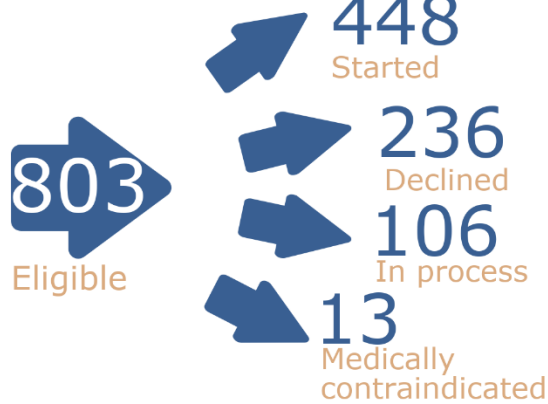


PRELIMINARY DATA

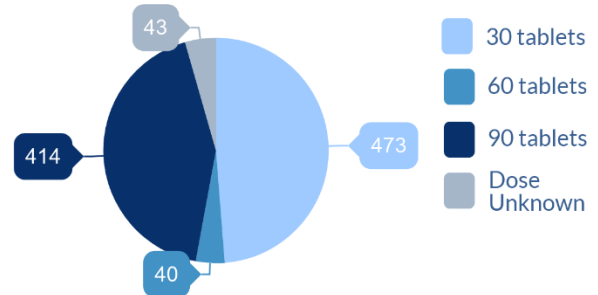
PRE-EXPOSURE PROPHYLAXIS FOR HIV (PrEP) PROVISION IN WALES

1st July 2017 - 31st March 2018, correct as at 4th May 2018

448 people prescribed PrEP



970 prescriptions for 448 patients



Of 448 patients who started PrEP...

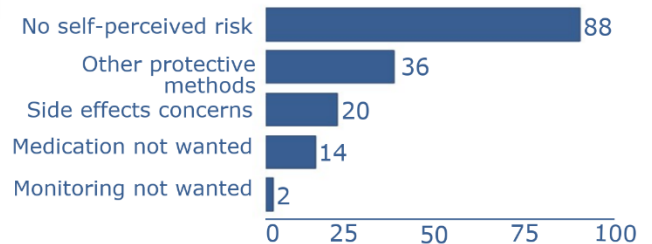


94% of PrEP was prescribed as daily



90% of prescribed PrEP covered all risk events

Reasons patients declined PrEP include...*



* NB: Not all patients declining PrEP gave a reason

Sexually transmitted infections diagnosed in patients since they have started PrEP include...

37

Chlamydia

41

Gonorrhoea

5

Syphilis

0

New HIV

Pre-exposure prophylaxis for HIV provision in Wales	
Author: Communicable Disease Surveillance Centre (CDSC)	
Date: May 2018	v2
Status: Approved	
Intended Audience: Sexual health professionals and Welsh Government	
Purpose and Summary of Document: <p>This interim report is an overview of the PrEP activity in Wales covering prescription, adherence and acceptability for attendances up to and including 31st March 2018, as at 4th May 2018. At the time of extract, PrEP data are expected to be approximately complete up to the end of March and patchy afterwards, and are therefore subject to change.</p> <p>It is accompanied by an infographic (cover page)</p>	
Publication/Distribution: <ul style="list-style-type: none"> • PrEP steering group 	

Interim report: Pre-exposure prophylaxis for HIV provision in Wales

Pre-exposure prophylaxis for HIV (PrEP) provision started in sexual health clinics in Wales on 17th July 2017, although activity around PrEP including assessment of patients started at the beginning of July. Data are being collected through the existing Sexual Health in Wales Surveillance System (SWS). This report is an overview of the reported PrEP activity in Wales covering prescription, adherence and acceptability up to and including 31st March 2018, as at 4th May 2018.

Key points

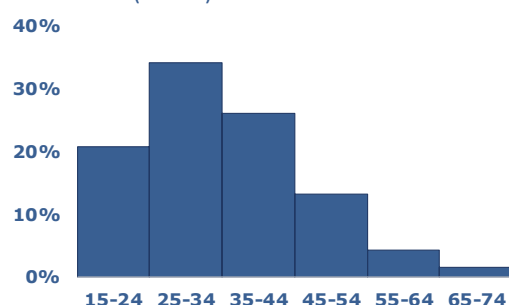


Between 1st July 2017 and 31st March 2018, 803 patients were deemed eligible for PrEP. Twenty-six percent (211) were relatively new to the service (not more than 2 months), and 16% (132) were completely new to the service. At least four individuals have been diagnosed with HIV at the baseline test (direct communication from clinics combined with SWS data).

