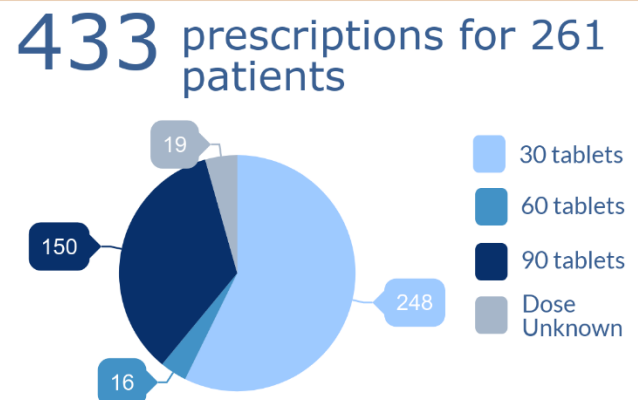
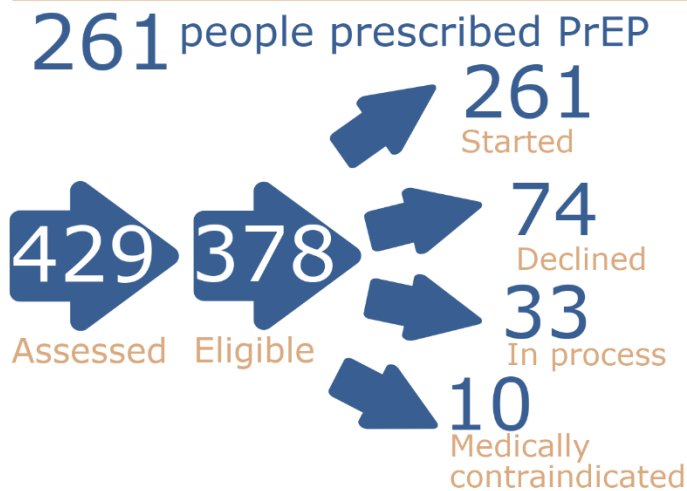


PRE-EXPOSURE PROPHYLAXIS FOR HIV (PrEP) PROVISION IN WALES

1st July - 1st December 2017, correct as at 2nd January 2018



Of 261 patients who started PrEP...



182 people are currently taking PrEP



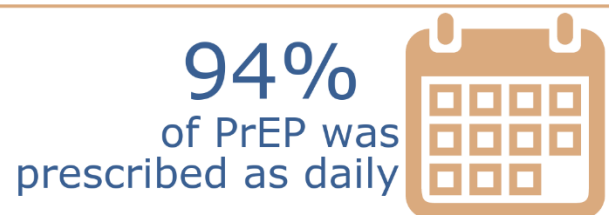
27 people have recently finished a prescription



8 people have stopped taking PrEP

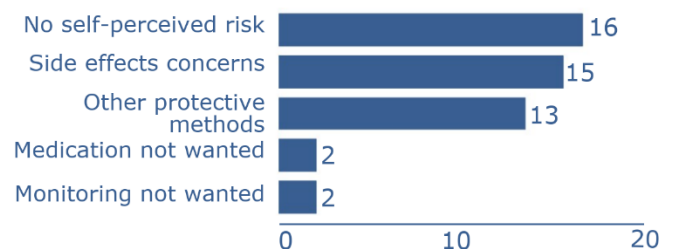


44 people are lost to follow-up/unknown



87% 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...



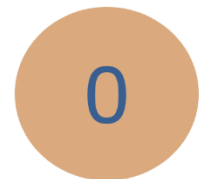
Chlamydia



Gonorrhoea



Syphilis



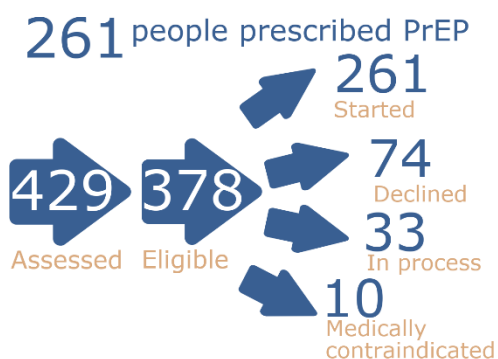
New HIV

Pre-exposure prophylaxis for HIV provision in Wales	
Author: Communicable Disease Surveillance Centre (CDSC)	
Date: January 2018	v2
Status: Approved	
Intended Audience: Sexual health professionals and Welsh Government	
Purpose and Summary of Document: This report is an overview of PrEP provision between 1st July and 1st December 2017 covering prescription, adherence and acceptability as at 2nd January 2018. It is accompanied by an infographic (cover page)	
Publication/Distribution: <ul style="list-style-type: none"> • PrEP steering group 	

Pre-exposure prophylaxis for HIV provision in Wales

Pre-exposure prophylaxis for HIV (PrEP) provision started in sexual health clinics in Wales on 14th July 2017. Data are being collected through the existing Sexual Health in Wales Surveillance System (SWS). This report is an overview of PrEP provision between 1st July and 1st December 2017 covering prescription, adherence and acceptability as at 2nd January 2018.

