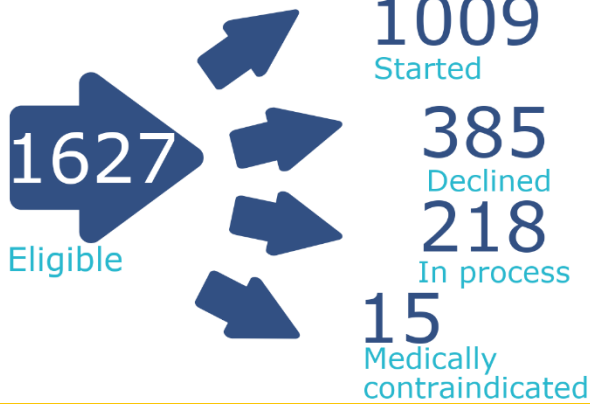


PRELIMINARY DATA

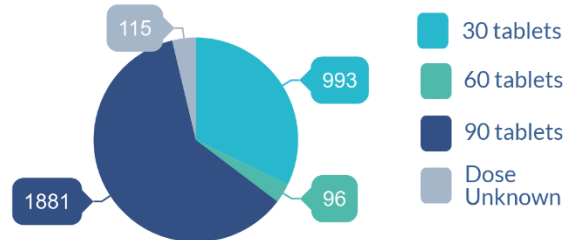
PRE-EXPOSURE PROPHYLAXIS FOR HIV (PrEP) PROVISION IN WALES

1st July 2017 - 31st March 2019, correct as at 22nd May 2019

1009 people prescribed PrEP



3085 prescriptions for 1009 patients



Of 1009 patients who started PrEP...

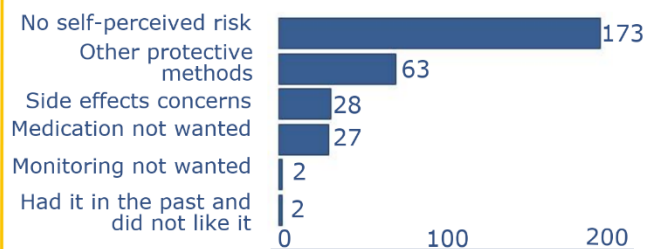


93% of PrEP was prescribed as daily



93% 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 taking PrEP include...



Pre-exposure prophylaxis for HIV provision in Wales	
Author: Communicable Disease Surveillance Centre (CDSC)	
Date: July 2019	v0a
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 2019, as at 22nd May 2019. At the time of extract, PrEP data are expected to be approximately complete up to the end of March, whilst STI diagnoses data may be incomplete and 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 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 2019, as at 22nd May 2019.

Key points

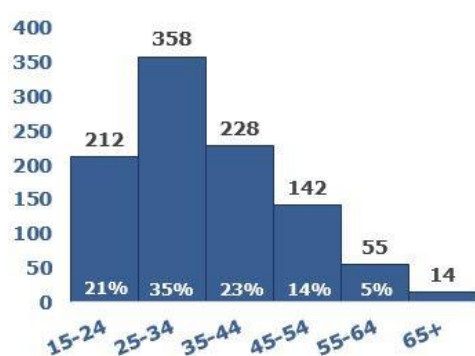


Between 1st July 2017 and 31st March 2019, 1627 patients were assessed as eligible for PrEP. Thirty percent (488) were relatively new to the service (not more than 2 months), of which 284 were completely new to the service. At least 8 individuals were newly diagnosed with HIV at the baseline test.

Where reported, 1401/1420 (99%) were MSM at high risk of acquiring HIV (eligibility category 1).

Of those eligible, 1009 (62%) started PrEP, and 385 (24%) declined. Fifteen (1.5%) did not start because of medical contraindications such as abnormal renal function. No further information is available on 218 (22%) eligible people at present.

Figure 1. Percentage age distribution of persons starting PrEP between 1st July 2017 and 31st March 2019 (n=1009)



Of the 1009 people who started PrEP, 998 (99%) were male, of whom 961 (96%) were MSM. The age range was 16-77, with a median of 32 years (Figure 1).

Of 1009 patients who started PrEP...

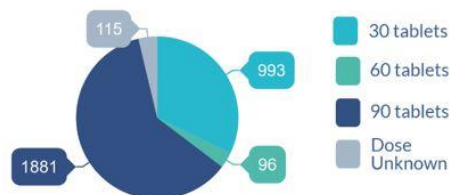


Of those who started PrEP, 523 (52%) people are still on PrEP, 45 (4%) have recently finished a prescription and 98 (10%) have stopped. Of the remaining 343, 290 (29%) are currently considered lost to follow up (over 2 months since their last prescription should have finished), and for 53 (5%) there is no further information.

Of those people considered lost to follow up, 138 (48%) have not returned to their clinic since they were last prescribed PrEP. The other 152 have returned to the service but have not been coded for PrEP.

Reasons for stopping PrEP are available for 88 people: 13 stopped due to medical contraindications, 15 were no longer eligible, and the remaining 61 stopped for personal reasons (please note some patients gave more than one reason for stopping).

