GE2 Activation System for Patients with Long Term Conditions

Scheme Name:	**GE2: Activation System for Patients with Long Term Conditions (LTCs)**
Eligible Providers	All providers offering services to patients with conditions meeting the specified criteria.
Duration	April 2016 to March 2018, with extension to cover other conditions.
CCG Complementarity	A CCG scheme has been developed to complement this one. It is one of two Patient Centred Care indicators available to CCGs.
Scheme Payment (% of CQUIN-applicable contract value available for this scheme)	CQUIN payment proportion [Locally Determined] should achieve payment of c. £50,000 for each centre with a patient group targeted for PAM of 500 patients or over. Target Number of Patients, by LTC: 1st LTC [Specify] number of patients: Add locally 2nd LTC [Specify] number of patients: Add locally Target Value: Add locally CQUIN %: Add locally

Scheme Description

Development of a system to measure skills, knowledge and confidence needed to self-manage long term conditions, and with that information to support adherence to medication and treatment and to improve patient outcomes and experience.

The CQUIN scheme aims to encourage use of the "patient activation measurement" (PAM) survey instrument, firstly to assess levels of patient skills, knowledge, confidence and competence in self-management for different groups of patients meeting the criteria below. The second stage, to be developed for the second year of the CQUIN, seeks to support Activation Interventions to tailor service provision according to self-management capability and/or to raise activation levels. (See more explanation in the Supporting Guidance and References section below.)

The whole scheme will be subject to evaluation - to build on the international evidence and on the work that is already under way in certain services, including the Learning Set of five CCGs and the Renal Registry in England.

Before contract, providers must select with the agreement of commissioners an appropriate group of patients (with a minimum to support a £50,000 target payment, of a group of 500 patients completing the PAM instrument – not including those refusing to complete, or who are excluded from being offered participation). A marginal variation in target payment of £25 per patient for smaller/larger groups of patients may be agreed.

Patient groups who stand to benefit include those with persistent conditions for which

1. There is a care regime of known effectiveness which is complex
2. Symptomatic abreaction to poor adherence is distal (so that patients will realise that poor adherence is responsible for deteriorating health)
3. Symptomatic consequences of poor adherence may – if poor adherence is not recognised – lead to misdiagnosis and mistaken prescription

4. The severity of the condition does not itself preclude self-care (e.g. through occluding insight *(an understanding of the nature of the condition and the factors that make it better/worse) or* capacity *(in terms of being able to make informed decisions regarding management of the disorder)*

Suggested conditions include: Teenage and Young Adult Cancer, Cystic Fibrosis (which is subject to a separate CQUIN scheme), chronic kidney failure, HIV, haemoglobinopathy, severe difficult to control asthma, ILD, severe faecal incontinence, inflammatory bowel disease, schizophrenia, severe depression, COPD, adult congenital heart disease, epilepsy. The HIV CRG has expressed a particular interest in developing patient self-management so to enhance the quality of life for people living with HIV.

Year 1 will (largely) be focused upon Measurement and Team capacity Building.
Specific activities:

- **Licence**. A licence is needed for setting up a PAM programme for each patient. These would be available under an NHS England contract with Insignia (to be accessed via NHS England[1]) at no additional cost to the provider.
- **Elicitation**. Per patient costs will have to be incurred in eliciting the information using the PAM tool. It is recommended that information is collected in the clinical context – as this has been shown to increase the response rate and to mitigate the risk of non-response bias. There are options regarding administration: paper or (possibly) electronic, to be explored with Insignia, which may affect costs. The administration of the questionnaire may take ten to fifteen minutes including explanation. Costs would depend upon:
    i. Mode of measurement
    ii. Frequency of measurement (per patient)
- **Team Capacity Building**. Staff training in the administration of the instrument element – for example some workshops to develop clinical engagement. The outcome here should be patient activation preparedness of the team: it would be helpful to specify what this will comprise more precisely.
- **Mechanisms for gathering, presenting and analysing Activation information**

Team building costs will be incurred early in the year, elicitation costs as the PAM is administered, in the later quarters of the year. Year 2 costs will be explored and assessed for the '17/18 CQUIN scheme.

Measures & Payment Triggers

Before contract

- Agree vision for use of PAM measure with cohorts of patients in context of increasing support for self-care;
- Agree the Year 1 metrics: number of patients in each condition recruited into the programme for application of the PAM; the number of staff to be trained.