Where reported, 704/715 (98%) were in eligibility category 1 (MSM at high risk of acquiring HIV).

Of those eligible, 448 (56%) started PrEP, and 236 (29%) did not start because they declined. Thirteen (2%) did not start because of medical contraindication due abnormal renal function or other relevant co-morbidities. No further information is available on 106 (13%) eligible people at present.

Figure 1. Percentage age distribution of persons starting PrEP between 1st July 2017 and 31st March 2018 (n=448)



Of the 448 people who started PrEP, 441 (98%) were male, of whom 433 (98%) were MSM. The age range was 16-74, with a median of 34.5 years (Figure 1).

Of 448 patients who started PrEP...

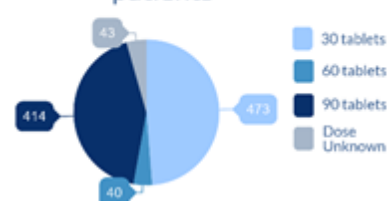


Of those who started, 297 (66%) people are still on PrEP, 26 (6%) have recently finished a prescription and 29 (6%) have stopped. Of the remaining 96 people, 73 (16%) are currently considered lost to follow up (over 2 months since their last prescription should have finished), and for 23 (5%) there is no further information.

Of those people considered lost to follow up, 32 (44%) have not returned to their clinic since they were last prescribed PrEP. The other 41 have returned to the service but have not been coded for PrEP.

Reasons for stopping PrEP are available for 25 people: six stopped due to medical contraindication, five were no longer eligible, and the remaining sixteen stopped for personal reasons.

970 prescriptions for 448 patients



94% of PrEP was prescribed as daily



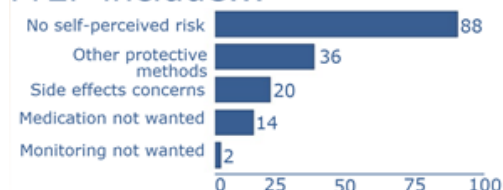
In total 448 people received 970 prescriptions. PrEP is prescribed in courses of 30, 60, or 90 tablets at a time. Where reported, 94% of PrEP was prescribed daily (as opposed to event-based).

Attendances where prescriptions are repeated are opportunities to assess adherence to the previous prescription of PrEP.

Where reported, 90% of these assessments considered that all risk episodes had been covered, and 5.3% that most risk episodes had been covered, whilst 4.6% (n=21) concluded that some or no episodes had been covered.

Where frequency of use was reported, 95% of PrEP had been taken daily (rather than event-based or other).

Reasons patients declined PrEP include...*



* NB: Not all patients declining PrEP gave a reason

Reasons for declining PrEP may be useful to assess acceptability of PrEP. However, not all declines have had a reason reported.

Of the 253 people who declined PrEP (of which 15 started it at a later date), 147 had at least one reason to decline reported: 88 (60%) did not believe themselves at risk, 36 (24%) preferred using other protective methods, 20 (14%) mentioned side effects concerns, 14 (10%) did not want to take medication, and 2 (1%) did not want to be monitored.

Sexually transmitted infections diagnosed in patients since they have started PrEP include...



There have been no diagnoses of HIV in people taking PrEP (the four new diagnoses of HIV mentioned above were in people being eligible for PrEP, but had not started). However, 64 people were diagnosed with 90 episodes of STIs after starting PrEP: 37 chlamydia, 41 gonorrhoea, 5 syphilis (2 early latent, 2 primary, and 1 secondary), and 1 LGV diagnoses; as well as 2 first episodes of herpes, 2 first episodes of warts, and 2 acute hepatitis A diagnoses.

Methods

Pre-exposure prophylaxis for HIV (PrEP) data are being collected from sexual health clinics in Wales since the start of PrEP provision in July 2017 through the existing Sexual Health in Wales Surveillance System (SWS). A series of 33 codes was added to SWS to capture activity around PrEP, including codes for eligibility for PrEP, outcome of the offer of PrEP, reasons for declining or stopping, frequency and number of doses, adherence and coverage of risk episodes (Figure 2 and Appendix B). A code for eligible people who did not start PrEP because of medical contraindication was added after the start of PrEP distribution in clinics, and has been used together with a questionnaire filled in by clinics previous to the addition of the code.

