# BI2 Severe Haemophilia Haemtrack Patient Home Reporting

| Scheme Name | **BI2 Severe Haemophilia Haemtrack patient reporting at home** |
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| Eligible Providers | All providers of haemophilia services |
| Duration | April 2016 to March 2019. |
| Scheme Payment (% of CQUIN-applicable contract value available for this scheme) | CQUIN payment proportion [Locally Determined] for the first year should be targeted to achieve payment of £3,000 per provider per quarter for maintaining at least half its eligible patients on Haemtrack, plus £200 per patient per quarter for the targeted increase (from Q3 '15/16 baseline) in numbers of patients with adequate data compliance to 70% enrolment, plus £1,500 per patient per quarter for patients enrolled and compliant between 70% and 95% of eligible patients.<br>Target Value: Add locally<br>CQUIN %: Add locally |

**Scheme Description**

The HAEMTRACK patient reporting system is an electronic (or paper) patient-reported record of self-managed bleeding and blood product home-therapy usage. This scheme aims to establish the use of the Haemtrack patient home therapy diary as an integral part of clinical care. In centres with high recruitment and good data, staff are convinced of its clinical utility. The scheme offers financial support to all centres to improve recruitment and data quality, and to use Haemtrack as a one of the tools in an increasingly interventionist approach to individual treatment optimisation.

The ambition is to raise Haemtrack use to at least 80% of eligible patients in each centre. (Some patients will refuse to participate.) It is also hoped to raise compliance with Haemtrack (data recording) by patients to an adequate standard as defined below.

***Patient eligibility is defined below.***

To calculate the CQUIN payment proportion, the following components should be included in the target payment:

**Payment Element (1)**: A base target payment per centre of £3,000 per quarter (payable according to trigger 1, below, payable to all centres for *recruitment* - irrespective of compliance - to Haemtrack of at least 50% of eligible patients).

**Payment Element (2**): A target payment of £200 per quarter per patient targeted to be *recruited and compliant* in each quarter during 2016/17 in excess of baseline (2015/16 Q3) up to 70% recruitment (payable according to achievement against trigger 2, below). Baseline is defined below.

**Payment Element (3)**: A target payment of £1,500 is made per quarter per patient targeted to be *recruited and compliant* in excess of 70% up to 95% recruitment, (payable according to achievement against trigger 3, below).

To calculate these figures, a decision has to be made as to how ambitious to be in 2016/17 in respect of compliant recruitment of eligible patients, quarter by quarter. The greater the ambition, the greater the payment available for this scheme.

The funding of the scheme should cover costs of enrolment and feed-back information and for coaching to reach adequate compliance, and recognises the additional incremental cost of pushing enrolment up towards 95%.

The contract CQUIN Payment Proportion is determined by taking sum of the three payment elements (i.e. the payment that would be triggered according to these rules for compliant recruitment of the *targeted* number of eligible patients in each quarter) as a proportion of forecast total CQUIN-applicable contract value for the relevant provider.

**For example: -**

For example, if a centre has one hundred eligible patients (denominator 100) and 45% 2015/6 Q3 baseline recruitment of whom only forty are compliant, and targets adequately compliant recruitment of eighty patients in Q1 and Q2, rising to ninety-five patients in Q3 and Q4 of 2016/17, its target payments would be:

- £3,000 x 4 = £12,000 base payment to raise recruitment above 50% in each quarter
- 30 x £200 x 4 = £24,000 to raise compliant recruitment from 40% to 70%, i.e. for an additional thirty patients, for four quarters,
- 10 x £1,500 x 2 + 25 x £1,500 x 2 = £105,000 to achieve compliant recruitment respectively above 70% at 80% for two quarters (ten patients), and above 70% at 95% for two quarters (twenty five patients),
- Giving a total CQUIN payment target of £141,000.

The CQUIN payment proportion for this scheme would then be £141,000 as a proportion of forecast CQUIN-applicable contract value.

The three payment elements are payable according to proportional achievement (see below).

Note that a centre with high recruitment but poor compliance can use this scheme to target increased compliance. For example, if a centre with one hundred patients has achieved in the base period (‘15/16 Q3) 85% recruitment (eighty-five patients) already, but only 20% compliance (twenty patients), it might target 80% compliance (an additional sixty patients) without increasing recruitment. The target payment would then be £12,000 for maintaining recruitment above 50% plus 50 x £800 (for four quarters of compliant recruitment for fifty additional patients up to 70%) + 10 x £6,000 (for four quarters of compliant recruitment up to its 80% target for the other ten patients) i.e. £112,000 for improving compliance without increasing recruitment.