Year One payment Triggers
ONE: Planning & Set-Up:

[1] E-mail ENGLAND.commercial@nhs.net

1. A working group has been established;
2. Implementation plan written and submitted to commissioners including:
    a. team building and training plan for staff who will administer PAM
    b. plan for creation of mechanisms for gathering, presenting and/or analysing data, with clarity regarding:
        i. To whom the data should be fed back (e.g. to the patient; to the team; to the PAM oversight group in the provider; for central evaluation in a standard pseudonymised format);
        ii. What immediate use is to be made of it.
3. Secure licence from Insignia of 2 years duration or more (via NHS England).

TWO: Team Building.

1. Team building and training plan for staff to administer the PAM has been implemented
2. Readiness Assessment of Patient Activation preparedness of team and any identified shortfalls have been addressed.

THREE: Elicitation of Activation Information via the PAM.

1. Pilot testing and evaluation of use of survey instrument completed
2. Baseline measure captured from PAM administered to first cohort of patients
3. The proportion of the patient groups targeted in each condition recruited into the programme for application of the PAM.

FOUR: Analysis and Response:

1. Elicited PAM responses gathered and submitted for benchmarking and evaluation.
2. Activation Intervention options developed (to feed into Year 2 planning).
3. Report to commissioners on progress against implementation plan including results from pilot and shared learning.

NOTES:

For consistency, and given its validation and the relationship and contract that is in place with NHS England it is proposed that all schemes involve use of the Patient Activation Measure PAM available from Insignia: see the annex for background and academic studies demonstrating the validity of the measure and the correlation between PAM measured activation and important patient outcomes.

Second year Payment Triggers.

Interventions expected to be covered by the CQUIN will be

1. The introduction of Intermediate Outcome Measures,
2. The introduction of Activation Interventions[2].
3. Improvement in PAM Score, and/or introduction of other interventions to sensitise service delivery to PAM level.
4. Aggregate improvement of patient reported health outcomes, improvement in adherence and a reduction in non-elective attendances/admissions, across patients in an LTC group, weighted by approximate QALY gain. (For some conditions, maintaining the score might be a good outcome – i.e. preventing deterioration.) These metrics might be developed in the context of the evaluation.

[2] The CQUIN Development and Reference Group will develop a list of intermediate outcome measures, by patient group, together with a taxonomy of Activation Interventions to be used for payment triggers.

Definitions
Denominator for trigger iii.3 Number of patients in each of the targeted LTCs whom it is agreed should be targeted for completion of the PAM. Numerator: Number actually completing the PAM in these groups creating usable data
Partial Achievement Rules
No partial payment for Trigger one and two. Payment on completion in full. Payment for Trigger three and four should be scaled down pro rata in line with achievement against Trigger three proportion of targeted group actually completing the PAM.
In year payment phasing and profiling
Quarters 1-2 70%: Paid on completion of Trigger one and two Quarter 4 30% Paid on completion of Trigger three and four.
Rationale for inclusion
The implementation of a patient activation system is designed to realise significant benefits to the healthcare system from improved patient outcomes and experience of care and from a reduction in the use of non-elective services. Adherence to treatment has been linked to improved health outcomes and has been shown to increase patient satisfaction by supporting independence which can also be linked to higher quality interactions with healthcare professionals.
Data Sources, Frequency and responsibility for collection and reporting
The source of data for elements i-iv of the Year One payment triggers (see below), will have to be developed as the PAM CQUIN is adopted at the level of individual providers for specific patient groups. If a software solution is adopted for administration of the PAM, then extracts from the implemented software will be usable to confirm active users and active records. It is likely that providers will need to identify internal systems to identify the patient cohort and record the data. It is likely that specialist nurses would be used as a resource to identify patients and support data collection; though for inpatients admission under the specialty code may be used as a marker, and to validate of report.

Baseline period/date &Value	To be reported by the Provider for the selected cohorts of patients with LTC.
Final indicator period/date (on which payment is based) & Value	The number of patients above baseline proportion completing PAM, to be reported by provider.
Final indicator reporting date	Month 12 Contract Flex reporting date as per contract.
CQUIN Exit Route *How will the change including any performance requirements be sustained once the CQUIN indicator has been retired?*	Incorporation of changes in the cost per care episode or year of care into core tariff payments for activation measures and interventions will be developed during the course of the CQUIN scheme's evaluation, based on the balance of expected savings from improved segmentation of care and adherence between providers and commissioners under the relevant payment mechanism for each patient group. Plans will be developed for each patient group to ensure that funding is sustainable.

