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ProNUT HIV Stakeholder Consultation Report 2011

Pamela Fergusson

February 2012

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Abbreviations and Acronyms

AIDS	acquired immune deficiency syndrome
CRS	Catholic Relief Services
FANTA-2	Food and Nutrition Technical Assistance II Project
HIV	human immunodeficiency virus
PLHIV	people living with HIV
TB	tuberculosis
U.N.	United Nations
USAID	United States Agency for International Development

Background

ProNUTRITION is a United States Agency for International Development (USAID)-funded interactive, online information resource¹ that supports health care providers, community health workers, policy makers, and program managers with current, relevant, and practical knowledge and tools for decision making in the context of nutrition and HIV and related areas. ProNUTRITION is managed by FHI 360. The website and associated mailing list are hosted and managed by the FHI 360-SATELLIFE Center for Health Information and Technology.

A wide range of information is available on the ProNUTRITION website, such as e-forums on timely topics, newsletters, online document libraries, links to websites, guidelines, and assessment tools, all offered to assist individuals in the provision of evidence-based care.

The ProNUT HIV e-forum, part of ProNUTRITION, was started in 2003. The original objectives of ProNUT were:

1. To promote the sharing of knowledge, information, and promising practices on nutrition and HIV/AIDS
2. To discuss the challenges in addressing nutrition care and support of people living with HIV (PLHIV)
3. To provide a medium where PLHIV can share their experiences and give testimonies on how proper nutrition care and support has helped them and what challenges they are facing in relation to their nutrition
4. To stimulate dissemination of up-to-date information on nutrition care and support for PLHIV

The ProNUT HIV e-forum offers the opportunity to disseminate key reports and research findings, share experience from practice, ask questions of the global nutrition and HIV community, and post relevant events and job and funding opportunities. ProNUT has helped promote global communication; membership extends around the world and any member is eligible to post. This creates an environment that encourages knowledge exchange and fosters north-north, north-south, and south-south sharing.

However, ProNUT and ProNUTRITION face some key issues.

- Although the discussion board is moderated, there have been some postings that conflict with established evidence in nutrition and HIV. This can create confusion for members, and damages the credibility of the forum.
- There is a nutrition and HIV document library on the ProNUTRITION website. Although this library contains useful reference material, most recent posted documents are from 2008.
- Through most of 2011, the e-forum was inactive. (It is currently being reactivated, thereby presenting an opportunity to revisit the objectives.)

Current subscriber membership stands at 1,158 representing 33 countries around the world. It is possible that representation of other countries is being missed, since ProNUT does not require any form of registration to participate in the forum.

Purpose of the Stakeholder Consultation

In October 2011, the FHI 360/Food and Nutrition Technical Assistance II Project (FANTA-2) assumed responsibility for moderating ProNUT. With the re-launch of ProNUT, FANTA-2 management felt that there was a need to update and refine ProNUT's objectives and mandate, to ensure that it is keeping pace with emerging technologies for online communities as well as new advances in the world of HIV and nutrition and meeting the needs of ProNUT users. To ensure that ProNUT was meeting its goals, FANTA-2 consulted with ProNUT stakeholders, by conducting a user survey to gather data on defining the new direction and improving ownership and participation.

¹ <http://www.pronutrition.org>.

Methods

In November 2011, the ProNUT e-forum was re-opened with a new moderator, and a user survey was conducted to inform ProNUT's direction. The survey questions (see annex) were pre-tested by stakeholders from low- and middle-income as well as industrialized countries. Participating stakeholders were Catholic Relief Services (CRS); the Centre for International Health and Development; the Institute of Child Health, University College London; the George Washington University; FHI 360/FANTA-2; the FHI 360/Livelihoods and Food Security Technical Assistance Project; USAID; Valid Nutrition; and the World Health Organization. The survey was delivered in an online format, using the Survey Monkey platform and was opened to ProNUT users on November 15, 2011. Reminder emails were sent to the ProNUT membership on November 23 and November 30. Final results were captured on December 2, 2011.

