AHF EUROPE WORKSHOP ON USER-DRIVEN CARE

TALINN, 12 NOVEMBER 2015
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FOREWORD

Narva, 1 December 2016

It is with great pleasure that I present the report of the workshop on user driven care that AHF Europe hosted on 12 November 2015 in Tallinn. We are very grateful to the participants and the presenters for their valuable input, in particular the contributions of Rupert Whitaker from the Tuke Institute in the UK and Marian Said from the user board of the Sørlandet Hospital in Norway; their best practice models of aspects of user driven care are a great inspiration to changing the perspective on care that is focused on the needs of the patients.

A year has passed since the workshop, which was organized simultaneously with the official opening of the Linda Clinic in Narva, Estonia. The clinic protocol that was developed in the meantime has the holistic approach to care as its solid foundation. We have social, physical and mental care all under one roof. With the recent launch of the patient advisory board we are ready for the next phase in the HIV response: a response that accepts HIV as a chronic disease, and that takes into account physical, psychological, social and spiritual needs.
We have a lot of work ahead of us, but we can make changes. I hope that the content of this report will be an inspiration to those that are working side by side with us on achieving those changes.

ZOYA SHABAROVA
AHF EUROPE BUREAU CHIEF

BACKGROUND

HIV treatment, care and support require an innovative approach that capitalises on the experience and knowledge of people living with HIV. In the past, the HIV response has been characterised as "an emergency" and carried out with a similar public health approach that happens with short-lasting outbreaks of infectious diseases, such as encephalitis, Ebola or influenza. While these measures have been essential in introducing programmes to test, treat and care for people living with HIV, they do not address the fact that HIV is a chronic disease, which requires a more holistic approach. People living with HIV come to the table with a multitude of physical, psychological, social and spiritual needs, as well as assets to help in the epidemic.

Aspects of user-driven care have been implemented in various settings in Western Europe. At the Sørlandet Hospital in Kristiansand, Norway, user-driven care has led to more effective and cost-efficient patient outcomes, with much more engagement from the patients themselves. In the UK, 56 Dean Street in London is a clinic that integrates various components of care for people living with HIV in a setting that is staffed with peers, as well as formally trained health care professionals.

Linda Clinic – a joint partnership between AHF Europe and the Estonian Network of People Living with HIV (EHPV) – recently added the delivery of treatment to its repertoire of services that also includes testing, care and psychosocial services. The inclusion of treatment at Linda Clinic provided the inspiration to hold the clinic's official opening on 13 November 2015. Because Linda Clinic strives to implement user-driven care, the opening was an excellent opportunity to bring participants together to explore the opportunities and challenges associated with implementing a model of care that is foreign to many clinical settings.

PARTICIPANTS

Over 30 participants from about 7 countries participated in the workshop. Approximately 2/3 of the participants were from Eastern Europe and the rest from Western Europe. Participants ranged in scope from academics and professionals with extensive experience in implementing use-driven care, to service providers and end users (patients). The range of experience and expertise resulted in a mix of theoretical and practical discussions and debates around the opportunities that exist with user-driven care for people living with HIV.

WORKSHOP GOALS

The main goals of the workshop were as follows:

- Present the concepts and provide examples of user-driven care in practice.
- Describe how to improve patient experiences and outcomes by implementing user-driven care.
- Reflect on and devise opportunities for participants in implementing user-driven care in their programmes.
- Identify the roles of individual participants to move forward in developing collective synergies in implementing user-driven care together.
- Identify any potential opportunities or challenges in implementing user-driven care.

PRESENTATIONS

User-driven Health Services for People Living with HIV

– Dr Rupert Whitaker – Tuke Institute

It is important to take bias into consideration when considering changes in healthcare settings. Bias is generated through those who hold power and assumptions are hidden beneath the way services are designed and delivered. If change is to occur, both the positive and the negative aspects of change need to be considered, free of bias.

In the context of user-driven care, health must be considered according to the WHO definition: "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." This directs that health should be approached from a holistic prospective and not from a disease-oriented perspective.

To properly understand a particular model of service delivery, it is important to take the view from the perspective of what drives them. Health of the body – or biomedical health – is physician driven. In contrast, the health of the body and mind in a more holistic context – biopsychosocial health – is fully participative, driven both by patients and clinicians in partnership, and is user-centred in nature.