Supporting Guidance and References

There has been wide review and implementation of a number of interventions to support the concept of self-care and management of long term conditions. The Kings Fund published an appraisal of the patient activation concept which describes the practical implementation of a behavioural change model and explores some of the potential benefits of implementing a scheme such as this[3].

The concept of a Patient Activation system, such as this scheme is designed to support, denotes an activation method which can first capture patient's knowledge and skills, and, second, includes population segmentation, interventions to improve engagement, and measuring performance across the healthcare system.

There are two broad categories of Activation interventions:

a. stratification of the patient groups to help diagnose problems and determine appropriate care plan;
b. work with patients to raise motivation, skills and self-management, etc)

Regarding activation of patients, there are a large number of behavioural change models available. It is recommended that the COM-B model is used as a default understanding of behaviour change: Capability + Opportunity + Motivation=> Behaviour change.

However, this should not restrict the range of interventions that may be useful in different contexts for different groups, including:

a. commitment support via:
    1. peer group (as proposed for example for HIV patients)
    2. joint appointments (e.g. as default)
    3. carer involvement, etc.
b. health coaching with Clinical Nurse Specialist or other professional input

EVIDENCE BASE:

The fundamental link between activation and outcomes is well substantiated[4]:

A B S T R A C T

Objective: A systematic review of the published literature on the association between the PAM (Patient Activation Measure) and hospitalization, emergency room use, and medication adherence among chronically ill patient populations.

Methods: A literature search of several electronic databases was performed. Studies published between January 1, 2004 and June 30, 2014 that used the PAM measure and examined at least one of the outcomes of interest among a chronically ill study population were identified and systematically assessed. Results: Ten studies met the eligibility criteria. Patients who scored in the lower PAM stages (Stages 1 and 2) were more likely to have been hospitalized. Patients who scored in the

[3] http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health

[4] Patient Education and Counselling 98 (2015) 545-552. "The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: A systematic review" Rebecca L. Kinney et al.

lowest stage were also more likely to utilize the emergency room. The relationship between PAM stage and medication adherence was inconclusive in this review.
Conclusion: Chronically ill patients reporting low stages of patient activation are at an increased risk for hospitalization and ER utilization.

Practical implications: Future research is needed to further understand the relationship between patient activation and medication adherence, hospitalization and/or ER utilization in specific chronically ill (e.g. diabetic, asthmatic) populations. Research should also consider the role of patient activation in the development of effective interventions which seek to address the outcomes of interest.

Adherence to medication and treatment is thus linked to health outcomes and patients who are more empowered were able to report greater level of satisfaction and ownership, which is linked to overall improved patient experience.

Health monitoring of biometric indicators can support the review and improve health outcomes for patients with long-term conditions and reduce non-elective attendances. More active patients engage in their own care so to comply with care regimes and to respond to such indicators.

Patient activation models have been shown also to be effective in improving the quality of interactions between patients and healthcare professionals. They involve assessment of activation levels, for example by use of the Patient Activation Measure, the PAM.

Measurement must be complemented by a range of interventions to make effective use of the information to improved patient outcomes. These may well have to be sourced from a separate provider. This might include supportive decision making, motivational interviewing and other interventions as part of a well-evidenced behavioural change model (such as the COM-B model, improving Capability and recognition of Opportunity and Motivation to achieve Behavioural change), to improve activation or engagement. Or, more simply, the information can be used better to understand outcomes for patients, to avoid misdiagnosis and mis-prescription. Both have been used dramatically to improve outcomes in the Cystic Fibrosis trailblazer for this programme in Sheffield – that is currently being piloted for a national RCT.
With a behavioural change component, the PAM can then be used at team level to benchmark success of different approaches to bringing about behavioural change. See ANNEX for more evidence regarding the PAM and its use to improve patient outcomes.

Ambition must be set separately with respect to different patient groups. For the programme as a whole, the ambition is to reach a range of appropriate patient groups. It is well documented that patients with long term conditions avoidably utilise emergency healthcare services on a regular basis resulting in poor outcomes for patients and decreased efficiency in the healthcare system. This scheme is designed to mitigate this phenomenon.