On issues where the results of the survey were inconclusive, responses were followed up on using a key stakeholder email discussion. Key stakeholders from the British Columbia Centre for Excellence in HIV/AIDS (researcher); CRS; the Centre for International Health and Development; the Institute of Child Health, University College London (frontline worker, researcher, and NGO staff); FHI 360 (nutritionist); the George Washington University (researcher); FHI 360/FANTA-2 (NGO staff); USAID (donors); and the World Food Programme (WFP) (United Nations [U.N.] agency staff) were included in the discussions, which continued until consensus was reached. These stakeholders were selected because of their leadership and experience in the field of nutrition and HIV and their membership and participation in ProNUT, and because they represented a range of professional affiliations similar to the make-up of the ProNUT membership, including NGO staff, researchers, frontline workers, donors, and U.N. agency staff.

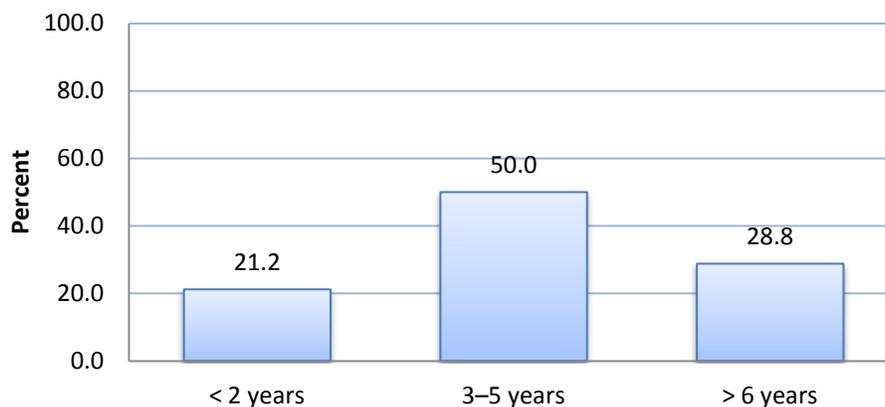
Results and Discussion

Fifty-two respondents from a total membership of 1,158 participated in the survey. This is a 4.5 percent response rate to the survey. This is the same number of respondents as participated in the 2005 member survey. When interpreting the survey data, it is important to consider that they are representative of a very small proportion of the membership, and may not reflect the views of all members. While the data from the survey are interesting and informative, this response rate is so low that it is valuable to look at other ways to engage with the membership, including posting brief, email-based questions on ProNUT and possibly following up with key stakeholders for further discussion by telephone or the web. The low response rate may also be indicative of poor and unreliable Internet access in low- and middle-income countries, a potential obstacle in completing the online survey.

The ProNUT Membership

As shown in **Figure 1**, 78.8 percent of respondents have been ProNUT members for at least 3 years.

Figure 1. Length of Membership in ProNUT



It is encouraging to see that ProNUT has such a well-established membership: almost 29 percent of respondents have been active since the forum began (more than 6 years ago), and another 50 percent of respondents have been active for at least 3 years. This represents a significant opportunity for organizational memory and continuity. To get a better idea of the composition of ProNUT's membership, it would be valuable to follow up the survey with a request to members to complete a brief profile with name, job title, organization, and country.

It is likely that ProNUT HIV would benefit from a membership drive to encourage new members to sign up. FANTA-2 organized a Nutrition and HIV meeting in Jinja, Uganda, in September 2010, and, in November 2011, the moderator of ProNUT sent an email to all the meeting's attendees inviting them to become ProNUT members. New membership was one of the issues discussed in key stakeholder emails following the survey. One of these stakeholders made the excellent suggestion of promoting ProNUT at conferences and meetings. The ProNUT team will continue to look for opportunities to refresh and add to ProNUT's membership.

