AIDS Activities
Coordinating Office

HIV LOW HEALTH LITERACY GUIDE 2022

WRITTEN &
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HIV Health Literacy & Comprehension Guide for Providers

This guide is for health care providers, medical case managers, direct service staff, and administrators. It has been created to build understanding, agency, and collaboration with clients/patients. This guide is designed to optimize engagement and increase the success of a client/patient's self-management.

This guide teaches how to accommodate individuals with low literacy (such as English as a second language, low vision/hearing ability, color blindness, and/or cognition-based disabilities) that affect their auditory or reading comprehension skills.

Contents

Introduction

There are many reasons why a client may have low health literacy. The average literacy levels for most adults are between 5th and 8th grade reading levels. In areas where other health disparities are high (such as poverty), literacy level averages can be as low as 3rd grade for many adults. Even with people who have higher incomes or more education, health literacy is ranked low.

Only one-third of people with graduate degrees can understand most medical information given to them. Making your program a welcoming place for people who have low health literacy requires changing the way information is provided. The following guide has been created to help make those changes.
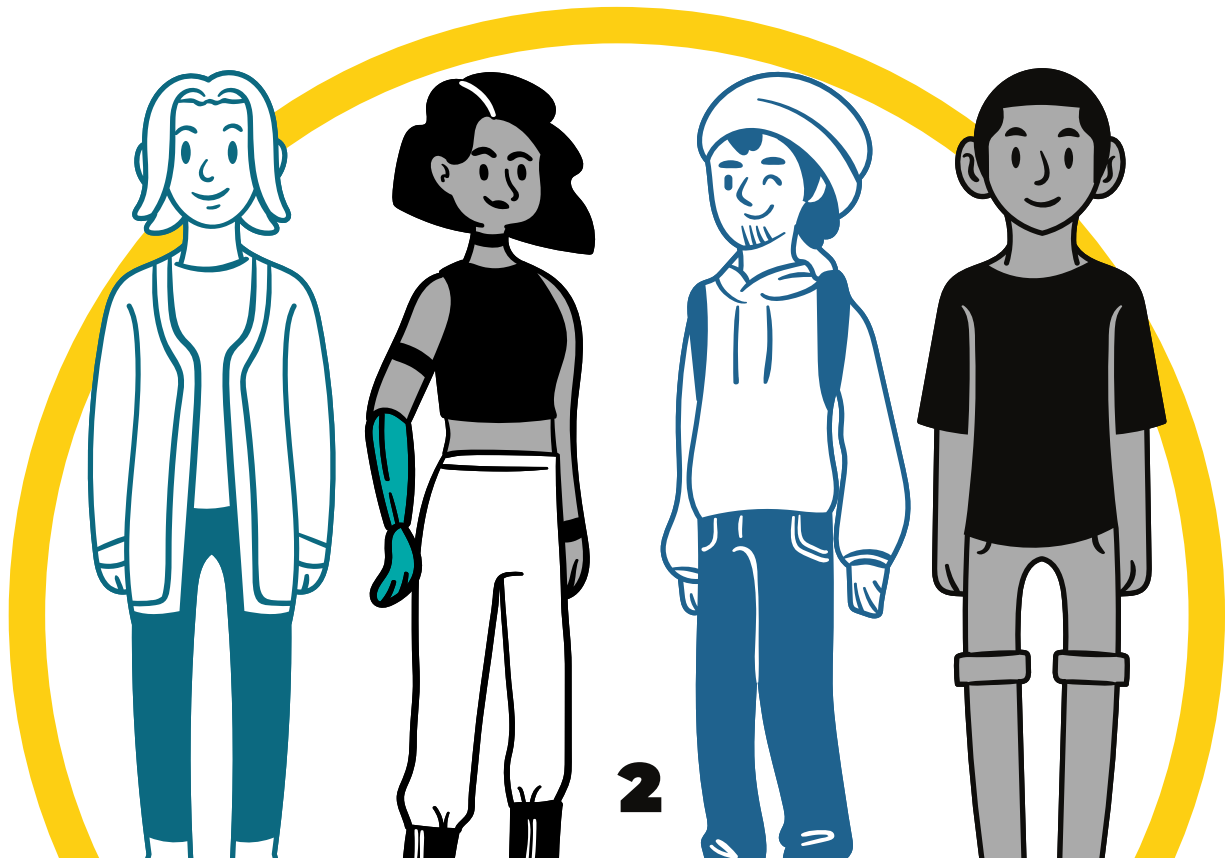
Step 1:
Assessing Literacy
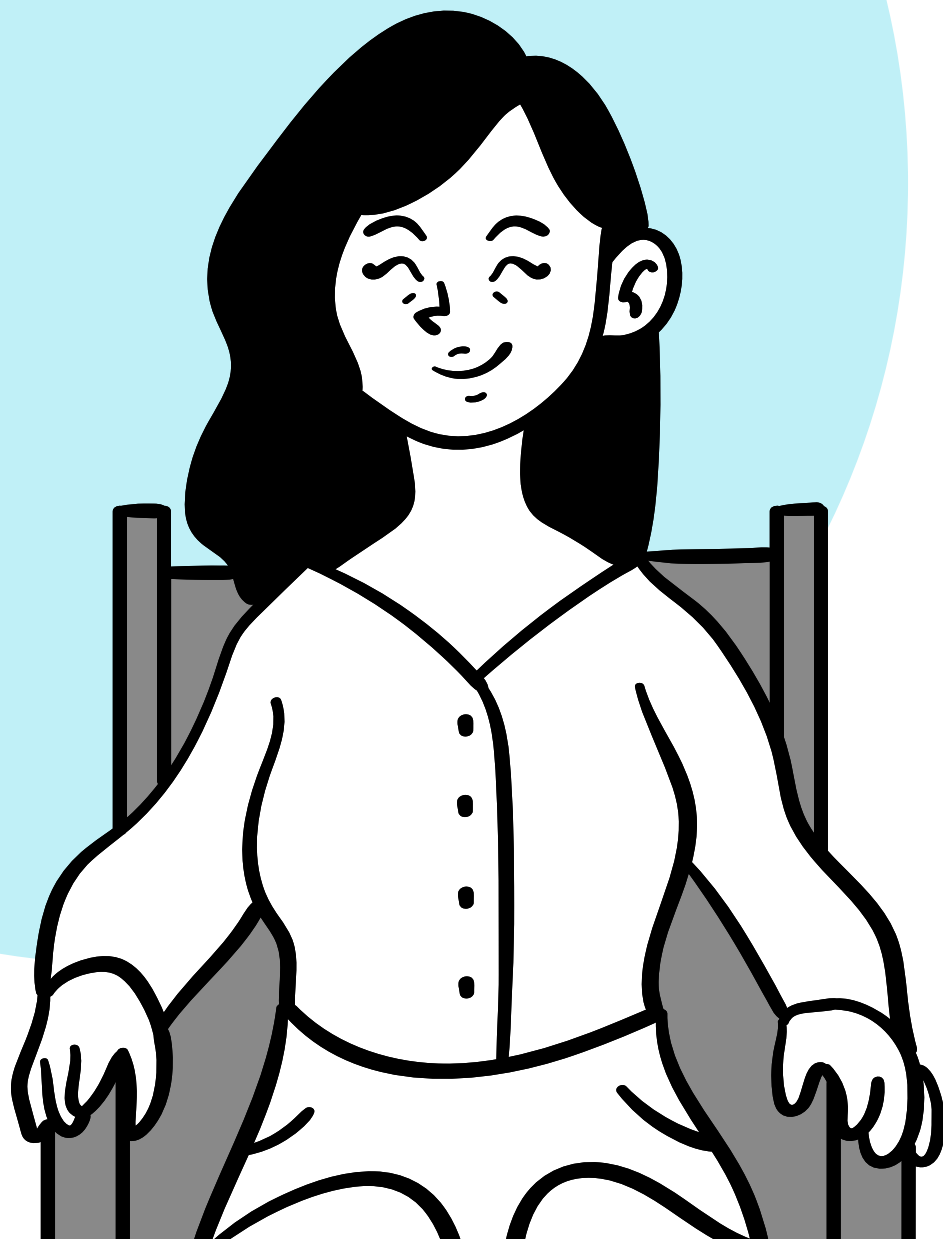
Form A
Assessing Literacy Instructions