The problem comes from the professional side. Clinicians are working to promote physician-centred services, while managers are promoting cost-effectiveness or consumerism. Neither of these models is user-driven.

The most important goal should be health-effective services, which would focus on achieving the WHO definition of health. However, there are no agreed-upon principles, standards, designs, processes, measures, etc. Intuitively, some think that user-led is the answer but how can we know if we do not know what to look for?

Avoid premature conclusions re: how/methods:

People living with HIV face many different problems in health services. Currently, services are physician-centred. Case management – where it exists – is only within service silos – there is no comprehensive case management for people living with HIV because services are not integrated. This results in health outcomes being not defined for the individual. There is no meaningful participation of users and an inadequate use of community resources (e.g. peer leadership). Health services are judged based on cost-effectiveness per service, instead of health-effectiveness from a holistic perspective. Finally, there is no credible accountability of services providers, including stigmatisation.

- Possible characteristics of health-effective services
    - Health-effective – for all ages
    - Participative and empowering
    - Person-centred
    - Biopsychosocial
    - Comprehensive
    - Integrated
    - High quality (including competence-based)

Health-effective services that incorporate user-driven care can be achieved by:

- Developing clear and universally accepted principles, similar to the Greater Involvement of people living with HIV (GIPA) principles. It needs to be clear what the values and conditions are in order to achieve health-effective services.
- Developing resource standards – both social and financial – to which service providers must strive.
- Developing an evidence base that scientifically documents the methodologies that lead to health-effective services.
- Documenting cases and models (both positive and negative) to illustrate the right and wrong ways to approach the implementation of health-effective services.
- Developing policy, including rationalisation of effectiveness.
- Ensure empowerment and participation of service providers and users at all levels, including governance.
- Develop public reporting using a standard index, similar to the PLHIV Stigma Index and the proposed Index for Health Services' Effectiveness in HIV.

In conclusion, user-driven care is only feasible in the context of health-effective service provision. The two go hand-in-hand and the one needs to be developed with the other. Both are critical for the addressing the needs of people living with HIV.

User/patient driven Medical Clinic for People Living with HLIV in Norway : Shaping tomorrow's health care services

– Maryan Said – User Board Sørlandet Hospital

This presentation outlined the process of developing and implementing user-driven care at Sørlandet Hosptial in Kristiansand, Norway.

The vision of healthcare should be through a holistic approach – it is not just physical health that is important. Also important are the psychological, social and spiritual well-being of the individual.

Transitioning to user-driven care was initiated by the head of infectious diseases, who was responsible for the HIV clinic. He invited a number of people living with HIV to brainstorm around the question, "How would you run the clinic differently". This resulted in a "patient order" that outlined the necessary components for better care as defined by the patients, including:

- Creating the position of "HIV Coordinator" to have oversight over all aspects of a user's care.
- Initiating interdisciplinary team meetings and Individual patient plans.
- Developing comprehensive checklists to ensure that all aspects of the user's care is addressed and monitored.
- Developing and implementing of the learning and mastering courses for all users to give them the knowledge and skills they need to participate in their own care.
- Systematic use of peer support.
- Secure communications via a mini-journal.
- Clinic needs to follow national guidelines.
- Psychosocial measures integrated into services.
- Need for management and responsibility for the project.

The initiative started as a pilot project and has since been applied to all 133 patients and has been proven successful.

One of the key concepts of user-driven care at the Sørlandet Hospital is the function of the HIV coordinator, who is a nurse. This position is a link between the patient, specialist health services, the GP and other services. The HIV coordinator assists the users in ensuring that all aspects of their care needs are addressed appropriately. The HIV coordinator also helps to develop and manage the individual plan with the user in to identify health outcomes and the services required to achieve them.

To facilitate the individual plan, quality of life checklists have been developed, which are available to the user and to the healthcare providers. The checklist is used throughout the lives of the patients. That way, even if one of the points on the list are not relevant at that time, you can still look back on it later. For new patients, low threshold testing is key.

Another important component of the clinic care is the intensive training that users undergo to ensure that they understand their role in user-driven care. These courses are mandatory to ensure that the interaction between service providers (including the HIV coordinator) and the user are productive.