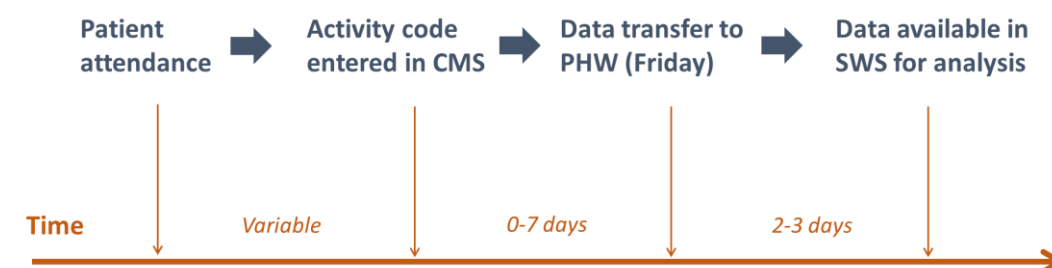
Sexual histories are routinely taken from all people attending sexual health services and PrEP is offered to those who meet the eligibility criteria.

Sexual Health in Wales Surveillance System: data flow

Sexual health clinics code their activity in their clinical management systems during or after patient attendances. In order to report to SWS, clinic staff send weekly exports of their clinical management systems to Public Health Wales (PHW), usually on Fridays. Once the data reach PHW, the informatics department make sure they are uploaded to SWS and made available to the Communicable Disease Surveillance Centre (CDSC), usually within 2-3 days. Data analysts can then clean the data ready for analysis (Figure 2).

In theory, under routine circumstances the data coded during the patient attendance could reach CDSC level in under 2 weeks. However, all of the above steps can add delays to the process. In exceptional circumstances, the whole process can be sped up by a joint coordinated effort.

Figure 2. Data flow diagram of the Sexual Health in Wales Surveillance System (SWS)



CMS: clinical management system

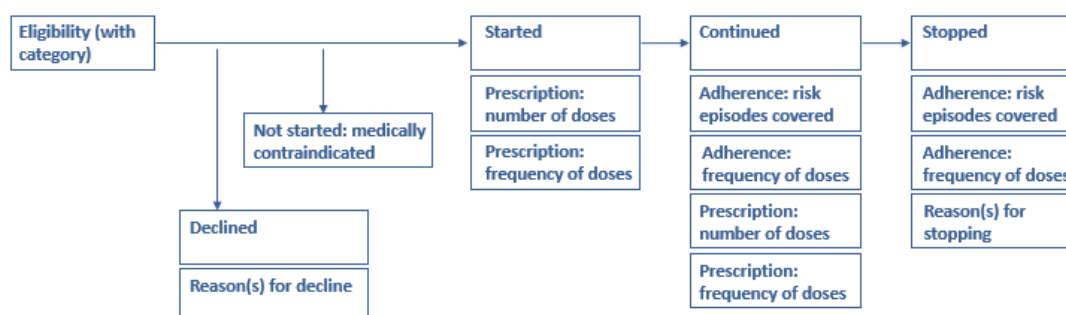
PHW: Public Health Wales

SWS: Sexual Health in Wales surveillance system

Coding for PrEP

Sexual health clinics code PrEP activity (Figure 3) in their clinical management systems using a series of 33 codes (Appendix B).

Figure 3. Flow diagram of data collected on persons assessed for PrEP*



* a complete list of codes with definitions can be found in Appendix B

Data transfer and dataset extract

For the purpose of PrEP monitoring, clinics were asked to send all their attendances since 1st July 2017, with PrEP coding complete at least until the end of March.

The data presented were exported from SWS on 4th May 2018. Clinic clients assessed for PrEP, starting on PrEP, or declining it between 1st July 2017-31st March were included.

Data cleaning and recoding assumptions

Cleaning of PrEP codes mainly involved capturing codes with typos and differing formats. Any duplicate codes (in terms of person and date) were deleted.

In people for whom the eligibility code was not completed, eligibility was assumed if other codes “downstream” of eligibility had been completed (any declined, started, continued, prescription, adherence, stopped codes). People who had been coded as eligible and not-eligible at different points in time, were counted as eligible only (n=17).