Key points

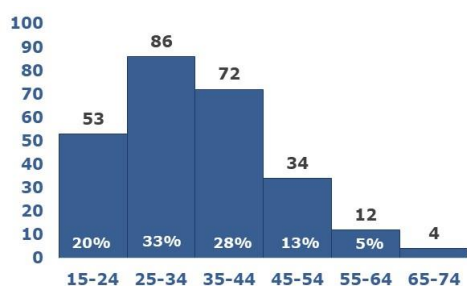


Of the 429 people assessed for PrEP eligibility between 1st July and 1st of December 2017, 378 (88%) were deemed eligible and 51 not eligible (12%) (assessed to eligibility ratio 1.1:1). Twenty seven percent of the assessed individuals were relatively new to the service (not more than 2 months), and 15% were completely new to the service when they were assessed. At least 3 new diagnoses of HIV have been made in people being assessed for PrEP (direct communication from clinics).

All but three of the eligible people were in the eligibility category 1 (MSM at high risk of acquiring HIV).

Of those eligible, 261 (69%) started PrEP, and 74 (20%) declined. Ten (3%) did not start because of medical contraindication due abnormal renal function or other relevant co-morbidities. No further information is available on 33 (9%) eligible people at present.

Figure 1. Age distribution of persons starting PrEP, 1st July 2017-1st December 2018, Wales (n=261)



Of the 261 people who started PrEP 98% were male, of whom 96% were MSM. The age range was 16-69, with a median of 33 years (Figure 1).

Of 261 patients who started PrEP...

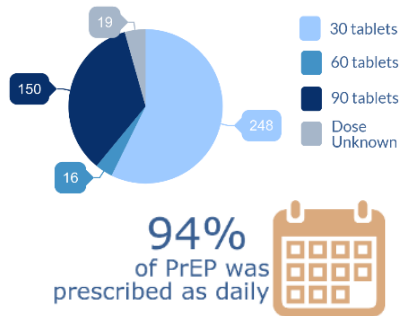


Of those who started, 182 (70%) people are still on PrEP, 27 (10%) have recently finished a prescription and 8 (3%) have stopped. Of the remaining 44 people, 30 (11%) are currently considered lost to follow up (over 2 months since their last prescription should have finished), and for 14 (5%) there is no further information.

Of those people considered lost to follow up, 31/44 have not returned to their clinic since they were last prescribed PrEP. The other 13 have returned to the service but have not been coded for PrEP.

Reason for stopping PrEP is available for three people: two stopped due to medical contraindication, one for personal choice.

433 prescriptions for 261 patients



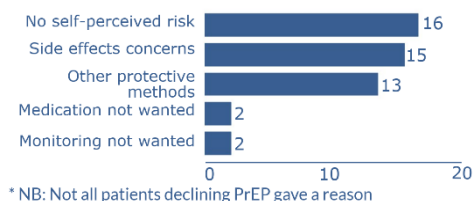
In total 261 people received 433 prescriptions. PrEP is prescribed in courses of 30, 60, or 90 tablets at a time. Frequency of dosing was reported for 333 prescriptions and for 94% of these PrEP was prescribed daily (as opposed to event-based).



87% of prescribed PrEP covered all risk events

Attendances where prescriptions are repeated are opportunities to assess adherence to the previous prescription of PrEP. Of the 187 repeat prescriptions, 158 (84%) had an adherence assessment in terms of risk episodes covered by PrEP. 87% of these assessments considered that all risk episodes had been covered, and 4% that most risk episodes had been covered, whilst 9% (n=14) concluded that some or no episodes had been covered. PrEP was taken daily (rather than event-based) in all 148 prescriptions for which this information was available.