SØRLANDET SYKEHUS

Results

Before 2012	2014: User-driven Clinic for PLWH (All changes initiated by the patients)
• Doctor-patient. Top-down. Focus on medicine, biomedical markers • Patient not looked at as a coherent whole. • Nurses unused resource • No cooperation between different parts of the healthcare services. E.g GP, mental health • No means of facilitating contact between PLWH.	• HIV-Coordinator => coordinating care, relieving doctor duties, guide in jungle • Mapping of needs via comprehensive checklist • Individual Plan for follow up • Mandatory interdisciplinary team meetings w. patient • HIV/STD clinic. Low threshold HIV/STD testing • Learning- and mastering courses

User involvement in care has increased significantly. Before 2012, there was minimal user input and now there is active engagement between users and service providers.

Today, there is increase adherence, improved quality of life and improved cost efficiency.

Questions still remain. Is there true power sharing and influence on all levels regarding diagnosis, prevention, treatment and care? Although a formalized user forum comprising patients are given formalized decision-making at the institutional level, does that mean that the goal should be absolute equality? Is user governance a means to get there?

The Sørlandet Hospital experience is almost ideal: those in power were ready to accept user influence; there was money and willingness to hire people to manage the new processes; and the Norway is a country where the laws and budgets allow for this kind of change.

Linda Clinic: Working towards user-driven care in Narva – Anna Żakowicz – Chair of the Management Board, Linda Clinic, Narva, Estonia

This presentation outlined the history and aspirations of Linda Clinic in Narva, which is situated in the Northeast of Estonia.

Narva has the highest HIV prevalence in the European Union (about 4%); the highest percentage of people living with HIV in Estonia (about 25%); and the highest rate of people who inject drugs in Estonia. Over 90% of the city inhabitants belong to the Russian minority in Estonia, with steady decline in the population of Narva, leading to a continuous rise of unemployment.

There is only one infectious diseases specialist in Narva hospital and a significant amount of stigma towards people living with HIV in healthcare settings, as shown by the EHPV-led PLHIV Stigma Index, an international tool that measures stigma in various settings.

The Linda Clinic Foundation was found in 2012 as a joint venture between AHF Europe and EHPV, which form the Oversight Board. The clinic was ready for patients in 2013 after extensive renovations and conducted services for care (not including ARVs), testing and psychosocial support. Between 2013 and 2015, significant advocacy and legal actions resulted in an agreement between Linda Clinic and Ida-Viru hospital to support the provision of ARVs at the clinic. The addition of ARVs will allow Linda Clinic to move towards implementing user-driven care.

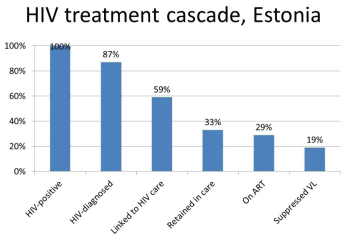
Up to 70% of all HIV infections in Northeast Estonia are acquired through injecting drugs. There needs to be a new model of care for those who cannot navigate through the current system. The model should be based on good practice and oriented on national, European and global guidelines.

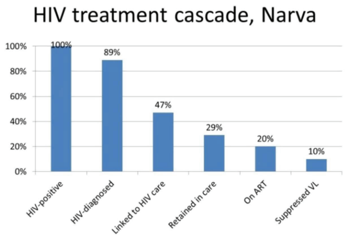
User-driven care at Linda Clinic will take the approach that patients should be involved in their own care in order for long term health outcomes to be achieved. The clinic will support a holistic approach to care that includes low-threshold testing, care (including ARVs) and psychosocial support. In addition, seamless referrals to other medical and non-medical services will be achieved through agreements with partners.

The approach will be based on the continuum of care, ensuring that support and care and support are part of individual patient plans to achieve better results.

AHF EUROPE

LINDA KLIINIK
AHF·EHPV


HIV treatment cascade, Estonia


HIV treatment cascade, Narva

Tartu University, 2014

Looking to 2016 and beyond, Linda Clinic will work to improve testing in hard-to-reach populations in the Narva region, with the aim to identify everyone who needs care and treatment. Linda Clinic will address the psychosocial needs of people living with HIV and those at risk of infection in order to improve their quality of life and connect with Linda Clinic services. Linda Clinic will strive to improve the cascade of care with the ultimate goal of achieving viral suppression in people living with HIV.

