 170 countries, dedicated to improving NCD prevention and control worldwide. Together with strategic partners, including the World Health Organization, the United Nations and governments, the NCD Alliance works on a global, regional and national level to bring a united civil society voice to the global campaign on NCDs.

Contact us at
ourviewsourvoices@ncdalliance.org
if you have any questions

www.ncdalliance.org