*This form and its instructions are based on the Rapid Estimate of Adult Literacy in Medicine (REALM) test developed by Peggy W. Murphy, Terry C. Davis, Sandra W. Long, Robert H. Jackson, and Barbara C. Decker. It has been adapted for HIV care specific language. *Please note: client scores are to be interpreted as estimates of literacy, not grade equivalents. Forms B and C follow.*

Provider Instructions

- Laminate Form C on **LIGHT PURPLE PAPER** and keep copies with staff who do intake or care directly with clients.
- Score answers on an unlaminated Form B attached to a clipboard that you hold away from the patient so they cannot be distracted by you scoring. Keep this copy in your client's records.
- With all clients, give them the laminated Form C and have them read aloud each word on each list one by one.
- Instruct them to say "pass" for words they are unable to read aloud or encourage them to skip a word if they spend too long on it.
- Score each "pass" with a minus (–) sign, each mispronounced word with a slash (/) sign, and each correct word with a plus (+) sign.
- Count the number of correct (+ signs) words in each list and put that number on the "Score" line below it. Add up all score lines together and put that number on the "Total Score" line.
- Ask the client to identify the color of the paper they are holding. If they correctly identify the color, make a plus (+) sign on the "Color" line. If they incorrectly identify the color, make a minus (-) sign on the "Color" line. A minus (-) signs means they most likely have limitations with color perception.
- Ask the client to choose 8 words each from List 2 and List 3 that they recognize then ask them to define them. If they cannot identify 8 words on each list ask them to identify and define as many as they can. If they do not recognize any words on a list instruct them to say "pass".
- Write the number of words correctly defined on the "Definitions" line.
- Ask the client **"An undetectable viral load is 20 copies/mL or less. If someone has a viral load of 130 copies/mL, are they undetectable?"** If they answer correctly make a plus (+) sign on the "Numbers" line. If they answer incorrectly, make a minus (-) sign on the "Numbers" line. A minus (-) signs means they most likely have limitations with number comprehension.
- Ask the client **"What ways do you learn best?"** and make a note of their answer at the bottom of their score sheet.

3

Literacy Results

0 - 18   Approximately third grade and below; cannot read or interpret most high literacy materials, will need verbal instructions repeated, will need materials that heavily rely on illustration, audio, and/or video, *will need all verbal instruction and materials translated if English is a second language

19 - 44   Approximately fourth to sixth grade; needs low literacy materials, can read some high literacy materials but does not interpret the information correctly, may struggle with complex literacy items such as instructions and prescription bottle information, should have verbal instructions repeated, should be given materials that use illustrations to clarify instructions or steps, *should be offered verbal instruction and/or most materials translated if English is a second language

45 – 60   Approximately seventh to eighth grade; can read high literacy materials but may not interpret the information correctly, can be given low literacy materials, may struggle with complex literacy items like prescription and adverse reaction information, can have verbal instructions repeated, can be given materials that use illustrations to clarify instructions or steps, *can be offered verbal instruction and/or should have some materials translated if English is a second language

61 – 66   Approximately high school and above; can read and interpret most materials provided, can be given low literacy materials, can read and interpret high literacy materials, can have verbal instructions repeated, can be given materials that use illustrations to clarify instructions or steps, *can be offered verbal instruction and/or materials translated if English is a second language but not required

Definitions

0 - 5 Most of the language used in HIV prevention and care is new to or not understood by this client. All terms will need to be introduced slowly and defined, then simpler synonyms or informal terms will need to be used when speaking candidly or answering their questions (see the synonym list in the Health Literacy Guide.)

5 -10 Some of the language used in HIV prevention and care has been experienced before or understood by the client. Client should be asked if they recognize terms being used, and simpler synonyms or informal terms are welcomed when speaking candidly or answering questions (see the synonym list in the Health Literacy Guide.)

10 - 16 Most of the language used in HIV prevention and care has been experienced before or understood by the client. Client can have terms used consistently, but simpler synonyms or informal terms are welcomed when speaking candidly or answering questions (see the synonym list in the Health Literacy Guide.)