In addition, Linda Clinic will establish a User Advisory Group to advise on the implementation of user-driven care services. An International Advisory Board will be created to provide guidance on protocol and procedures. In order to promote and develop the implementation of user-driven care, Linda Clinic will actively engage with other user-driven care clinical sites in Europe to share experiences and exchange ideas.

RESPONDERS' PANEL

Five panellists were asked to provide a few comments reflecting on the preceding presentations, highlighting potential opportunities and challenges of implementing user-driven care. The purpose was to highlight different perspectives and to challenge participants to think critically about user-driven care.

Latsin Alijev, EHPV, Estonia

- The PLHIV response has always been alive and vibrant but has suffered from a lack of funding.
- The most important factor is to have political commitment in terms of funding but also in terms of inclusion.
- There are still challenges but EHPV is supportive of the move towards user-driven care.

Kim Fangen, Nye Pluss, Norway

- There are good intentions from professionals and institutions to implement user-driven care but it is difficult to move forward if doctors do not want it because it entails a shift in the power balance between patients and doctors.
- There is a need for evidence on the effectiveness of user-driven care in order to be able to advocate for its implementation.
- A user-driven care conference would be useful to describe best practice and to develop mechanisms to document evidence.

Silvia Petretti, Positively UK

- User-driven care is not free! There needs to be funding, training and infrastructure to encourage its implementation.
- Patient-centred care addresses power structures in the health system. At the same time, patients involved in user-driven care need to share power as they become more involved in service delivery.

Gregory Vergus, ITPCru, Russia

- In the future we are going to deal with new type of patients. They will start their treatment from 500 CD4 cells will not be motivated based on opportunistic diseases and fear of death. Ease and convenience of the treatment (regime, side effects and medical care) will become crucial for adherence.
- User-driven care is an opportunity to create a comfortable environment for people engaged in services.

Vinay Saldanha, Eastern Europe Central Asia Regional Coordinator, UNAIDS

- Since the introduction of the Sustainable Development Goals (SDGs), the emphasis on HIV/AIDS under the Millennium Development Goals has substantially changed. Under the SDGs, HIV no longer has its own stand-alone, goal, but the target under SDG 3.3 is clear and ambitious: to end the AIDS epidemic by 2030.
- The new UNAIDS strategy (2016-2021), which is fully aligned to the Sustainable Development Goals, aims to revolutionize HIV prevention, catalyse the next phase of HIV treatment, care and support, and advance human rights and gender equality. This Strategy is useful resource and tool to support efforts to enhance patient-centred and user-driven models of care for HIV.

GENERAL DISCUSSION

A discussion among the whole group then took place, with many people echoing the thoughts of the respondents. The main points were:

- User-driven care is the future and it will work. However, it will be necessary to educate both doctors and patients to ensure that the right tone is set and that the possibility of changing the model will lead to better outcomes for both.
- Advocacy is extremely important to ensure that change happens. Users (patients) in some settings may need to be active in demanding a user-driven care approach.
- It might not be possible to implement all aspects of user-driven care but it will be possible to implement mechanisms to engage with users differently. For instance, questionnaires asking for user input might be a good first step in moving forward.

Brainstorm:
Practical ideas for collaboration

The participants broke into two groups: Russian-speaking and English-speaking. There was a mix in expertise about user-driven care within the two groups, resulting in rich discussions.

Summary of Points from the Russian-speaking Group

- Many users might not be willing to engage so actively in their own care. It will be important to find out why and to address these issues.
- The implementation of user-driven care will have budget implications. User input might be more expensive in the short run to achieve better cost-effectiveness in the long run. This needs to be managed.
- There needs to be an assessment of what needs to change: management or the system. The response of what needs to be changed will be influenced by who needs to change.
- Every country setting will be different. There needs to be flexibility in adapting and implementing user-driven care.

Summary of Points from the English-speaking Group

- It is important to consider the implementation of user-driven care from two perspectives: the provider and the user.
- The provider needs to be willing and able to change to a new model. Once change has occurred, the user can be asked to provide an evaluation. It could be useful to engage an educator or social worker to help with the implementation.
- In a user-driven care setting, the focus needs to be on ensuring that the services are extremely friendly and attractive to the user. It is difficult to measure this and will differ from user to user. However, in order to engage the users in a new, more interactive model, there needs to be a focus on the human side of the interaction.