Note that that over-achievement relative to target will not be rewarded – hence it is important to agree ambitious targets.

**Measures & Payment Triggers**

1. Recruitment on Haemtrack in excess of 50% of eligible patients, quarter by quarter.
2. Increase in compliant recruitment (number of patients) on Haemtrack up to 70% relative to Q3 2015/16 baseline (as defined below), as proportion of targeted increase in compliant recruitment up to 70%, quarter by quarter.
3. Compliant recruitment on Haemtrack from 70% to 95% (number of patients) as a proportion of targeted compliant recruitment from 70% up to 95%, quarter by quarter. First 70% of eligible patients must be compliant before these payments are triggered.

(2) & (3) are subject to adequate compliance as defined below.

All numerators and denominators as defined below.
**Participation in this scheme also requires the provider to fund a subscription to the** National Haemophilia Database of £250 per quarter.

**Definitions**

**Denominator**:
**Patient eligibility is defined as follows: - Non-inhibitor Patients with severe or moderate-severity Haemophilia A or B on prophylaxis with Factor VIII/IX.**

**Numerators:** Patients with severe and moderate haemophilia A and B on home delivery of Factor VIII/IX registering and reporting on Haemtrack with adequate compliance.

**Baseline for Payment Element 2 and for Payment Trigger 2.** The increase targeted and that achieved are both relative to the following baseline: the number of patients that were recruited and adequately compliant at that centre in Quarter 3, 2015/16.

**Adequate compliance**, i.e. completeness of Data is defined as (i) data supplied for > 10 weeks in a quarter, and (ii) >75% of treatment issued recorded. (Fully complete data is defined as >45 weeks data/year, 11 weeks per quarter, and between 90% and 110% of treatment issued to them is recorded.)

**Partial Achievement Rules**

Actual payment depends upon performance in achieving each of the three outcomes in each quarter.

Payment element (1) in each quarter depends upon achieving Trigger (1) in each quarter. Payment elements (2) and (3) in each quarter depends upon applying triggers (2) and (3) (which are %s) to the targeted payment for that quarter.

The following example extends that given above for a provider with one hundred eligible patients (denominator 100) and 45% enrolment of whom forty are compliant in 2015/6 Q3, which targets adequately compliant recruitment of eighty patients in Q1 and Q2, rising to ninety-five patients in Q3 and Q4 of 2016/17. As set out above, its targeted payment amount would be £141,000.

The CQUIN payment proportion for this scheme would then be £141,000 as a proportion of forecast CQUIN-applicable contract value.

The following illustrates the payments that should be made to such a centre according to various outturns.

1.) If the centre continued without increased recruitment, it would receive no payment under this scheme.

2.) If the centre improved recruitment to above 50% (fifty patients) for all four quarters but compliance remained at 40%, it would achieve a payment of **(12,000/141,000) times the contracted CQUIN payment proportion of actual CQUIN applicable contract value for '16/17.**

3.) If the centre increased recruitment to eighty for all four quarters, of whom sixty were compliant for four quarters (i.e. twenty up on baseline), it would achieve the base payment (targeted at £12,000) plus 20 x the payment for compliant recruitment up to 70% (targeted at £200 per patient per quarter), and so would achieve a payment of (**28k/141,000) times the contracted CQUIN payment proportion of actual CQUIN applicable contract value for '16/17.**

4.) If it increased recruitment to ninety of whom eighty-five (85%) were compliant, its payment would be based on eighty (80%) compliant patients in Q1 and Q2 (as that was the target agreed and there is no payment for over-achievement), and eighty-five compliant patients in Q3 and Q4 (as the target for those quarters was set at 95%). With, in addition to base payment for trigger 1, thirty patients above trigger point 2 for the entire period, and ten above trigger point 3 for Q1 and Q2, and fifteen above trigger 3 for Q3 and Q4 (targeted at £1500 per patient quarter), giving indicative amounts of £12,000 + £24,000 + £3,000 + £45,000, the centre would achieve a payment of **(111,000/141,000) times the contracted CQUIN payment proportion of actual CQUIN applicable contract value for '16/17.**

All payments are subject to Trigger 4 – i.e. an arrangement must be in place to transfer the appropriate funding to NHD quarterly in advance

**In Year Payment Phasing & Profiling**

Quarterly

**Rationale for inclusion**

At a patient and centre level, to promote the use of Haemtrack, which may be used for patient education and to optimise patient replacement therapy, so to achieve the most clinically-appropriate approach to Haemophilia treatment whilst maintaining or improving patient outcomes.

