

Words matter: Co-producing the PORADA HIV disclosure decision aid for older adults in Ukraine

I. Pykalo¹, O. Zeziulin¹, I. Zaviriukha¹, S. Shenoi², A. Deac³, J. Rozanova²

¹European Institute of Public Health Policy, Kyiv, Ukraine; ²Yale University, New Haven, United States;

³University of East London, Institute for Connected Communities, London, United Kingdom

BACKGROUND

Older people with HIV (OPWH) in Ukraine face unique challenges in disclosing their HIV status due to pervasive stigma and intersecting vulnerabilities, such as substance use disorders (SUD). The humanitarian crisis caused by the ongoing war further exacerbates these challenges.

In response, the PORADA intervention (Pursuing Optimal Results over Aging via Decision Aid) was developed as a structured, culturally tailored tool to support informed decision-making about disclosure. This intervention considers the complex realities of a war-torn country and aims to reduce decisional conflict while promoting client-centered disclosure aligned with personal values and goals.

DESCRIPTION

Using the ADAPT-ITT framework, the intervention was co-produced with OPWH (as peer consultants), HIV physicians, social workers, and psychologists. Initial development incorporated qualitative findings and feedback from four focus groups (two with OPWH and two with HIV clinicians) to ensure relevance and usability. A pilot of four sessions was conducted with two facilitators to assess PORADA's feasibility and acceptability.

The paper-based Decision Aid includes tools for systematically weighing the pros and cons of disclosure, guided exercises for planning disclosure conversations, real-life examples tailored to Ukrainian OPWH experiences, and techniques for addressing challenges such as stigma and building supportive networks. Implementation will be supported by a detailed facilitators guide, ensuring confidentiality and consistency in delivering the intervention by social workers and OPWH peers to participants.

LESSONS LEARNED

The co-production process underscored the critical role of language and terminology in creating a culturally sensitive tool. For example, while "status disclosure" is neutral in English, Ukrainian participants perceived it as coercive, requiring careful adjustments to convey neutrality. Refining phrasing to resonate with the audience fostered trust and engagement, ensuring the tool was empowering rather than directive.

CONCLUSIONS/NEXT STEPS

- The PORADA intervention underscores the value of participatory design in developing tailored decision aids.
- The next step involves implementing the intervention for OPWH at Kyiv City Clinical Hospital No. 5 by integrating the Decision Aid into routine care and gathering data on its effectiveness to inform further broader adaptation of the approach for similar settings, addressing the unique challenges faced by aging OPWH.



With sincere gratitude to the team of Peer Consultants of the PROST project for their participation in the development and evaluation of the guide; and the staff of Kyiv City Clinical Hospital No. 5 for their contribution to the content of the guide.

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The following sections of the guide discuss how to think through the decision of whether to disclose your condition. Please go through each section of the guide in order and answer the questions provided. After working through the sections of this guide, you will be able to make a well-considered decision about disclosing your information to others. We recommend that you take your time, read carefully, and answer the questions thoughtfully, as a considered and informed decision requires sufficient time.

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1. Should I disclose and why?

In this section, please identify the reasons why you do or do not wish to share information about your health condition.

Reasons to disclose status:

- ☐ Support for me
- ☐ It will be easier for me
- ☐ Openness
- ☐ Support other people
- ☐ Everyday affairs
- ☐ Referral to medical facilities
- ☐ Other

Reasons NOT to disclose status:


- ☐ Privacy
- ☐ Judgement
- ☐ Anxiety
- ☐ Other

Next, you can explore each of the listed reasons in more detail. This will help you objectively assess your situation and analyze all the pros and cons of discussing your illness with others.

7 Section 1

NOTES

The following pages are intended for your notes on each section of this guide. You can use each of these pages to make separate notes about a specific person or situation.



Section 1.

For me the main **pros** of disclosure are:

1.

2.

3.

For me the main **cons** of disclosure are:

1.

2.

3.

Section 2.

Let's think about whom do you want to disclose. What is their name? (If you wish, please use a nickname)

.....

What is your relationship?

How close are you?

How sure are you that you want to disclose?

- ☐ Very sure
- ☐ Somewhat sure
- ☐ Unsure

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Section 3.

Write the most important details that you would like to share and those that are not important.

I want to share details about:	I don't want to share details about:
.....
.....
.....

Section 4.

How would you like to disclose information?

- ☐ In person
- ☐ Over the phone
- ☐ Text, letter or email
- ☐ Through mediator, a trusted person

Section 5.

Are you ready to disclose?

- ☐ Ready right now
- ☐ Not yet ready
- ☐ Ready to disclose in the future

Section 8.

When talking about my illness, I will say the following:

.....

.....

.....

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Intervention was adapted from the **Disclosing Recovery intervention**¹.

¹Earnshaw VA, Sepucha KR, Laurenceau JP, et al. Disclosing Recovery: A pilot randomized controlled trial of a patient decision aid to improve disclosure processes for people in treatment for opioid use disorder. *J Subst Use Addict Treat.* 2024;160:209291. doi:10.1016/j.josat.2024.209291