Next Steps

The final session involved identifying and prioritising concrete steps for moving the user-driven care agenda forward. The participants made the following suggestions, which are organised according to category:

- High-level, systems based
    - o Conduct a situation analysis (scoping document) in order to identify a baseline for user-driven care
        - - Develop the spectrum of user-driven care from basic patient satisfaction to full implementation and describe the specific components of user-driven care.
        - - Identify the evidence that is required to measure the effectiveness and efficiency of user-driven care.
        - - Describe best (and worst) practice examples.
    - o Develop indicators to measure the extent to which user-driven care is being implemented.
        - - UNAIDS suggested that it would be possible to revise the user-driven global indicator as a response to supporting the new SDGs.
    - o Changing the law
        - - In many settings, many aspects of user-driven care will not be implementable due to restrictions in national laws. This is particularly true for the EECA region.
- Clinic level
    - o Address multiple morbidities in clinic patients in order to begin the journey towards holistic, patient-centred care.
    - o Add psychologists to the team to support users but also the process of moving towards user-driven care.
    - o Establish patient counsels and support them. These will take different forms in different settings (some advisory, others with decision-making powers).
    - o Find incentives for clinics to want to be seen as a "best practice" site.
- Advocacy
    - o For user-driven care to be successful, there needs to be a strategic and comprehensive approach to advocacy that takes into consideration:
        - - The current situation in which the clinic is operating.
        - -The willingness for officials to support user-driven care in clinics.
        - -The availability of medicines and support personnel.

WORKSHOP CONCLUSIONS

There was consensus that this was an important meeting, not just to discuss a theoretical approach to care but indeed to strategize around concrete actions to facilitate the implementation of user-driven care in a variety of settings. The Norway example was seen as an important best practice example and Linda Clinic was identified as the one to watch. Many participants from Eastern Europe are hopeful that the Linda Clinic experience will assist them in finding ways to implement aspects of user-driven care in their contexts.

Appendix I - Agenda

- 13.00h Group Lunch

- 13.45h Registration

- 14.00h Welcome and introductions
    - o Anna Żakowicz, AHF Europe, The Netherlands

- 14.15h The fundamentals of user-driven care
    - o Rupert Whitaker, Tuke Institute, UK

- 14.30h User-driven care in practice
    - o Maryan Said, User Board, Sørlandet Hospital, Norway

- 14.45h Linda Clinic – towards a model of user-driven care
    - o Anna Żakowicz, AHF Europe, The Netherlands

- 15.00h Respondents' Panel (5 minutes each)
    - o Latsin Alijev, EHPV, Estonia
    - o Kim Fangen, Nye Pluss, Norway
    - o Silvia Petretti, Positively UK
    - o Gregory Vergus, ITPCru, Russia
    - o Vinay Saldanha, UNAIDS

- 15.25h Discussion

- 16.15h Break

- 16.30h Brainstorm: Practical Ideas for next steps in joint collaboration. What we can do together. Next steps for the future. (Small groups.)

- 17.00h Feedback from groups.

- 17.30h Prioritisation and agreement on next steps.

- 18.00h Closing

- 19.30h Group dinner

Appendix II - Participants' List

AHF Europe Workshop
on User-Driven Care
Tallinn, 12 November 2015
Participants' List

Vinay Patrick Saldanha
Kaarle Olavi Elo
Tatyana Vinogradova
Andrey Skvortsov
James Fieldhouse
Tom Ovlien
Kim Fangen
Svetlana Kulsis
Loretta Stoniene
Yuliia Kalancha
Gregory Vergus
Rupert Whitaker
Silvia Petretti
Nikos Dedes
Georgios Papadopetrakis
Luís Mendão
Érica de Almeida Postiço
Jekaterina Smirnova
Latsin Alijev
Anastassia Peterson
Anna Zakowicz
Denis Godlevskiy
Andrey Zlobin
Konstantin Kandlen
Sergey Fedorov
Aleksander Chuykov
Victor Stanilevskiy
Natalia Mironova
Mariëtte Prinsen
Kevin Moody