Reasons patients declined PrEP include...*



Reasons for declining PrEP may be useful to assess acceptability of PrEP. However, these were not available at the time of this report for people attending Swansea and Cardiff clinics, due to a technical issue, and not all declines have had a reason reported. Forty eight reasons for declining PrEP were available for 39 people. The most common reason was not believing oneself at risk of HIV (33%), closely followed by concern around side effects (31%), and preference for other risk reduction methods (27%).

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



There have been no diagnoses of HIV in people taking PrEP. However, 17 people were diagnosed with 20 STIs whilst on PrEP: 9 gonorrhoea diagnoses, 7 chlamydia diagnoses, 2 syphilis and 2 hepatitis A.

Methods

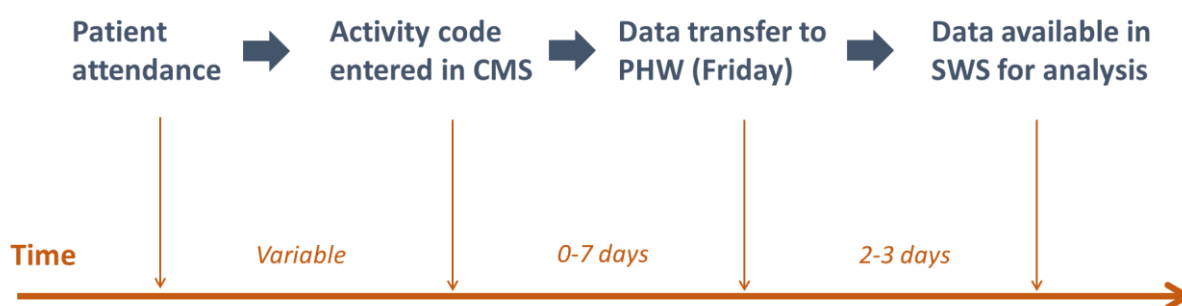
Pre-exposure prophylaxis for HIV (PrEP) data are being collected from sexual health clinics in Wales since the start of PrEP provision in July 2017 through the existing Sexual Health in Wales Surveillance System (SWS). A series of 33 codes was added to SWS to capture activity around PrEP, including codes 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. The data included in this report around this was obtained from clinics filling in a short questionnaire.

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

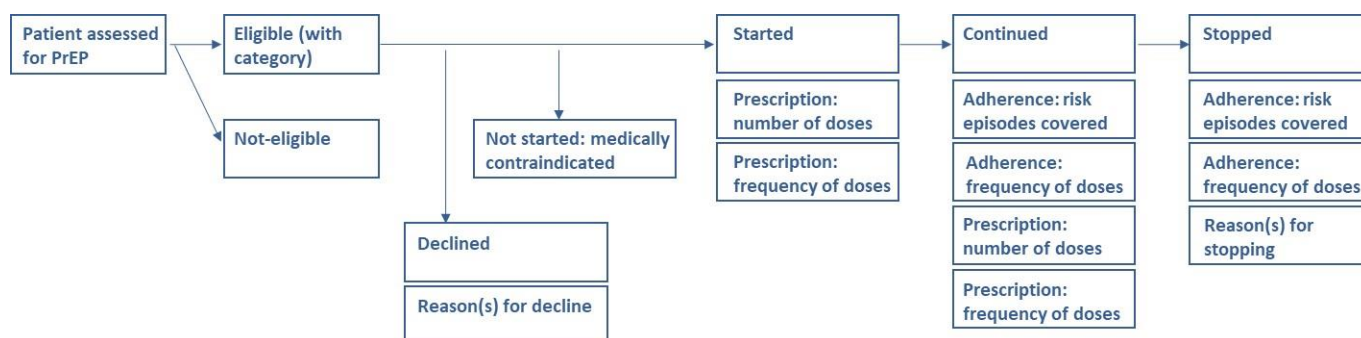
PHW: Public Health Wales

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, therefore covering the whole PrEP provision period.

The data presented were exported from SWS on 2nd January 2018. Clinic clients assessed for PrEP, starting on PrEP, or declining it between 1st July and to 1st December 2017 were included as data had been received for all clinics up to that date.

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)

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

- SWS has gone from a passive surveillance system for STIs, to having to also collect precise data around PrEP, which requires higher data quality.
- An audit of the data transfer from two clinics to SWS revealed a 95% match in PrEP codes (672 out of 705 PrEP codes matched). Of the 33 unmatched codes, 29 are explained by a mapping issue at PHW level affecting “reasons for decline” and “reasons for stopping”, which are not yet available for analysis for Swansea and Cardiff clinics. This will be fixed in future data extracts and analysis.
- 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% (42/378) of eligible people were assumed eligible because of “downstream” codes, and 20% (51/261) 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), 3% of prescriptions (414/433) missed codes on number of doses and 20% (333/433) did not have frequency codes. Of the adherence check opportunities, 21% (39/187) were missing codes for frequency, and 16% (29/187) for risk episodes covered.