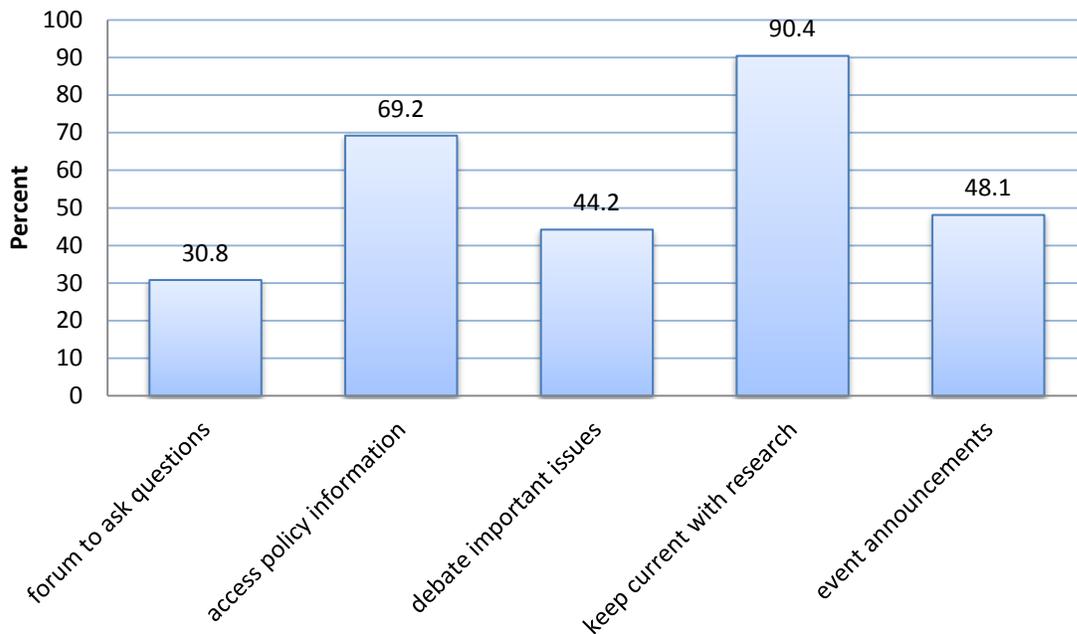
Survey participants were asked to share the type of organization they work for. Forty-eight of 52 participants answered this question (**Table 1**). Although the instructions in this question suggested that members should choose one best answer, some people selected more than one response, so the responses do not total to 100 percent. This is likely representative of the fact that many ProNUT e-forum participants have more than one professional designation (for example being a health care professional and an NGO staff person). A significant proportion of respondents identified as 'other'. Most of these people explained that they were independent consultants or students.

Table 1. ProNUT Members' Professions

Professions	#	%
Health care professional	16	33.3
University or research institute staff member	12	25.0
NGO staff member	21	43.8
Private/for-profit company staff member	4	8.3
Government staff member	1	2.1
Other	11	22.9

Reasons for Using ProNUT

According to survey responses, 90.4 percent of respondents use ProNUT to stay current with new HIV and nutrition research (**Figure 2**). Accessing policy and programmatic information was also an important reason for forum use (69.2 percent). These results may reflect the fact that access to current journal content in libraries may be limited in the developing world. Full-text articles are sometimes freely available online in open access archives, but many journals require a subscription.