Form B:
Assessing Literacy Score Sheet

Client Name:_____   **DOB:**_____

Grade Completed:_____   **Spoken Language(s):**_____

Date:_____   **Examiner:**_____

LIST 1		LIST 2		LIST 3	
Red	__	Prevention	__	Testicle	__
Sex	__	Consistent	__	Emergency	__
Care	__	Infection	__	Medication	__
Test	__	Prescription	__	Sexuality	__
Pill	__	Behavior	__	Gonorrhea	__
Dose	__	Symptoms	__	Diagnosis	__
Virus	__	Information	__	Seroconversion	__
Cells	__	Genitals	__	Epidemiologist	__
Active	__	Instructions	__	Hepatitis	__
Needle	__	Syringe	__	Disclosure	__
Blood	__	Evaluation	__	Coinfection	__
Detect	__	Appointment	__	Antiretroviral	__
Rectal	__	Nausea	__	Contraception	__
Attack	__	Directed	__	Prophylaxis	__
Service	__	Pneumonia	__	Adherence	__
Client	__	Vaginal	__	Prognosis	__
Hormones	__	Adverse	__	Undetectable	__
Herpes	__	Immune	__	Chlamydia	__
Disease	__	Abnormal	__	Suppressed	__
White	__	Decrease	__	Antibodies	__
Program	__	Syphilis	__	Discordant	__
Positive	__	Notify	__	Deficiency	__

Score:_____   **Score:**_____   **Score:**_____

Total Score:_____   **Color:**_____   **Definitions:**_____   **Numbers:** _____

6

Form C

LIST 1	LIST 2	LIST 3
Red	Prevention	Testicle
Sex	Consistent	Emergency
Care	Infection	Medication
Test	Prescription	Sexuality
Pill	Behavior	Gonorrhea
Dose	Symptoms	Diagnosis
Virus	Information	Seroconversion
Cells	Genitals	Epidemiologist
Active	Instructions	Hepatitis
Needle	Syringe	Disclosure
Blood	Evaluation	Coinfection
Detect	Appointment	Antiretroviral
Rectal	Nausea	Contraception
Attack	Directed	Prophylaxis
Service	Pneumonia	Adherence
Client	Vaginal	Prognosis
Hormones	Adverse	Undetectable
Herpes	Immune	Chlamydia
Disease	Abnormal	Suppressed
White	Decrease	Antibodies
Program	Syphilis	Discordant
Positive	Notify	Deficiency

Step 2: Verbal Communication

Verbal Communication

When speaking to all clients, understanding what you are saying is key to their consistency, accurately taking medication, and ongoing engagement. The following practices should be used with all clients/patients regardless of education or their score on Form B.

1

Best Practices

Always define large or new medical terms and diagnoses.
(i.e., "You tested positive for HIV, a disease caused by a virus that you get from condomless sex or needle sharing. That is why you were feeling sick.)

2

Ask clients if there are terms or language they prefer to use that cause less feelings of shame or discomfort.
(i.e., "What word do you prefer, or do you know HIV by?" "I usually heard it called the virus, I am ok calling it that.")

8

3

Use simple, informal language to discuss care, answer questions, and explain treatment.
(i.e., "we will start you on some meds that should clear up the symptoms of the virus and lower your viral levels. You may still feel sick for a week or two though.")
**Ask about familiar terms in a client's language of origin if English is a second language.**

4

Use short, non-compound sentences when giving important explanations or instructions.
(i.e., "I will give you a prescription today. Take it to CVS and have them fill it. Try to go right after this appointment. I will call ahead for you.")

5

Repeat instructions kindly.
(i.e., "Make sure you finish all of the medication. Even if you feel better quickly you must take all of the pills for the best outcome.")

9
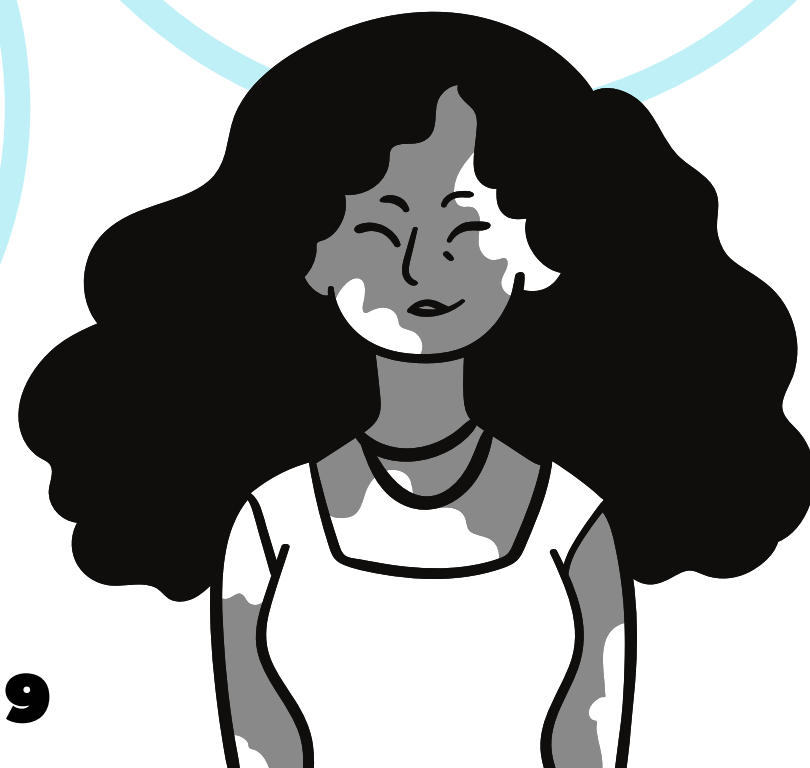
6

Give direct and clear instructions.
Instead of "Take 2 pills a day" (which is hard to interpret and can cause incorrect dosing) say "Take one pill in the morning before work and one pill at night with dinner".

7

Ask client/patient to repeat the instructions in their own words.
Have clients engage in the "teach back" method. (i.e., "Can you tell me what your care plan is so I know I did a good job explaining it?" or "It is important that you hold me accountable and see that I gave you the correct info. Can you repeat to me the next steps I told you so we can check and make sure I did it right?"

8

Be aware of and intentional with your tone.
Stay away from inflection that are condescending or passive aggressive. Kindness and humility are essential. It is important clients do not feel they are being talked down to or that you may be judging them.

10

9

Provide visual tools.
Drawing what you are explaining or giving a prepared image so they can see what you are talking about helps people learn better. (i.e., hand the client an infographic of important facts about HIV or an illustration of their prescription instructions.)