In the absence of a “start” code, the PrEP start was assumed for people with other “downstream” PrEP codes (PrEP continued, prescription, adherence, stopped codes).

An “assessed” variable was created for “eligible” and “not eligible” people.

In attendances coded with a “decline reason” and no “decline” code, this was created.

In attendances coded with a “stopped reason” and no “stop” code, this was created.

A prescription was assumed each time any of the two types of prescription codes were used (number prescribed codes or frequency prescribed codes).

Men who have sex with men were identified from the patient sexuality data field and from the eligibility codes (Eligibility category 1 is used for MSM at high risk of acquiring HIV).

Definitions

Definitions of the PrEP data collected can be found on the code definition list in Appendix B.

Current status

People who started PrEP were classified in the following “current status” groups using all the data available in the system at the time of the data extract (2nd January 2018):

- *stopped*; if there were codes indicating PrEP stop

OR:

- *currently on PrEP*; if within 30 days after their last theoretical dose (assuming daily dose taking from their last prescription date, given the number of doses prescribed is known).

- *recently finished a prescription*; if between 31 and 60 days since their last theoretical dose.

- *lost to follow up*; if over 60 days since their last theoretical dose.

- *unknown*; if the number of doses of their last prescription was not available

Data quality

- Previous audits of the data transfer of PrEP codes from the clinics to SWS revealed a very good match between clinic exports and SWS exports for both patient management systems.
- Codes are completed as much as possible at the cleaning phase in PHW. For instance, in people for whom the eligibility code was not completed, eligibility was assumed if other codes “downstream” of eligibility had been completed (any declined, started, continued, prescription, adherence, stopped codes) (see details in methods). In order to keep track of the level of incompleteness, “unknown” categories were created where possible. In the current dataset, 11% (88/803) of eligible people were assumed eligible because of “downstream” codes, and 13% (56/448) of started people were assumed started for the same reason. This should capture most people receiving PrEP, but it does not help for codes that are at the end of the process, as “declined PrEP” and “stopped PrEP” codes, which may therefore be more incomplete. In addition, assuming all prescriptions had been coded with either or both required codes (one for number of doses and one for frequency), 4% of prescriptions (43/970) missed codes on number of doses and 16% (152/970) did not have frequency codes. Of the adherence check opportunities, 18% (96/530) were missing codes for frequency, and 15% (80/530) for risk episodes covered.

Appendix A: Summary Table by LHB

Table 1. Summary of PrEP data by Local Health Board (LHB) for attendances up to 31st March 2018, as at 4th May 2018, Wales