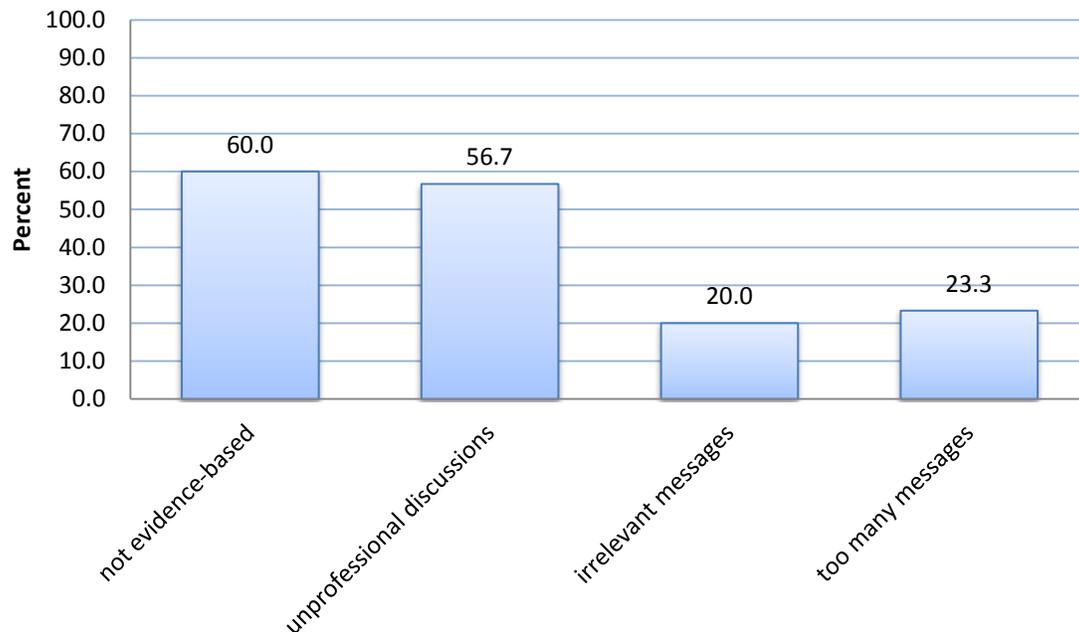
Figure 2. Reasons for Using ProNUT

Additional resources on the ProNUTRITION website were also rated as valuable by e-forum users; 93.5 percent of respondents felt that the online library of documents should continue to be updated. The online library of documents is maintained jointly by the moderator and the administrator of ProNUT at FHI 360-SATELLIFE. This library could be an excellent resource, but there is a lot of updating that needs to be done to improve the online holdings, as the most recent documents were uploaded in 2008. Because staying current with research was reported as the most important reason to use ProNUT, there is clearly a need to upload open access full-text journal articles, along with other policy and programmatic documents. The number of journals offering free full-text publication is continuing to increase, and ProNUTRITION.org could take advantage of this by sharing some relevant articles in its library. This would be particularly useful to house documents that are referred to in the text of postings, as the ProNUT e-forum is not able to accept attachments.

Respondents also valued the searchable archive of postings. Almost 70 percent of respondents felt that the archive should definitely be maintained, and another 30.2 percent felt that the archive should probably be maintained.

ProNUT Negatives

There were some negatives mentioned about the ProNUT e-forum experience, with 60.0 percent of survey participants stating that discussions are sometimes not evidence-based and 56.7 percent stating that the discussions sometimes become unprofessional (**Figure 3**). This is obviously something that the ProNUT community feels is very important. Opportunities to improve the professionalism and scientific rigor of ProNUT will be explored, for example, by sharing more abstracts and open access full-text articles; encouraging members to refer to evidence from articles, reports, and personal field experience to enrich the discussions; and creating a warm and professional environment where members are treated with respect.

Figure 3. ProNUT Negatives

Notably, only 30 of the 52 (57.7 percent) respondents answered this question, indicating that perhaps other respondents did not have any complaints about ProNUT.

Several participants provided additional comments in the “other” response option of this question. One participant noted that the issues of non-communicable diseases were rarely featured on ProNUT, and overnutrition among PLHIV in many countries is emerging as a critical challenge. It is important that ProNUT is responsive to changes in the clinical environment of nutrition and HIV.

Another respondent added a comment in the “other” responses stating that he or she was concerned about the moderator potentially censoring postings. This is potentially a serious issue, and something that has been discussed at length with key stakeholders in follow-up emails. ProNUT welcomes postings from everyone, but asks potential message posters to declare their names, job titles, country where they are working, and any commercial interests they may have. This helps members understand the context of postings on the e-forum. It is also essential that postings have a professional and collegial tone and are free from abuse and rhetoric. Finally, it is important that this be a forum where critical thinking is encouraged, assumptions can be challenged, and research evidence and field experience can be used to build a better understanding of the issues in nutrition and HIV. The moderator has the potential to ameliorate the ProNUT experience for the members by helping message posters clarify ambiguities before their postings are shared, by encouraging discussion, and by disallowing postings that are not in accordance with the ProNUT mandate. However, there is a risk that the moderator could bias the postings by unfairly disallowing postings or by editing postings in a way that changes the intended meaning (intentionally or unintentionally). Key stakeholders felt that ProNUT should continue to be moderated, and it will be important for controversial issues to be discussed with key stakeholders so that the decisions are not made by only one person. Although the final decision regarding postings rests with the moderator, having the advice of key stakeholders when necessary will be advantageous. Having a clear document with updated and agreed-to ProNUT objectives and mandate will also be useful in ensuring that the moderation is conducted in accordance with the wishes of the membership.