10

Ask English as a second language or Deaf/Hard of Hearing individuals what language they would prefer.
Do not assume they will request ASL or another language, be proactive and ask. Be prepared to use an onsite interpreter or interpretation service for them if they reveal they would prefer ASL or another language. **If the client is using an interpreter, speak directly to the client and not the person interpreting.**
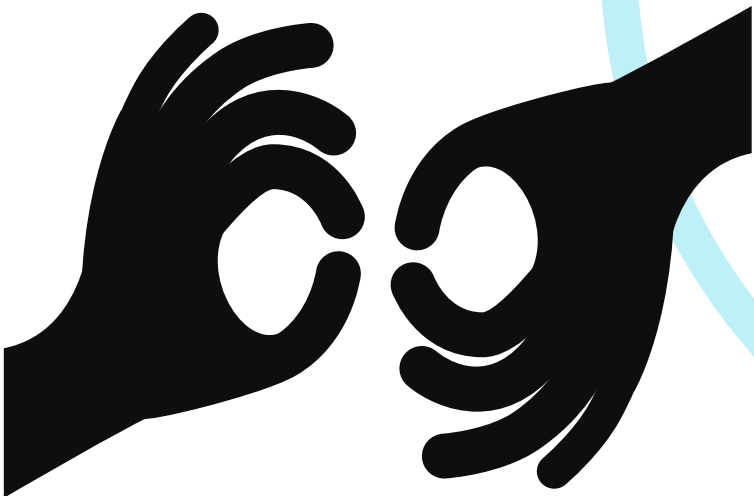
# A great way to check the conversation you had is to ask yourself;

- *Could an 8- or 9-year-old explain it?*
- *Could someone who just learned English understand it?*
- *Could someone over 85 be able to remember it?*
- *Could someone without their glasses be able to read it?*
- *Could someone with dyslexia be able to interpret it?*
- *Could someone who's color blind or low vision see it?*
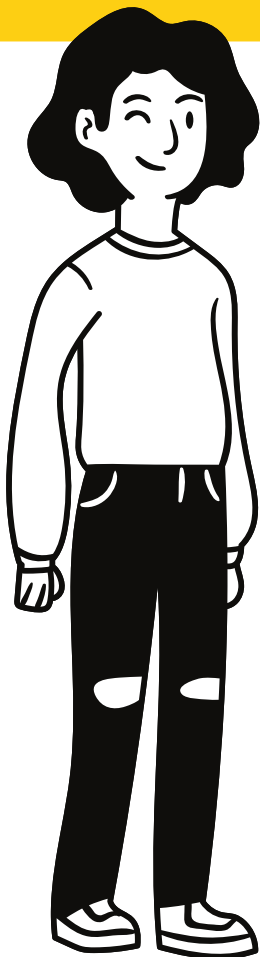
These are not all the groups that need to be considered, but being able to answer yes to all the above questions means that many people can access and understand.
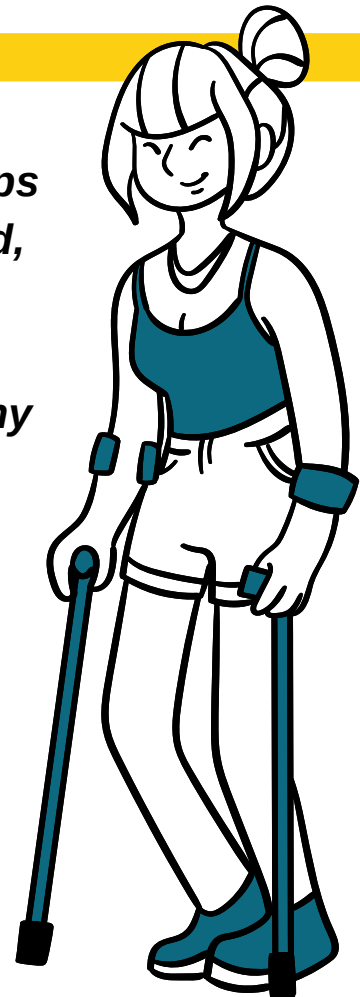
Step 3:
Written Instructions & Resource Materials
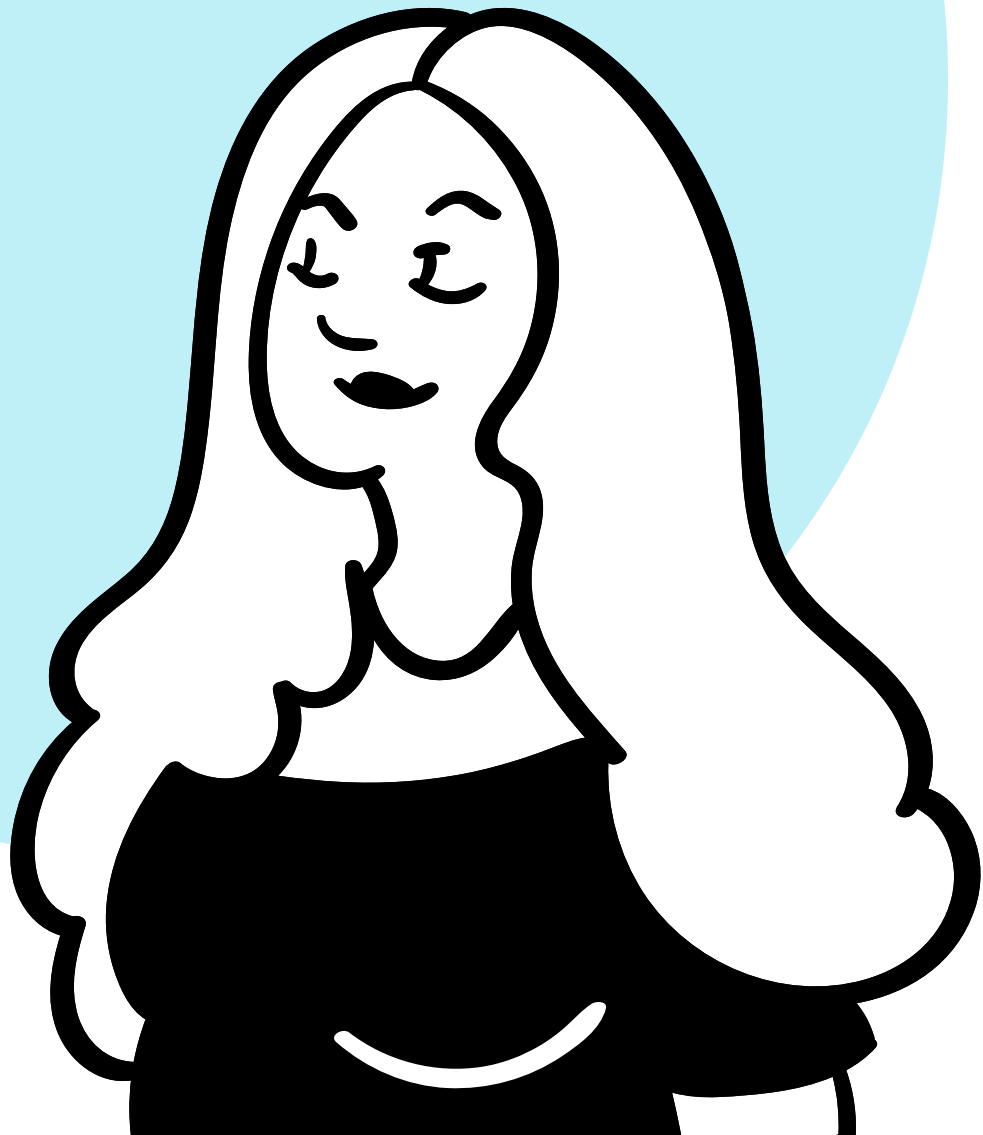
Written Instructions & Resource Materials

When creating materials (such as printed and virtual resources, social media posts, or prescription and diagnosis information, etc.) ensuring a client will take care of themselves relies on them understanding and being able to revisit that information. To achieve this, all media and materials should follow these guidelines;

Best Practices

1

Focus on pictures and imagery. Simple pictures that show actions, what an item looks like, or helps identify words should be with all instructions. (i.e., having a picture of a clock set to the time a client/patient should take a certain medication next to the text of the dosing instructions. (See the print media example on Form D.)