	Wales		LHB1		LHB2		LHB3		LHB4		LHB5		LHB6	
Patients eligible for PrEP	803	-	58	-	231	-	157	-	221	-	34	-	102	-
Eligibility category:														
Category 1	704	88%	51	88%	211	91%	136	87%	189	86%	32	94%	85	83%
Category 2	5	1%	0	0%	1	0%	3	2%	0	0%	1	3%	0	0%
Category 3	6	1%	0	0%	0	0%	5	3%	0	0%	0	0%	1	1%
Unknown category (assumed eligibility)	88	11%	7	12%	19	8%	13	8%	32	14%	1	3%	16	16%
Of those eligible														
Started	448	56%	24	41%	131	57%	79	50%	107	48%	24	71%	83	81%
Declined (of those not started)	236	29%	21	36%	53	23%	47	30%	104	47%	1	3%	10	10%
In process/Unknown/Contraindicated*	119	15%	13	22%	47	20%	31	20%	10	5%	9	26%	9	9%
Current status of those who started														
Stopped	29	6%	1	4%	5	4%	5	6%	10	9%	3	13%	5	6%
Currently on PrEP	297	66%	14	58%	85	65%	52	66%	74	69%	15	63%	57	69%
Recently finished a prescription	26	6%	4	17%	4	3%	8	10%	5	5%	3	13%	2	2%
Lost to Follow-up	73	16%	4	17%	28	21%	11	14%	16	15%	1	4%	13	16%
Unknown	23	5%	1	4%	9	7%	3	4%	2	2%	2	8%	6	7%
Prescriptions provided to those who started	970	-	51	-	294	-	167	-	260	-	43	-	155	-
Prescription: number of doses														
30 doses	473	49%	32	63%	117	40%	82	49%	142	55%	20	47%	80	52%
60 doses	40	4%	5	10%	14	5%	16	10%	1	0%	0	0%	4	3%
90 doses	414	43%	13	25%	147	50%	59	35%	114	44%	19	44%	62	40%
Unknown	43	4%	1	2%	16	5%	10	6%	3	1%	4	9%	9	6%
Prescription: frequency of doses														
Daily	772	80%	41	80%	187	64%	118	71%	243	93%	34	79%	149	96%
Event based	46	5%	0	0%	25	9%	19	11%	1	0%	0	0%	1	1%
Unknown	152	16%	10	20%	82	28%	30	18%	16	6%	9	21%	5	3%
Opportunities to check for adherence	530	-	27	-	166	-	88	-	153	-	20	-	76	-
Adherence: Risk episodes covered by PrEP														
All risk episodes covered	405	76%	9	33%	112	67%	68	77%	139	91%	12	60%	65	86%
Most risk episodes covered	24	5%	1	4%	11	7%	3	3%	4	3%	4	20%	1	1%
Some risk episodes covered	12	2%	5	19%	4	2%	2	2%	1	1%	0	0%	0	0%
No risk episodes covered	9	2%	8	30%	1	1%	0	0%	0	0%	0	0%	0	0%
Not reported	80	15%	4	15%	38	23%	15	17%	9	6%	4	20%	10	13%
Adherence: frequency of doses														
Frequency taken: daily	413	78%	21	78%	129	78%	60	68%	128	84%	12	60%	63	83%
Frequency taken: event based	12	2%	0	0%	4	2%	7	8%	0	0%	0	0%	1	1%
Frequency taken: other	9	2%	0	0%	3	2%	3	3%	1	1%	2	10%	0	0%
Not reported	96	18%	6	22%	30	18%	18	20%	24	16%	6	30%	12	16%

*13 eligible patients did not start because of medical contraindication (data source: clinic questionnaire and SWS)

Appendix B: PrEP codes*

Eligibility codes		
O31W	PrEP eligibility: category 1	For those who, after a risk assessment, meet PrEP eligibility category 1 – <i>MSM who have had an HIV negative test on the day of starting PrEP and have had another HIV negative test in the preceding year and report condomless intercourse in the past 3 months and affirm likelihood of condomless intercourse in the next 3 months</i>
O32W	PrEP eligibility: category 2	For those who, after a risk assessment, meet PrEP eligibility category 2 – <i>HIV negative partner of an HIV positive person not known to be virally suppressed and condomless intercourse is anticipated before treatment of the HIV positive partner takes effect</i>
O33W	PrEP eligibility: category 3	For those who, after a risk assessment, meet PrEP eligibility category 3 – <i>HIV negative persons who are considered to be at a similar risk of HIV acquisition as those in category 2</i>
O34W	PrEP eligibility: not eligible	For those who, after a risk assessment, did not meet PrEP eligibility categories 1, 2 or 3
Decline of PrEP/PrEP not started codes		
O35W	Outcome of the offer of PrEP: PrEP offered and declined	For those offered a new course of PrEP at the current attendance who decline to take up PrEP.
O35aW	<i>Reasons for PrEP decline*: Do not believe themselves at risk</i>	<i>Does not believe that they are at risk of HIV *use all that apply</i>
O35bW	<i>Reasons for PrEP decline*: Prefers other methods</i>	<i>Prefers to use other risk reduction methods *use all that apply</i>
O35cW	<i>Reasons for PrEP decline*: side effects concern</i>	<i>Concerned about side effects *use all that apply</i>
O35dW	<i>Reasons for PrEP decline*: Does not want medication</i>	<i>Does not want to have medication *use all that apply</i>
O35eW	<i>Reasons for PrEP decline*: Does not want to be monitored</i>	<i>Does not want to be monitored *use all that apply</i>
O35fW	<i>Reasons for PrEP decline*: Had it in the past and did not like it</i>	<i>Had it in the past and did not like it *use all that apply</i>
O999W	Outcome of the offer of PrEP: Not started: Medically contraindicated	For those who are eligible to receive PrEP based on the criteria laid out but who, when put through preparatory investigations, are found to have co-morbidities that preclude them from PrEP
Started/continued PrEP codes		
O37W	Outcome of the offer of PrEP: PrEP started	For those starting a new course of PrEP at the current attendance.
O38W	Outcome of the offer of PrEP: PrEP continued	For those continuing PrEP at the current attendance regardless of who supplied. - PrEP patients should be coded at every attendance (even where the attendance is not specifically related to PrEP e.g. attended with STI symptoms to be treated please also code O38).
Stopped PrEP codes		
O39W	PrEP stopped	PrEP stopped at the current attendance
O39aW	<i>Reasons to stop PrEP: no longer eligible</i>	<i>No longer eligible (e.g. change in risk behaviour)</i>
O39bW	<i>Reasons to stop PrEP: personal choice</i>	<i>Personal choice (but still eligible). Please code further with "Reasons for decline code" (see O35a-O35f)</i>
O39cW	<i>Reasons to stop PrEP: now contraindicated</i>	<i>Now contraindicated (e.g. toxicity)</i>

