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Tip Sheet 5 How can I construct or compare a continuum of care?

What is the continuum of care?

The continuum of care is a public health tool used to monitor the delivery of care for people living with HIV and to understand the proportion of people living with HIV achieving viral suppression.

It is often used to assess how far countries are from achieving the 90-90-90 target outlined by UNAIDS, which aims to have 90% of people living with HIV diagnosed, 90% of people diagnosed with HIV receiving antiretroviral therapy (ART), and 90% of people receiving ART virally suppressed. But it can also be used for a city or region, or even a clinic, to see where barriers might be and where change should be prioritised.

What measures are included in the continuum of care?

The continuum of care can contain up to six measures:

- 1 Number of people living with HIV
- 2 Number of people diagnosed with HIV
- 3 Number of people linked to HIV care

4 Number of people retained in HIV care

5 Number of people on HIV treatment (ART)

6 Number of people with an undetectable viral load.

Some of these may be easier for you to collect or find than others. You don't need to have all of them, but we recommend at least the ones in the WHO targets (diagnosed, on treatment, virally suppressed). The more you can get, the clearer the picture you will have of how your services are doing.



Example of a continuum of care

Above is the continuum of care for the UK in 2015, taken from the Public Health England annual report. In this example, 87% of people living with HIV were diagnosed, 96% of those



diagnosed were on ART and 94% of those on ART were virally suppressed. So you can see that while two of the 90-90-90 targets are being met, the UK's highest priority is targeting testing at those people still undiagnosed.

Your gaps may differ – you may be diagnosing a lot of people, but if the numbers drop heavily between there and those in care, there may be something wrong with your referral systems. Similarly, if people are reaching care but not being retained, you can ask what is putting them off staying in care.

Definition of the continuum of care measures

When interpreting a continuum of care and comparing different continuums, it is important to consider the definitions used to calculate each stage. Also, which data were used to create the continuum and at what level is the continuum presented (clinic, region or national)?

- 1. **Number of people living with HIV.** This number includes people living with HIV whether they have been diagnosed or not. This is best estimated through statistical modelling. If working on a regional or town level, you may have to rely on a national estimate of undiagnosed numbers, unless your Public Health system publishes broken-down local figures. This number is the 100% you start from.
- 2. **Number of people diagnosed with HIV.** This is the cumulative number of people who have been diagnosed with HIV in the area. It should exclude anyone who has died or left the area.
- 3. Number of people linked to care. This definition can vary from country to country. WHO defines someone living with HIV as linked to care if they have had a clinical or laboratory assessment (e.g. CD4 count or viral load taken) or are on ART. If you are comparing your region or country with another, check what measure they are using to define this.
- 4. **Number of people retained in care.** Retention in care is measured by taking the number of people who attended for care in a certain year and comparing it with those who were still in care the following year.
- 5. **Number of people on ART.** This is the number of people who are diagnosed with HIV, in care and also receiving ART.
- 6. **Number of people with an undetectable viral load.** Viral suppression is when HIV is no longer detectable in the blood. This depends on the laboratory test used, so the definition of viral suppression can vary. As with linkage to care, if comparing across countries, it is important to use the same definition of viral suppression.

Calculating the continuum of care

The continuum of care can be presented as numbers or as a percentage of the total people living with HIV. It may be easiest to illustrate the gaps if you use percentages.

For example: a country has 100,000 people living with HIV. 80,000 of those people have been diagnosed, 65,000 are on treatment, and 50,000 are virally suppressed.

To show the continuum as simple percentages, each measure is divided by the total people living with HIV e.g. the percentage of people living with HIV diagnosed is $80,000/100,000 \times 100 = 80\%$.

But to assess how close the continuum is to achieving the UNAIDS 90-90-90 target, each number should be divided by the one before:

- 80,000/100,000 x 100 = 80%
- 65,000/80,000 x 100 = 81%
- 50,000/65,000 x 100 = 77%

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So, in this example 80% of people living with HIV are diagnosed, 81% of those people diagnosed are on ART, and 77% of people on treatment are virally suppressed.

Advantages of the continuum of care

- The continuum of care provides a structure to analyse the quality of HIV care within a certain region and/or period of time.
- It demonstrates how many people are living with HIV but are unaware of their HIV status, which is useful for health promotion campaigns.
- It is easy to see where there is the most need for improvement along the continuum and identify gaps/barriers
- The UNAIDS 90-90-90 target unites countries in a common effort to help end the AIDS epidemic by 2020.

Points to consider when interpreting the continuum of care

- When comparing different continuums, it is important to understand the data sources and check whether the same definitions have been used to calculate the measures e.g. viral suppression.
- It will be hard to estimate the number of people living with HIV on a local level and thus there may be quite high uncertainty around the estimate
- There may be gaps in the data, depending on the healthcare system used in that particular region.
- The quality of the data reported could vary depending on the methods of data collection and what data are available.

Questions you might explore about gaps

A gap in those being diagnosed – are you testing the right people? Where is HIV being passed on the most (by MSM, by sharing needles, amongst particular groups) and how are you targeting testing at them? Why don't they want to test?

A gap between testing and linkage to care – why are people reluctant to access care? How easy is it to negotiate the system?

A gap between linkage and retention – what deters people from returning? How could it be made easier?

A gap between retention and treatment – are prescribing guidelines up to date? What is stopping doctors from putting people on treatment?

A gap between treatment and viral suppression – what is it in people's lives that hinders adherence? Is anything making it difficult for them to get their treatment regularly? Do they need better support or information?

There are examples in other European countries of how people have tackled all of these problems, in conference papers or in the <u>AIDS Action Europe</u> resources.

Where can I find the data for this?

Some countries have better data collection systems than others, and some systems are more public than others. It is worth getting to know your national and local public health bodies; a friendly relationship may increase your chances of accessing the data, if they trust that you will use it responsibly. Clinicians may find this easier than people from NGOs or community groups.

On a national basis, most of this data should be collected and there is no reason why it should not be made public, though it may be a year or two later. On a local level, it should be

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collected by the people responsible for commissioning services. If you are in a system where there is only one major diagnostic or treatment service, they should also have that data but there may be sensitivities about making it public, even in aggregate. You may need to demonstrate the benefits of using the data to show progress and where things are working (rather than where they are not).

Useful links

- 1. ECDC Thematic Report HIV continuum of carehttp://ecdc.europa.eu/en/publications/publications/dublin-declaration-continuum-ofcare-2014.pdf
- 2. 90–90–90 An ambitious treatment target to help end the AIDS epidemic http://www.unaids.org/en/resources/documents/2014/90-90-90
- 3. PHE Annual report (a good example of national data collection) <u>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477702</u> <u>/HIV_in_the_UK_2015_report.pdf</u>

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