2

Make all important text easy to see. Use large, visibly accessible fonts in dark colors, bolded where attention is needed most. (See the print media example on Form D.)

abc

3

Use visibly accessible color palettes.
Use varying shades of the same color range or patterns rather than different colors for graphs and charts. Most people can see pattern and contrast but cannot see all forms of color. (See the print media example on Form D.)

4

Use simple, non-compound sentences.
Put steps in bullet points with clear spacing between each so they are easy to see and read. (See the print media example on Form D.)

5

Have simple backgrounds.
Make all backgrounds white or light colors, especially where text is provided. (See the print media example on Form D.)

6

Use simple design and layout.
Do not fill space with unnecessary images, designs, text, or patterns. These can be confusing or distracting. (See the print media example on Form D.)

14

7

Have materials interpreted into other languages.
For distributed materials always have them produced in the most common languages locally.

Ask and assist clients with filling out forms and paperwork.
Provide ergonomic pens or pen grips and ergonomic tablet hand grips for clients with low grip strength. Be prepared to physically fill out forms and paperwork for clients who are not able to read or write independently.

8

A great way to check materials is to ask yourself;

- *Could an 8- or 9-year-old read it?*
- *Could someone who just learned English understand it?*
- *Could someone over 85 be able to remember it?*
- *Could someone without their glasses be able to read it?*
- *Could someone with dyslexia be able to interpret it?*
- *Could someone who's color blind or low vision see it?*

# Step 4: Presentations & Presentation Tools

Presentations & Presentation Tools

When creating workshops and PowerPoints, ensuring the audience has the highest chance of understanding the information being provided is important to communities being able to make the best decisions possible. To achieve this, all media and materials for presentations should follow these guidelines;

Best Practices

1

Focus on pictures and imagery. Simple pictures that show actions, what an item looks like, or helps identify words should be with all instructions. (i.e., having a picture of a clock set to the time a client/patient should take a certain medication next to the text of the dosing instructions. (See the print media examples on Forms D & E.)
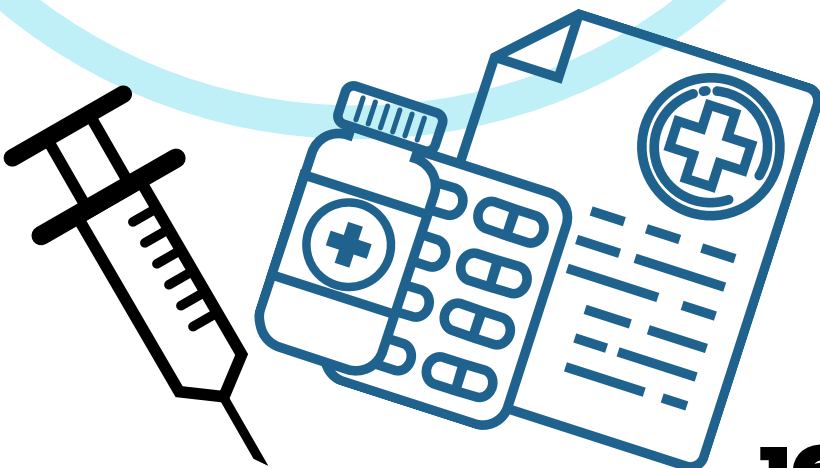
2

Make all important text easy to see. Use large, visibly accessible fonts in dark colors, bolded where attention is needed most. (See the media example on Forms D & E.)

3

Use visibly accessible colors palettes.
Use varying shades of the same color range or patterns rather than different colors for graphs and charts. Most people can see pattern and contrast but cannot see all forms of color. (See the media examples on Forms D & E.)

4

Use simple, non-compound sentences.
Put steps in bullet points with clear spacing between each so they are easy to see and read. (See the media examples on Forms D & E.)

5

Have simple backgrounds.
Make all backgrounds white or light colors, especially where text is provided. (see the media examples on Forms D & E.)

6

Use simple design and layout.
Do not fill space with unnecessary images, designs, text, or patterns. These can be confusing or distracting. (See the media examples on Forms D & E.)

7

Speak slowly and clearly.
Do not rush through slides, use a lot of big vocabulary words, or talk fast. Repeat important points. **When presenting in person, always use microphones when available.**

8

Read everything on the slide and describe important images.
Do not assume everyone who is in the audience can see your slides. Read all the text you place on slides and describe aloud any important images you are using to make a key point like a graph or a chart.

9

Apply captions on virtual platforms and/or have an ASL interpreter.
Try to use platforms that have a caption feature and always use it when it is available. Have an ASL interpreter at presentations that are in person, and when it is possible on a virtual platform. If recording a presentation to be posted online or used later, apply captions to the recording.

10

Provide the PowerPoint in a PDF format to attendees ahead of the presentation.

11

Make the PowerPoint readable for text-to-speech apps.
Check that all slides and text on them can be read by a text-to-speech app. Important information cannot be in JPGs on the pages. Pictures on the pages must have the alt-text feature applied to them.

12

For community information presentations, offer it in another language.
Provide a presentation in English and in another language that is dominant in the community you are trying to reach. Advertise the interpreted presentation in the language it is being offered in. (i.e., Spanish in a Latine population, French in a Congolese or Haitian immigrant population, etc.) If recording a presentation to be posted online or used later, apply translated captions to the recording.