Based on the outcomes of the stakeholder consultation process, including the user survey and additional stakeholder discussions, FANTA-2 recommends that ProNUT should have an updated set of objectives, mandate, and code of conduct. These should clearly outline the scope of the e-forum, the types of postings that will be welcome, and the professional standard of online etiquette that will be expected.

Online etiquette on ProNUT includes acknowledging and respecting other e-forum member's points of view, as well as presenting unique ideas in a balanced and evidence-based manner. This mandate and objectives document will also clarify the role of the moderator. This document should be drafted by FANTA-2 with reference to the findings of the stakeholder consultation and posted on the e-forum with an opportunity for members to comment before finalization.

The ProNUT Mandate

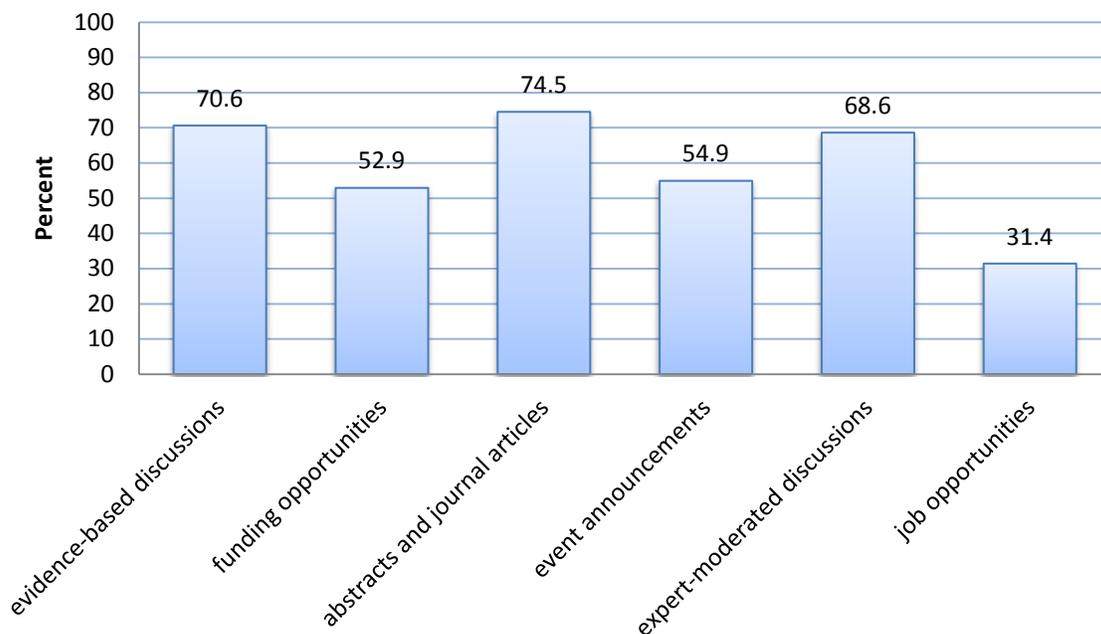
Survey participants were split in terms of their feelings regarding the mandate of ProNUT. Respondents could only select one response and just over half (52.1 percent) felt that ProNUT should either stay focused on nutrition and HIV (22.9 percent) or be broadened to include nutrition and other infectious diseases, such as tuberculosis (TB) (29.2 percent). The other participants (47.9 percent) felt that ProNUT should include all aspects of nutrition relevant to the developing world.

As this was a topic where the membership was split, the ProNUT team engaged in further discussions with key stakeholders. Consensus was reached that ProNUT would focus on nutrition and HIV, TB, and other infectious diseases. Stakeholders were concerned that the forum could become too broad and therefore not relevant to users and that it would be difficult to find a moderator capable of adequately keeping abreast of a broad forum that includes all nutrition issues in the developing world. Finally, it was acknowledged that there are other popular forums (for example en-net²) that already cover some of this material. The ProNUT mandate and objectives will be further clarified in a document that will be shared with the membership for comment before finalization.

ProNUT Priorities

As **Figure 4** demonstrates, ProNUT members value evidence-based discussions and sharing new relevant abstracts and journal articles. This focus on research is in line with members' stated reasons for using ProNUT (90.4 percent of respondents said that they use ProNUT to stay current with emerging research; see **Figure 2**) and is also consistent with respondents' shared concerns that ProNUT is not evidence-based (see **Figure 3**).

