

GE2 Activation System for Patients with Long Term Conditions

Scheme Name:	GE2: Activation System for Patients with Long Term Conditions (LTCs)
Eligible Providers	<p>All providers offering services to patients with conditions meeting the specified criteria.</p> <p><u>For 2017/8 and 2018/19:</u> The PSS CQUIN scheme is available only to providers who adopted have adopted the PAM system in 2016/17, and are therefore able to embark upon the second year of the scheme.</p>
Duration	April 2016 to March 2019.
Scheme Payment	<p>CQUIN payment proportion [Locally Determined] should achieve payment of c. £60,000 for each centre for each new patient group targeted for PAM of 500 patients, plus/minus £30 per head for larger/smaller cohorts</p> <p>Plus an amount to be agreed with commissioners and the national team, to cover costs of interventions adopted for respectively year two and year three patient groups</p> <p>Target Number of Patients, by LTC: <i>[Add additional groups as required]</i></p> <p>2017/18 Year One Patient Groups 1st LTC [Specify] number of patients: Add locally 2nd LTC [Specify] number of patients: Add locally Year Two Patient Groups 1st LTC [Specify] number of patients: Add locally 2nd LTC [Specify] number of patients: Add locally Target Value: Add locally</p> <p>2018/19 Year One Patient Groups 1st LTC [Specify] number of patients: Add locally 2nd LTC [Specify] number of patients: Add locally Year Two Patient Groups 1st LTC [Specify] number of patients: Add locally 2nd LTC [Specify] number of patients: Add locally Year Three Patient Groups 1st LTC [Specify] number of patients: Add locally 2nd LTC [Specify] number of patients: Add locally Target Value: Add locally</p>
Scheme Description	

Problem to be addressed

There is a substantial body of evidence demonstrating that patients with long term conditions with higher levels of activation (the knowledge, skills and capacity to manage their own condition) have better outcomes including reduced frequency of exacerbations and associated high cost interventions. There is also evidence that information about activation levels can be used effectively to focus intervention on patients groups more effectively. There is currently no regular and consistent systematic assessment of activation levels for PSS patient groups who are likely to benefit from implementation of an activation system.

Change sought

For each patient group with a potential to benefit from it, development of a system to measure patients' level of activation, i.e. the 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 therefore 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, for the second and third years of the scheme, seeks to support Activation Interventions to tailor service provision according to self-management capability and/or to raise activation levels.

Only the PAM instrument, licenced from Insignia, is to be used to assess activation rates. The Insignia questionnaire is independently validated as representing the level of patient engagement in such a way as accurately to reflect likelihood of adherence to care plan and likelihood of avoiding exacerbations. Use of a standard instrument across the NHS also will facilitate benchmarking. There are alternative versions for parents, MH patients, carers, and for Clinicians (to test whether they are able to support patients in self-management of their conditions). The survey questions are interpreted via the software that is available with the licence, and allows a patient group to be stratified according to level of self-management of their clinical condition; and also diagnoses the nature of any shortfall - thus helping to determine appropriate remedies – ways in which patient adherence to care plan can be enhanced.

Use of information about activation levels can take two forms:

- 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). It is recommended that the COM-B model is used as a default understanding of behaviour change: Capability + Opportunity + Motivation=> Behaviour change.

LTC Groups Who Should Benefit

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

- There is a care regime of known effectiveness which is complex
- Symptomatic abreaction to poor adherence is distal (so that patients will realise that poor adherence is responsible for deteriorating health)
- Symptomatic consequences of poor adherence may – if poor adherence is not recognised – lead to misdiagnosis and mistaken prescription
- 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, solid organ transplantation patients, severe faecal incontinence, inflammatory bowel disease, schizophrenia, severe depression, COPD, adult congenital heart disease, epilepsy, LSD to support Enzyme Replacement Therapy adherence.

Year 1 (2016/17) has focused upon Measurement and Team capacity Building. These activities will be required also for Year 2 where the programme is expanding to new patient groups.

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 England¹) 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:
 - Mode of measurement
 - 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.

Setting Provider Specific Parameters for 2017/18 and 2018/19

On agreeing adoption of this scheme for 2017/18 and 2018/19, the following should be set for each provider in advance of contract, in order to determine precisely what is required of each provider, and/or to determine appropriate target payment.

For any new condition-group for whom an Activation System is being developed:

- Agree vision for use of PAM measure with cohorts of patients in context of increasing support for self-care;
- Agree the first year metrics:
 - Patient group(s) –in each year.
 - Number of patients in each condition to be recruited into the programme for application of the PAM.

¹ E-mail ENGLAND.commercial@nhs.net

- The number of staff to be trained to administer the PAM.

For existing condition groups, agree the second year Metrics;

- The number of patients to be re-tested with what frequency
- Interventions to be undertaken in support of patient groups according to their level of activation.
- These interventions should in general be drawn from those recognised as effective in the patient activation literature and endorsed by the national team. A taxonomy of patient activation interventions is available here:

: <https://www.ucl.ac.uk/health-psychology/bcttaxonomy>

- . However, innovative alternatives will also be considered subject to expert clinical and behavioural-psychologist input.