HOLA

A great way to check materials is to ask yourself;

- *Could an 8- or 9-year-old read it?*
- *Could someone who just learned English understand it?*
- *Could someone over 85 be able to remember it?*
- *Could someone without their glasses be able to read it?*
- *Could someone with dyslexia be able to interpret it?*
- *Could someone who's color blind or low vision see it?*
- *Could someone with a cochlear implant get all the information spoken?*
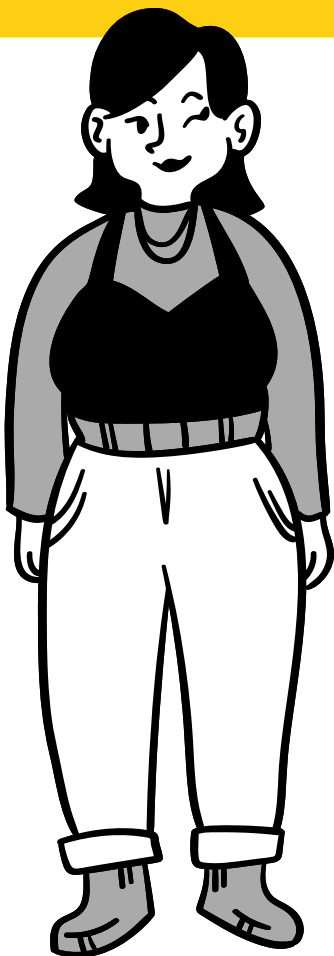
These are not all the groups that need to be considered, but being able to answer yes to all the above questions means that many people can access and understand.
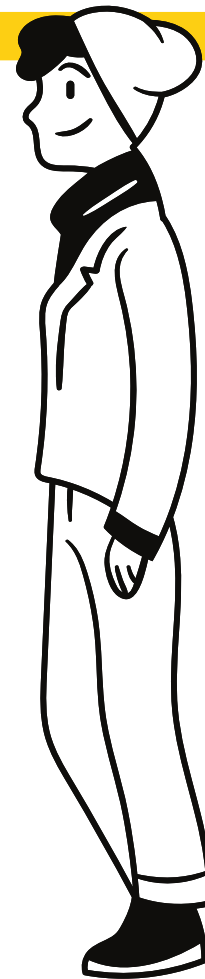
Step 5:
Digital Literacy

Digital Literacy

When using digital tools (such as patient portals, sign up and reminder apps) or intake technology (like iPads and touch screens, etc.) ensuring a client has access to information and follow up relies on them navigating these items. To achieve this, all technology should follow these guidelines;

Best Practices

1

Focus on pictures and imagery. Simple pictures that show actions, what an item looks like, or helps identify words should be used with all instructions. (i.e., having a picture of a clock set to the time a client/patient should take a certain medication next to the text of the dosing instructions. (See the digital media example on Form E.)

2

Make all important text easy to see. Use large, visibly accessible fonts in dark colors, bolded where attention is needed most. (See the digital media example on Form E.)

3

Use visibly accessible colors palettes.
Use different shades of one color or patterns instead of different colors for graphs. Most people can see pattern and contrast but cannot see all forms of color. (See the digital media example on Form E.)

4

Use simple, non-compound sentences.
Put steps in bullet points with clear spacing between each so they are easy to see and read. (See the digital media example on Form E.)
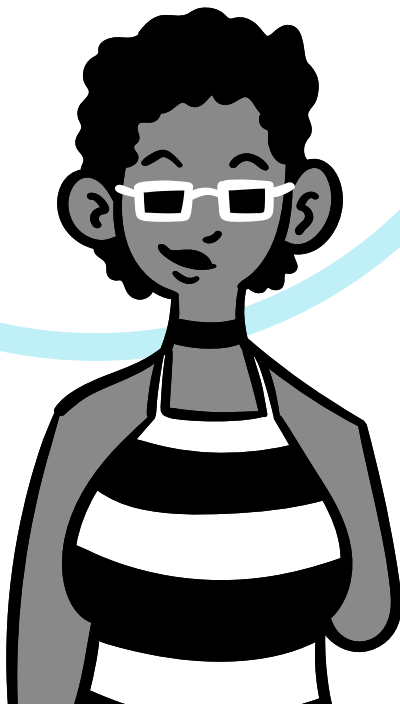
5

Have simple backgrounds.
Make all backgrounds white or light colors, especially where text is provided. (See the digital media example on Form E.)

6

Use simple design and layout.
Do not fill space with unnecessary images, designs, text, or patterns. This can be confusing or distracting. (See the digital media example on Form E.)

7

Have materials interpreted into other languages.
For distributed materials always have them produced in the most common languages locally.

8

Make the website readable for text-to-speech apps.
Check that all webpages are readable by a text-to-speech app. Important information cannot be embedded in JPGs on the pages. Pictures on the pages must have the alt-text feature applied to them.

9

Show clients how to setup and access their patient portal.
Setting up a patient portal can be very difficult for clients. Many may not have easy access to a computer or internet to do it at home. Have someone assist with creating a login and password. Then do a short walk through the site to gain familiarity. Be available for a few minutes to answer any questions related to using the patient portal.

23

Use phone calls or robocalling for appointment reminders.
Do not only rely on sending appointment confirmations, check ins, and reminders through email, a patient portal, or text. Some clients may not be able to receive these reminders because of limited access to internet, low visibility, or low digital literacy.

When calling a client, leave a message with a return number stated and repeated if they do not answer. **Be mindful not to leave any confidential information on answering machines or over text and email. Some clients may share phones and accounts with other members of their households.**

11

Assist clients with technology-based appointment sign in.
On tablets and iPads ask clients if they need the brightness or font size adjusted. Make the adjustments to their liking before handing it to them. Try to have a manual form on a clipboard as an option. Also provide ergonomic pens or pen grips and ergonomic tablet hand grips for clients with low grip strength.
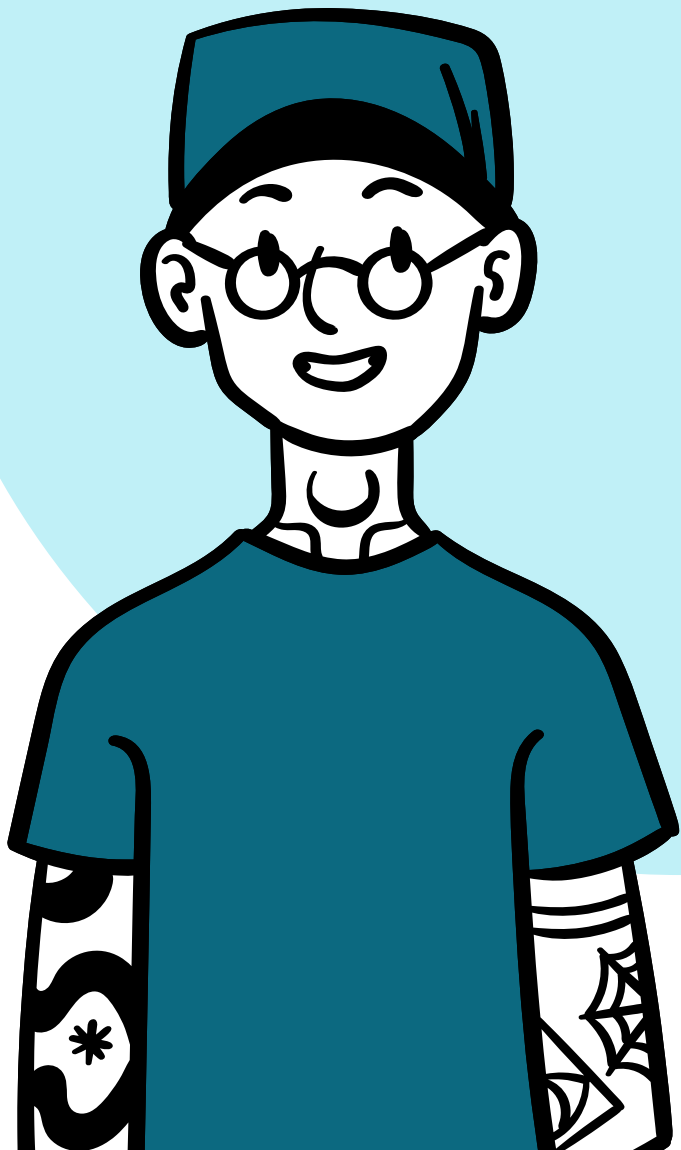
12