Prescription codes: frequency (daily/event based), and number of doses		
O40W	PrEP regimen: daily	Daily PrEP regimen prescribed at this attendance for those starting or continuing PrEP
O41W	PrEP regimen: event based	Event-based PrEP regimen prescribed at this attendance for those starting or continuing PrEP
O42W	PrEP prescribed: 30 tablets	To indicate the number of tablets prescribed to those starting or continuing PrEP (30 tablets)
O43W	PrEP prescribed: 60 tablets	To indicate the number of tablets prescribed to those starting or continuing PrEP (60 tablets)
O44W	PrEP prescribed: 90 tablets	To indicate the number of tablets prescribed to those starting or continuing PrEP (90 tablets)
Adherence codes: frequency (daily/event based/other), and coverage of risk episodes		
O45W	PrEP dose taken: daily (or nearly daily)	To assess whether daily doses of PrEP were taken for those continuing or stopping PrEP at this attendance - Patients must be taking at least 5 doses of PrEP per week to qualify as 'daily/nearly daily' usage
O46W	PrEP dose taken: event based	To assess whether event based doses of PrEP were taken for those continuing or stopping PrEP at this attendance
O47W	PrEP dose taken: other	To assess how doses of PrEP were taken for those continuing or stopping PrEP at this attendance where dosing was neither daily nor event based)
O48W	PrEP adherence: All risk episodes covered	To assess the proportion of sexual risk episodes covered by PrEP (all) since last visit
O49W	PrEP adherence: Most risk episodes covered	To assess the proportion of sexual risk episodes covered by PrEP (most) since last visit
O50W	PrEP adherence: Some risk episodes covered	To assess the proportion of sexual risk episodes covered by PrEP (some) since last visit
O51W	PrEP adherence: No risk episodes covered	To assess the proportion of sexual risk episodes covered by PrEP (none) since last visit
Other codes		
O36W	Outcome of the offer of PrEP: PrEP being obtained online	For those eligible for PrEP but are already obtaining online and will continue to do so
CHEM	Chem sex	Use of recreational drugs before/during sex in the last 3 months
O60W	PrEP patient characteristic: Transgender	Gender identity changed since birth

*Codes in PrEP Operational guide July 2017, with the addition of O999W. Note: Mill clinics use the codes with a "PREP" suffix instead of an "O" suffix (e.g.: PREP31W instead of O31W)

Coding guidance:

If coded *eligible*, also code *started* or *reason(s) for decline* (or *not starting* PrEP), and vice versa.

At/around first prescription: 4 codes: *eligibility*, *start*, 2 *prescription codes* (number and frequency)

At subsequent prescriptions: 5 codes: *continued*, 2 *adherence codes** (risk episodes covered and frequency), 2 *prescription codes* (number and frequency)

If PrEP stopped: at least 3 codes: *reason(s) for stopping*, 2 *adherence codes** (risk episodes covered and taken frequency)

If patient attends between prescriptions: please give consideration to whether PrEP codes are also applicable. E.g., if other STIs are diagnosed, you may want to code PrEP. If patient continues on PrEP, consider coding 3 codes: *continued*, 2 *adherence codes** (risk episodes covered and taken frequency)

Code chem sex and transgender if applicable, in patients whose eligibility is assessed (once is enough).

*adherence since last time adherence was recorded - whether it was in a prescription attendance or between prescriptions- and up to current date or to stopped date