3085 prescriptions for 1009 patients



93%
of PrEP was
prescribed as daily



In total 1009 people received 3085 prescriptions. PrEP is prescribed in courses of 30, 60, or 90 (the most frequent prescription) tablets at a time. Where reported, 93% of PrEP was prescribed daily, rather than event-based.



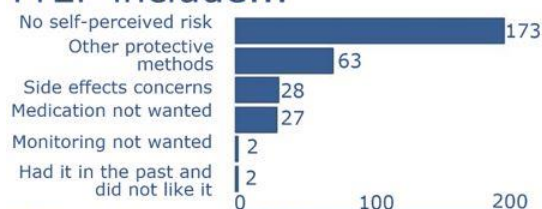
93%
of prescribed PrEP
covered all risk
events

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

Where reported, 93% of these assessments considered that all risk episodes had been covered, and 4% that most risk episodes had been covered, whilst 3% (n=52) concluded that some or no episodes had been covered.

Where frequency of use was reported, 92% 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 can give an indication of its acceptability. However, not all those who declined had a reason reported.

Of the 440 people who declined PrEP, 267 had at least one reason reported: 173 (65%) did not believe themselves to be at risk, 63 (24%) preferred using other protective methods, 28 (10%) mentioned side effects concerns, 27 (10%) did not want to take medication, and 2 (1%) did not want to be monitored, and another 2 declined because they had had PrEP in the past and did not like it.

Sexually transmitted infections diagnosed in patients taking PrEP include...



There have been no diagnoses of HIV in people taking PrEP (the eight new diagnoses of HIV mentioned above were in people eligible for PrEP, but who had not started). However, 242 people were diagnosed with 380 episodes of STIs whilst on PrEP: 149 chlamydia, 176 gonorrhoea, 34 syphilis (18 early latent, 10 primary, and 6 secondary); as well as 6 first episodes of herpes, 11 first episodes of warts, and 3 LGV diagnoses.

Methods

Pre-exposure prophylaxis for HIV (PrEP) data have been 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.

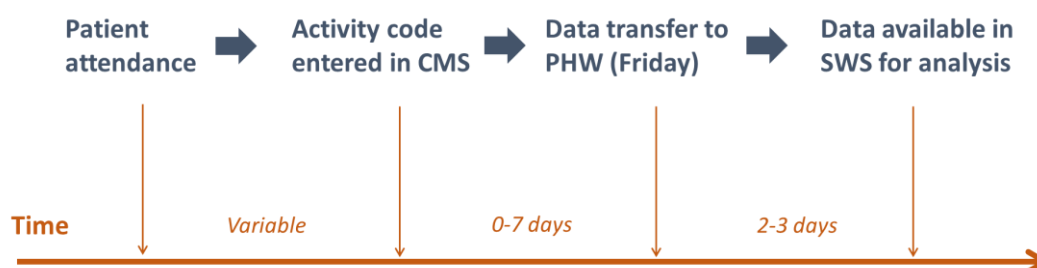
Sexual histories are routinely taken from all people attending sexual health services and PrEP is offered to those who meet the eligibility criteria.

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 in under 2 weeks. However, all of the above steps can add delays to the process. In exceptional circumstances, the process can be shortened by a joint coordinated effort.

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



CMS: clinical management system

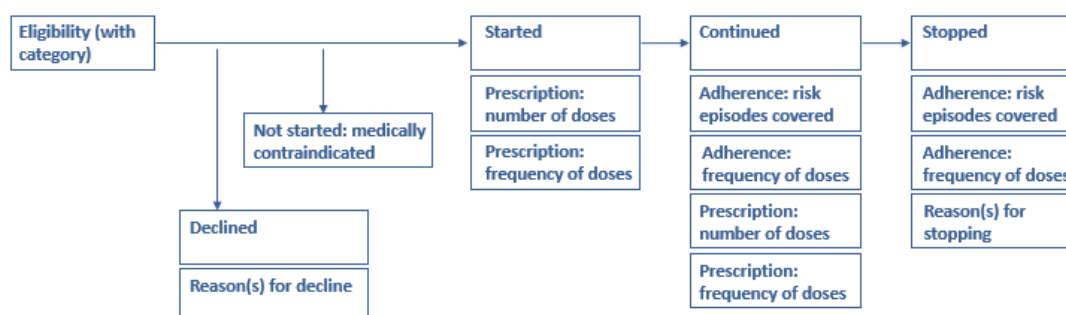
PHW: Public Health Wales

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 December 2018.

The data presented were exported from SWS on 22nd May 2019. Clinic clients assessed for PrEP, starting on PrEP, or declining it between 1st July 2017 – 31st March 2019 were included.

Data cleaning and recoding assumptions

Cleaning of PrEP codes mainly involved capturing codes with errors 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=69).