Appendix A: Summary Table by LHB

Table 1. Summary of PrEP data by Local Health Board (LHB), 1st July 2017-1st December 2018, Wales

	Wales		LHB1		LHB2		LHB3		LHB4		LHB5		LHB6	
People assessed for PrEP eligibility	429	-	27	-	141	-	91	-	106	-	10	-	54	-
Not eligible	51	12%	2	7%	24	17%	20	22%	5	5%	0	0%	0	0%
Eligible	378	88%	25	93%	117	83%	71	78%	101	95%	10	100%	54	100%
Eligibility category:														
Category 1	333	88%	20	80%	105	90%	64	90%	90	89%	9	90%	45	83%
Category 2	2	1%	0	0%	1	1%	1	1%	0	0%	0	0%	0	0%
Category 3	1	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	2%
Unknown category (assumed eligibility)	42	11%	5	20%	11	9%	6	8%	11	11%	1	10%	8	15%
Of those eligible														
Started	261	69%	12	48%	87	74%	36	51%	76	75%	9	90%	41	76%
Declined	74	20%	11	44%	16	14%	19	27%	21	21%	1	10%	6	11%
In process/Unknown/Contraindicated*	43	11%	2	8%	14	12%	16	23%	4	4%	0	0%	7	13%
Current Status of those who started														
Stopped	8	3%	1	8%	3	3%	1	3%	1	1%	0	0%	2	5%
Currently on PrEP	182	70%	8	67%	59	68%	17	47%	61	80%	8	89%	29	71%
Recently finished a prescription	27	10%	2	17%	7	8%	7	19%	6	8%	0	0%	5	12%
Lost to Follow-up	30	11%	1	8%	12	14%	7	19%	7	9%	0	0%	3	7%
Unknown	14	5%	0	0%	6	7%	4	11%	1	1%	1	11%	2	5%
Prescriptions provided to those who started	433	-	27	-	149	-	51	-	139	-	13	-	54	-
Prescription: number of doses														
30 doses	248	57%	19	70%	76	51%	31	61%	84	60%	6	46%	32	59%
60 doses	16	4%	3	11%	7	5%	4	8%	1	1%	0	0%	1	2%
90 doses	150	35%	5	19%	57	38%	12	24%	51	37%	6	46%	19	35%
Unknown	19	4%	0	0%	9	6%	4	8%	3	2%	1	8%	2	4%
Prescription: frequency of doses														
Daily	312	72%	21	78%	76	51%	40	78%	115	83%	10	77%	50	93%
Event based	21	5%	0	0%	14	9%	3	6%	3	2%	0	0%	1	2%
Unknown	100	23%	6	22%	59	40%	8	16%	21	15%	3	23%	3	6%
Opportunities to check for adherence	187	-	16	-	65	-	18	-	65	-	4	-	19	-
Adherence: Risk episodes covered by PrEP														
All risk episodes covered	138	74%	4	25%	43	66%	15	83%	55	85%	3	75%	18	95%
Most risk episodes covered	6	3%	0	0%	3	5%	0	0%	2	3%	1	25%	0	0%
Some risk episodes covered	6	3%	3	19%	3	5%	0	0%	0	0%	0	0%	0	0%
No risk episodes covered	8	4%	7	44%	1	2%	0	0%	0	0%	0	0%	0	0%
Not reported	29	16%	2	13%	15	23%	3	17%	8	12%	0	0%	1	5%
Adherence: frequency of doses														
Frequency taken: daily	148	79%	14	88%	53	82%	15	83%	49	75%	4	100%	13	68%
Frequency taken: other	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Frequency taken: event based	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Not reported	39	21%	2	13%	12	18%	3	17%	16	25%	0	0%	6	32%

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

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</i> <i>*use all that apply</i>
O35bW	<i>Reasons for PrEP decline*: Prefers other methods</i>	<i>Prefers to use other risk reduction methods</i> <i>*use all that apply</i>
O35cW	<i>Reasons for PrEP decline*: side effects concern</i>	<i>Concerned about side effects</i> <i>*use all that apply</i>
O35dW	<i>Reasons for PrEP decline*: Does not want medication</i>	<i>Does not want to have medication</i> <i>*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</i> <i>*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</i> <i>*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