At a national level, it will provide insight into the reasons for the considerable variation between Haemophilia Centres in treatment intensity and to explore the relationship between treatment intensity and clinical outcome as reflected by annualised bleed-rate. Information should allow optimisation of treatment.

A previous CQUIN successfully incentivised patient registrations and reporting via Haemtrack giving a patient led record of blood product usage. The annual Haemtrack report shows this had a benign impact on product use and so contributed to the optimisation of dosing. Recruitment increased rapidly and factor use briefly stabilised.

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| Since it ceased to be a CQUIN further recruitment has been slower.<br><br>Cost implications of the introduction of Haemtrack are mainly related to nursing input, clinical review of Haemtrack treatment records, explaining and enthusing patients, monitoring and correcting data. As the system beds in, the effort required reduces, but there is need for ongoing input to maintain patient compliance and to monitor the data. However, since Haemtrack is a central tool in maintaining treatment compliance, optimising home therapy and home stock control, this should be necessary for ongoing patient management anyway. It should be noted that 90-95% of the cost of managing a patient with haemophilia relates to drug costs. The average patient with severe haemophilia costs >£100,000 pa to treat. Staff costs are only about 5%. Increased staff input into treatment optimisation and patient education is appropriate. | |
| **Data Sources, Frequency and responsibility for collection and reporting** | |
| The data downloads into the Centre Haemophilia Centre Information System (HCIS), where it is available for review in MDTs and Clinic. It is checked at centre level and downloads, once checked, to the National Haemophilia Database. This data will be rich enough to allow evaluation of impact (see under “evaluation”).<br><br>Reporting should be quarterly in arrears.<br><br>All IT systems and data collections are already currently in place and operational thus would incur no extra cost. Data analysis may be analysed quarterly and annually and would be submitted to NHS England or any other designated agency. Additional cost may be incurred by the National Haemophilia Database reimbursement may be sought.<br><br>Central analysis allows various data quality checks to be conducted. | |
| Baseline period/ date & Value | Q3 2015/16 as defined. |
| Final indicator period/date (on which payment is based) & Value | As above. |
| Final indicator reporting date | Month 12 Contract Flex reporting date as per contract |
| **CQUIN Exit Route**<br><br>*How will the change including any performance requirements be sustained once the CQUIN indicator has been retired?* | Lack of staff has been cited by some centres as a barrier to uptake. Once the system is established with CQUIN funding, and producing good data, the clinical utility becomes self-evident to centre staff and it becomes established as an important element in normal clinical management, it should be self-sustaining.<br><br>To ensure continued compliance following conclusion of the CQUIN, it is intended that the Haemtrack system be embedded in service specification and built into the payment mechanism for these patients. |

## Supporting Guidance and References

There are 28 comprehensive care centres with in excess of forty patients with severe haemophilia. Some centres have more than one hundred patients. There are about 60 smaller centres with fewer than forty patients. Some are networked to larger centres and some not, some with as few as five patients. Larger centres tend to have better recruitment and compliance than smaller centres.

There are in excess of 2,500 patients with all diagnoses and all severities in the whole UK (not just England) using Haemtrack. About 1,200 English haemophilia A patients are using Haemtrack; these are mostly patients with severe haemophilia. Bleeding severity amongst patients with moderate haemophilia is very variable, with some bleeding as badly as patients with severe haemophilia; these patients are on home therapy, and thus appropriate for Haemtrack; others rarely bleed and are not on home therapy. Moderate haemophilia is probably about 10% of the home therapy total. At the moment about 65-70% of eligible haemophilia patients are registered on Haemtrack. This varies between centres in England from about 15% to 90% recruitment. Across all groups, about 50% of recruited patients provide near complete or complete data but that varies amongst English centres between 0% and 90% of those registered with the system. Those with poor recruitment also have the most incomplete data and poor quality data is of very limited use.

Analysis to date has already provided valuable insights into the sources of treatment variability between centres and suggests no correlation between varied treatment intensity and outcome. This suggests that Haemtrack will be a very valuable tool to optimise treatment regimens. More widespread clinically interactive use of Haemtrack will lead to greater optimisation of treatment.