Assist clients with setting up their patient portal on their own device.
Walk clients through setting up their patient portal on their phone or other technology they bring in. Afterward show them how to navigate the patient portal site. Point out the important tabs they will usually need.
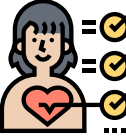
25
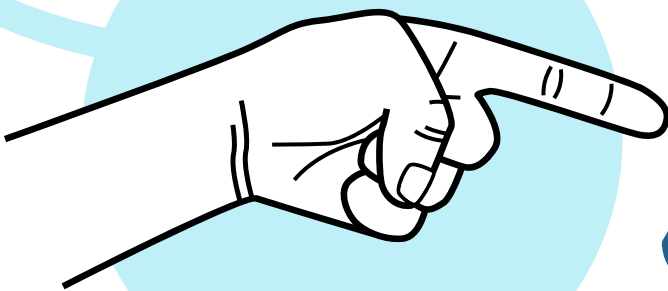
Accessible Resource Design Examples

Form D
Accessible Resource Design Example

1 **What Your Status Means...**

**2** You will need to take medication to manage the virus.

- You will need to get regular checkups.

- You will need your viral load tested regularly.

- You will still be the coolest person we know!

3 **Still Have Questions?**

4 Talk to your case manager or contact our patient info line at:

555-555-5555

5

Note*: To help with deciding what colors to use for print materials and how they appear to people with limited color perception, see the 4 color wheels below (from <u>Venngage</u>.) If you decide to use a color that is not visible for people who are colorblind, make sure it is on items that are not important to messaging, or that you use them with other colors that contrast them well (i.e., using bright red and dark blue instead of bright red and bright green.) For more resources or to check your materials for accessibility you can also use the Coblis tool.
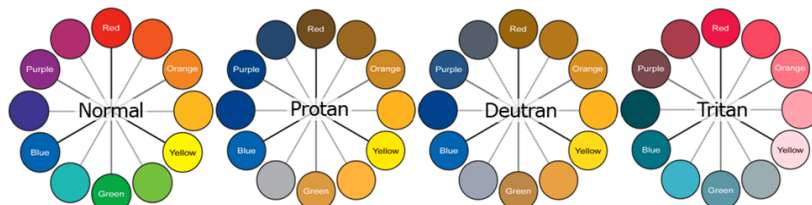
Accessible Resource Design Example Key

1   Use bold, large text in areas of importance with dark colors for readability. Colors used are varying shades of the same color or within the color wheel of visibility to those with limited color perception.

2   Important steps are non-compound sentences in well-spaced bullets. Use simple pictures/images that relate to or indicate the messaging in the text.

3   Use visibly accessible fonts in any of the serif/sans serif category (Arial, Tahoma, Helvetica, Verdana, etc) with sizing being no smaller than 12.

4   Important information is contained using simple shapes to limit confusion in reading and comprehending messaging.

5   Have a simple, white, or light background so text and images show up. Leave plenty of unfilled space between different sections of text and images.

27

Form E
Accessible Digital Media Example

1 **The People's HIV Clinic**

CLICK HERE TO ACCESS PATIENT PORTAL **4**

2

LET'S END THE EPIDEMIC TOGETHER

5

Use this site to;

- **Connect with a Physician**
- **Get a Case Manager**
- **Get Tested**
- **Find Resources near You**
- **Schedule an Appointment**

6

Check out the data

3

Note*: To help with deciding what colors to use for print materials and how they appear to people with limited color perception, see the 4 color wheels below (from Venngage.) If you decide to use a color that is not visible for people who are colorblind, make sure it is on items that are not important to messaging, or that you use them with other colors that contrast them well (i.e., using bright red and dark blue instead of bright red and bright green.) For more resources or to check your materials for accessibility you can also use the Coblis tool.

Normal   Protan   Deutran   Tritan

28
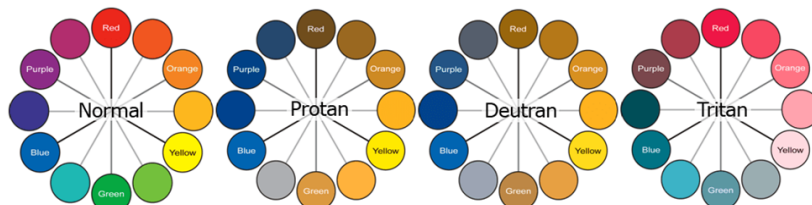
Accessible Digital Media Example Key

1 Use bold, large text in areas of importance with dark colors for readability. Colors used are varying shades of the same color or within the color wheel of visibility to those with limited color perception.