Figure 4. ProNUT Priorities



² <http://www.en-net.org.uk/>.

Here we see that the ProNUT membership highly values research and evidence-based discussions. The responses to this question indicate more interest in discussions than was reflected in **Figure 2**, where only 44.2 percent of respondents said they wanted to “debate” issues. Perhaps respondents were more comfortable with the term “discussions” than with “debate.” ProNUT will continue to contain a variety of postings, including relevant research, funding opportunities, event announcements, and job opportunities, but the focus will be on research and evidence-based discussions since this has been clearly demonstrated in this survey as important to the membership. Expert-led discussions are also something that ProNUT will do more often in the future, on the advice of its membership. There is a potential to explore using a real-time, web-based platform for these expert-led discussions. One key stakeholder mentioned that on another forum on which it is a member, discussions take place for a stated length of time, and then the moderator shares a “summing up” of the discussion.

While it is good to see that ProNUT members so highly value an e-forum with evidence-based discussions, creating evidence-based postings does take more time and could be intimidating for some members. This could be an opportunity to take advantage of the ProNUTRITION website to link to websites like PubMed³ and possibly to offer some tutorials on searching for and critically evaluating evidence.

Potential ProNUT Improvements

Sixty-seven percent of respondents felt that ProNUT would definitely (26.7 percent) or perhaps (40.0 percent) be improved by taking advantage of new communication technologies like Facebook and Twitter. A few members added comments that an improved interface between the website, the posted information, and the user would be beneficial. They suggested that ProNUT needs to have a greater focus on the ProNUTRITION.org website and links to other material, such as appropriate e-learning, blogs, videos (e.g., YouTube), podcasts, collective information/data sharing, combined research projects, and program descriptions. This is a new area for ProNUT to explore and should prove fruitful, as the availability and quality of these additional technologies and communication resources have progressed a great deal since ProNUT’s inception in 2003.

One contributor suggested:

“ProNUT HIV would be improved if the interface extended beyond email discussion groups to focus more on a website component. The service should include diseases such as TB given the management in clinical and community settings is almost indivisible for HIV services. There is a great potential to share data between projects, research protocols, [and] national policies in one centralized repository. It would certainly make it easier for those of us who work in the area to find information in one centralized area. Other services the site could offer include ‘wiki’ style (i.e., resources continually evolve through contributor input) resources on technical issues, such as ‘NACS,’ costing, programming, M&E, and other issues; monthly newsletters; new research concepts; M&E guidance documents (global indicators); [and] blogs.”

One concern raised by participants was to “make sure there is not invasion of food manufacturers and commercial interests in the postings.” This is something that also came up in key stakeholder discussions. Eight percent of survey participants identified themselves as private/for-profit company staff, but a significantly higher proportion of postings in the archives are from food manufacturers. ProNUT welcomes postings from all sectors and perspectives, but some members feel that specialized food manufacturers may be trying to market their products and sometimes do not declare their potential conflict of interest.

Another suggestion was to clearly denote the content of a message in the subject line, so busy participants can easily screen the messages that are of interest to them. In the future, the ProNUT team will try to make the subject lines of emails very clear to aid this process. Other possible solutions could be explored with FHI 360-SATELLIFE, like giving members the option to receive the digest version in which several emails are bundled together in one message when a designated size is reached.

³ <http://www.ncbi.nlm.nih.gov/pubmed/>.

Some survey participants acknowledged that they do not often post on ProNUT. One respondent suggested something that might encourage them to post:

“Being able to contact the moderator to see if what I’m thinking of posting is relevant. I’m shy and online forums, the idea of something going out to the whole world . . . it’s scary to me. I guess I need to build up my confidence.”

As the moderators of ProNUT, FANTA-2 wants to encourage every member of the forum to feel part of the community and to post questions and comments. Over the years, many people have participated in ProNUT, some of whom have many years of experience and some of whom are new to the field. One of the great benefits of ProNUT is the fact that the membership is made up of a diverse group of people with different expertise and experience. Cultivating an atmosphere where all members feel welcome to post is a key priority for ProNUT’s next steps.