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 (as at 31st March 2019) using all the data available in the system at the time of the data extract (22nd May 2019):

- *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, 13% (207/1627) of eligible people were assumed eligible because of “downstream” codes, and 15% (152/1009) 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 (115/3085) missed codes on number of doses and 9% (270/3085) did not have frequency codes. Of the adherence check opportunities, 14% (287/2101) were missing codes for frequency, and 12% (258/2101) 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 2019, as at 22nd May 2019, Wales

	Wales		LHB1		LHB2		LHB3		LHB4		LHB5		LHB6	
Patients eligible for PrEP	1627	-	104	-	447	-	348	-	380	-	83	-	265	-
Eligibility category:														
Category 1	1401	86%	94	90%	378	85%	305	88%	355	93%	79	95%	190	72%
Category 2	10	1%	0	0%	3	1%	5	1%	0	0%	1	1%	1	0%
Category 3	9	1%	0	0%	0	0%	7	2%	0	0%	1	1%	1	0%
Unknown category (assumed eligibility)	207	13%	10	10%	66	15%	31	9%	25	7%	2	2%	73	28%
Of those eligible														
Started	1009	62%	59	57%	249	56%	192	55%	216	57%	58	70%	235	89%
Declined (of those not started)	385	24%	25	24%	112	25%	75	22%	152	40%	7	8%	14	5%
In process/Unknown/Contraindicated*	233	14%	20	19%	86	19%	81	23%	12	3%	18	22%	16	6%
Current status of those who started														
Stopped	98	10%	1	2%	13	5%	23	12%	20	9%	12	21%	29	12%
Currently on PrEP	523	52%	25	42%	143	57%	83	43%	126	58%	23	40%	123	52%
Recently finished a prescription	45	4%	2	3%	3	1%	8	4%	11	5%	7	12%	14	6%
Lost to Follow-up	290	29%	28	47%	77	31%	59	31%	57	26%	13	22%	56	24%
Unknown	53	5%	3	5%	13	5%	19	10%	2	1%	3	5%	13	6%
Prescriptions provided to those who started	3085	-	182	-	756	-	556	-	781	-	155	-	655	-
Prescription: number of doses														
30 doses	993	32%	80	44%	142	19%	202	36%	280	36%	44	28%	245	37%
60 doses	96	3%	11	6%	31	4%	29	5%	2	0%	1	1%	22	3%
90 doses	1881	61%	86	47%	551	73%	281	51%	494	63%	99	64%	370	56%
Unknown	115	4%	5	3%	32	4%	44	8%	5	1%	11	7%	18	3%
Prescription: frequency of doses														
Daily	2624	85%	149	82%	605	80%	360	65%	766	98%	121	78%	623	95%
Event based	191	6%	1	1%	57	8%	101	18%	4	1%	5	3%	23	4%
Unknown	270	9%	32	18%	94	12%	95	17%	11	1%	29	19%	9	1%
Opportunities to check for adherence	2101	-	125	-	515	-	366	-	566	-	99	-	430	-
Adherence: Risk episodes covered by PrEP														
All risk episodes covered	1715	82%	57	46%	409	79%	269	73%	529	93%	64	65%	387	90%
Most risk episodes covered	76	4%	3	2%	42	8%	7	2%	10	2%	5	5%	9	2%
Some risk episodes covered	31	1%	6	5%	10	2%	5	1%	6	1%	3	3%	1	0%
No risk episodes covered	21	1%	8	6%	2	0%	0	0%	4	1%	7	7%	0	0%
Not reported	258	12%	51	41%	52	10%	85	23%	17	3%	20	20%	33	8%
Adherence: frequency of doses														
Frequency taken: daily	1669	79%	81	65%	412	80%	217	59%	528	93%	53	54%	378	88%
Frequency taken: event based	85	4%	1	1%	25	5%	43	12%	4	1%	0	0%	12	3%
Frequency taken: other	60	3%	0	0%	31	6%	14	4%	13	2%	2	2%	0	0%
Not reported	287	14%	43	34%	47	9%	92	25%	21	4%	44	44%	40	9%

*15 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	Reasons for PrEP decline*: Do not believe themselves at risk	<i>Does not believe that they are at risk of HIV</i> *use all that apply
O35bW	Reasons for PrEP decline*: Prefers other methods	<i>Prefers to use other risk reduction methods</i> *use all that apply
O35cW	Reasons for PrEP decline*: side effects concern	<i>Concerned about side effects</i> *use all that apply
O35dW	Reasons for PrEP decline*: Does not want medication	<i>Does not want to have medication</i> *use all that apply
O35eW	Reasons for PrEP decline*: Does not want to be monitored	<i>Does not want to be monitored</i> *use all that apply
O35fW	Reasons for PrEP decline*: Had it in the past and did not like it	<i>Had it in the past and did not like it</i> *use all that apply
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	Reasons to stop PrEP: no longer eligible	<i>No longer eligible (e.g. change in risk behaviour)</i>
O39bW	Reasons to stop PrEP: personal choice	<i>Personal choice (but still eligible). Please code further with "Reasons for decline code" (see O35a-O35f)</i>
O39cW	Reasons to stop PrEP: now contraindicated	<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