2 Alt-text is applied to images so text-to-speech apps can describe images for blind/low visibility consumers.

3 Use patterns and/or shades on graphs to create visual difference instead of varying colors.

4 Important information is contained using simple shapes to limit confusion in reading and comprehending messaging.
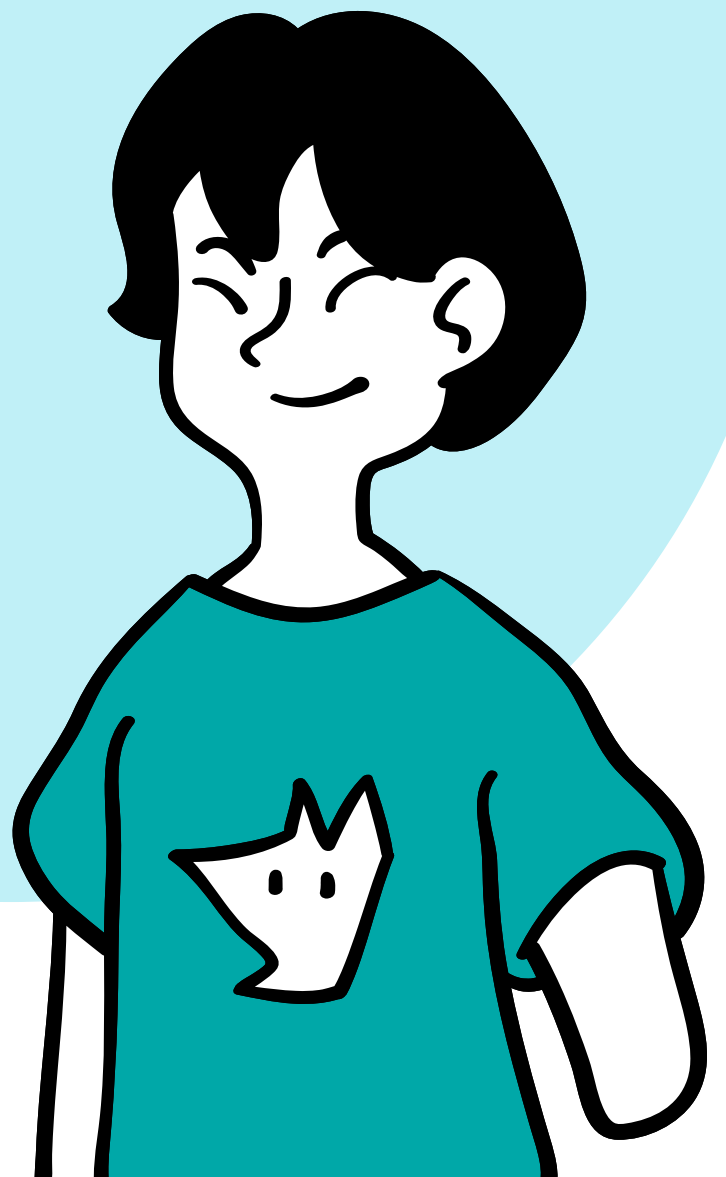
5 Have a simple, white, or light background so text and images show up. Leave plenty of unfilled space between different sections of text and images.

6 Use visibly accessible fonts in any of the serif/sans serif category (Arial, Tahoma, Helvetica, Verdana, etc.)
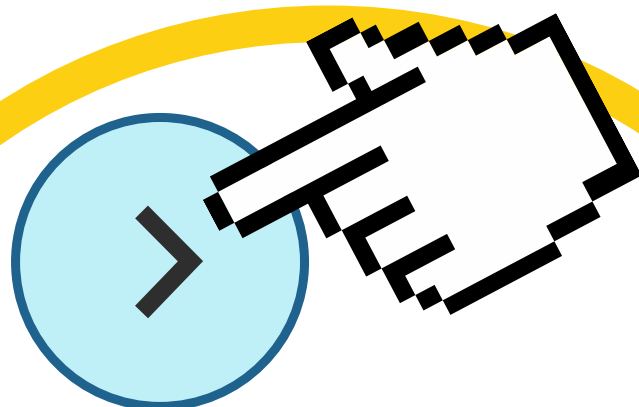
Informal Terms & Synonyms

Informal Terms & Synonyms

Abnormal – not normal, different, not right, weird
Acute – recent and bad, serious in a short time
Adherence – stick to
Adverse – bad, not good
Anal – butt, butthole
Antibiotic – meds that fight bacteria
Antibodies – proteins that attack bad things in blood
Antifungal - meds that fight fungus
Antiretroviral – meds that treat HIV
Antiviral – meds that fight viruses
Apthous ulcer – mouth sore
Asymptomatic – Having no signs of being sick, not feeling sick
Behavior – things you are doing, actions
CD4 Count – Amount of virus in your blood, viral load
Chlamydia – drip, clap, STD, STI
Chronic – constant, long-standing, continuing, keeps going
Coinfection – have more than one infection at the same time, infections that are happening at the same time
Comorbidity – more than one disease at the same time
Concordant – the same, both have, same status
Consistent – stay the same, do regularly
Contraception – different items that protect against pregnancy and some STIs (give examples like condoms, rubbers)
Decrease - lower
Deficiency – lack, not enough, need more of
Detect – find, saw, found, spotted, could see
Diagnosis – what is causing how you are feeling and signs you have
Disclosure – to tell, tell, reveal
Discordant – different, opposite, mixed status
Ejaculate – nut, cum
Emergency – serious and in need of quick response
Epidemiologist – virus doctor, doctor who knows about diseases
Evaluation – test

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Gender – How you identify yourself (give examples like man, woman, non-binary)

Genitals – private parts, privates, penis, vagina, crotch

Gonorrhea – the clap, the drip, STD, STI

Hepatitis – Hep, liver disease

Herpes – STD, STI, disease that causes crotch/penis/vagina sores

Hormones – chemicals in your body that control how cells and organs work

Immune – your body being able to avoid a disease

Infection – disease that invades your body as a virus or bacteria

Information – info

Instructions – orders, steps, plan of action, plan

Intercourse – sex, had sex

Medication – drug, drugs, meds

Nausea – feel like you are going to throw up, feel sick, barfy

Notify – alert, tell, warn, send a message, tip off

Opportunistic Infection – disease that happens when you are weak from HIV

Penis – junk, tool, knob, prick, joystick, willy, dong

Perinatal – Giving a baby a disease when you are pregnant

Pneumonia – disease the fills your lungs with fluid

Prescription – pills, meds, drugs, scripts

Prevention – stop, avoid

Prognosis – what the disease could do or become

Pronouns – how you talk about yourself (give examples like he, him, she, her, they)

Prophylaxis – steps you take to avoid getting a disease (give examples like wearing a condom, taking PrEP, etc)

Rectal – butt, butthole, anus, guts, inside, inside the butt, yams

Replicate - copy

Seroconversion – going from HIV negative to HIV positive

Sex – what you were assigned at birth

Sexuality – what you do sexually with other people

Sexual Identity – what you call yourself (give examples like gay, straight, bisexual)

Suppressed – make smaller, get in check, get under control

Symptoms – signs of being sick or hurt

Syphilis – syph, STD, STI, drip

Syringe - needle

Testicle – ball, balls, nut, nuts

Trichomoniasis – STI caused by a bug

Undetectable – tiny, small, little, hard to find, small viral load, small amount of virus in your blood

Vaginal – vag, in the vagina, in the hole, inside

Vagina – coochie, hole, yoni