Improving the links between the ProNUTRITION website and the e-forum is a key message from the survey, as 93.5 percent of respondents thought that the document library should be updated and maintained. Forging stronger links between the updated website and the e-forum is a clear next step. The same contributor who suggested this also suggested some other new directions for ProNUT, including using the site and forum as a “one-stop shop” for research and programmatic information about nutrition and infectious diseases in developing countries.

Key Recommendations

Based on the results of the participant survey and follow-up key stakeholder discussions, we recommend the following steps be taken.

- Create an updated set of objectives, mandate, and code of conduct for the ProNUT e-forum.
- Organize a membership drive to increase membership, including more systematically promoting ProNUT at relevant meetings and conferences.
- Update the document library and forge stronger links between the ProNUT e-forum and the ProNUTRITION website.
- Expand the ProNUT mandate to include nutrition and infectious diseases for the developing world, particularly HIV and TB.
- Improve the focus on sharing research and evidence-based discussions through increased sharing of new full-text, open access journal articles and sharing postings and questions with reference to research evidence. Links to websites with relevant full-text journal articles and searchable databases could be included on the ProNUTRITION website, as well as an updated library of documents. Tutorials on searching for and evaluating nutrition research evidence could also be included. Following the advice of the membership to provide opportunities for time-limited, expert-led discussions and a conclusion or summing up by the moderator will also help the discussions stay focused and keep members engaged and participating.
- Explore new communication interfaces like Facebook and Twitter as opportunities to expand the reach of ProNUT and make it more accessible for users of these technologies.
- Explore the possibility of holding some discussions (for example expert-led discussions) using real-time, web-based platforms.
- Cultivate a warm and collegial atmosphere on the e-forum by asking relevant questions of the membership and probing for more information to encourage postings so that all members feel welcome to contribute. Responding to postings in a timely and professional manner will allow participants to feel valued and hopefully encourage dialogue. The use of a variety of types of postings, including some that are informative and others that are more interactive, will contribute to meeting the needs of the entire range of ProNUT users.

- The use of email signatures to disclose the name, professional affiliations, and country of members when they post will be a policy on ProNUT. This is good practice as it helps members understand the context of and lends credibility to postings. Members will also be asked to declare any potential conflict of interest.
- Send instructions to the group on how to subscribe to the digest version of ProNUT to prevent email overload.
- Use brief, email-based questions/surveys on any emerging issues related to ProNUT scope, content, and functionality to ensure that members have an opportunity to comment.

Annex: ProNUT HIV User Survey 2011

ProNUT HIV User Survey 2011

I have been a member of the ProNUT e-forum for...

- less than two years
- three to five years
- more than 6 years

2. I use ProNUT as a ... (select all answers that apply)

- way to learn about important upcoming events such as trainings and conferences
- way to keep up to date with new Nutrition and HIV research
- opportunity to discuss and debate important issues in Nutrition and HIV with colleagues from around the world
- way to access emerging programmatic and policy information related to Nutrition and HIV
- forum to ask questions about Nutrition and HIV

Other (please specify)

3. I think that ProNUT should continue to update the following resources...

	definitely	perhaps	definitely not
the online library of documents	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
the online searchable archive of postings	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

4. I think the ProNUT mandate....

- should stay focused on nutrition and HIV
- should be broadened to include nutrition and other infectious diseases such as TB
- should be broadened to include all aspects of nutrition relevant to the developing world

5. Something I would like to see more often on ProNUT is... (select all answers that apply)

- job opportunities in Nutrition and HIV
- special discussions on specific topics moderated by subject experts
- announcements of upcoming courses, conferences and events related to Nutrition and HIV
- relevant abstracts and/or links to full-text research papers
- funding opportunities
- engaging and evidence-based discussions of important topics in Nutrition and HIV

6. What I don't like about ProNUT is... (select all answers that apply)

- there are too many messages
- the messages are often not relevant to me
- the discussions sometimes become unprofessional
- the information is sometimes not evidence-based

Other (please specify)

7. I think that ProNUT would be improved by...

	definitely	perhaps	definitely not
taking advantage of links to new communication opportunities like Facebook and Twitter	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Something that would encourage me to post messages on ProNUT more often is...

9. My interest in ProNUT is because I am a... (chose one best answer)

- health care professional
- university or research institute staff person
- NGO staff person
- private/for profit company staff person
- government staff person

Other (please specify)

10. Something I would like to add is....