Calculating the Target Payment for a Provider for each year

For new patient groups:

£60,000 is an indicative amount for a single group of 500 patients. If the group is larger or smaller, the amount should be adjusted by £30 per head; so

- for a group of 100 patients, £60,000 – (400x£30)=£48,000
- for a group of 1000 patients, £60,000 + (500x£30)=£75,000.

The calculation is done separately for an additional group of patients, as new training would be required for the clinicians etc.

For existing patient groups, for both year two and year three: an amount to be agreed with the commissioner and the national team, determined by:

- the numbers in each patient group at each activation level (from Year 1 outcomes, or by estimation)
- the intervention to be piloted, costed plus 50% CQUIN premium
- the frequency of PAM administration, costed at £30 per application.

Measures & Payment Triggers, and proportions of Year Payment

First Year Triggers, for new groups of patients

ONE: Planning & Set-Up: 20%

1. A working group has been established; signing of Affiliation Agreement with Insignia – to obtain Licences and PAM Materials (under NHS England contract with Insignia);
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. 20%

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. 20%

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

FOUR: Analysis and Response:20%

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.

FIVE: Planned Intervention and Monitoring. 20%

1. Activation Intervention options developed and agreed (to feed into Year 2 planning). (A taxonomy of Activation Interventions is available.)
2. Identification of Intermediate Outcome and Final Outcome Measures, where available, to be used alongside the PAM score to monitor progress. Intermediate outcomes might include: adherence indicators, non-elective attendances/admissions. Final outcomes might include: patient reported health outcomes. (For some conditions, maintaining the score might be a good outcome – i.e. preventing deterioration.)
3. Establishment of information system to support monitoring (using patient identifiable information) and benchmarking (using pseudonymised data).

Second Year Triggers, (2017/18 for Existing Groups of patients)

ONE: Intervention. 50%%

Implementation of actions designed to improve activation or otherwise to respond to information about activation levels.

TWO: Measurement and Reporting.25%

Repeat applications of PAM, and of selected intermediate and final outcome measures.

THREE: Ambition-setting 25%

1. Agreement of ambition for improvement in PAM score and associated intermediate outcome measures to determine payment in Year Three (2018/19 for patient groups initiated in 2017/18), Covering as appropriate:
 - i. Improvement in PAM Score,
 - ii. Improvement in adherence and a reduction in non-elective attendances/admissions, or other intermediate health outcomes
 - iii. Aggregate improvement of patient reported health outcomes or in clinical health outcomes. (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.)

Third Year Triggers, (2018/19 for Existing groups of patients):

ONE: Measurement and Reporting.25%

Repeat applications of PAM, and of selected intermediate and final outcome measures.

<p>TWO: Performance 75% Patient outcomes measured as per Year two, trigger three.</p>	
<p>Definitions</p> <p>Denominator for SCALAR (for partial achievement): Number of patients in each of the targeted LTCs whom it is agreed at contract signature should be targeted for completion of the PAM. Numerator: Number actually completing the PAM in these groups creating usable data.</p> <p>The targeted number of patients should reflect the number who are expected to be willing to participate, i.e. excluding those who will refuse. Note that it is not recommended to post surveys; they should be administered in a clinical setting, so response rate should be higher.</p>	
<p>Partial Achievement Rules</p> <p>SCALAR: All Year One payments, and all measurement payments for Years Two and Three to be scaled down proportionately if less than 80% of patients targeted to complete the PAM, and to be monitored, do so.</p> <p>For Year Two, trigger one, payment proportional to the number of patients receiving the intervention promised.</p> <p>For Year Three, trigger two, payment proportional to performance against the metrics set.</p>	
<p>In year payment phasing and profiling</p> <p>Standard/</p>	
<p>Rationale for inclusion</p> <p>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.</p> <p>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.</p>	
<p>Data Sources, Frequency and responsibility for collection and reporting</p> <p>The NHS England Patient Centred Care team has obtained licences from Insignia. There is no further cost. Insignia will also provide training and support for implementation.</p> <p>The source of data for the Year One payment triggers will be the information available from the application of the PAM for specific patient groups.</p> <p>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.</p> <p>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.</p>	
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 <i>How will the change including any performance requirements be sustained once the CQUIN indicator has been retired?</i>	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 this².

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.

Support for devising interventions may be drawn the work of the Behavioural Change Centre at UCL. See

<https://www.ucl.ac.uk/behaviour-change-techniques/Resources/BCTTv1Publications>

² <http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health>

See also:

<http://www.behaviourchangewheel.com/>

which explains how to develop an intervention systematically, including choosing which behaviour change techniques from the taxonomy to include in an intervention.

EVIDENCE BASE:

The fundamental link between activation and outcomes is well substantiated³:

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 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.*

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,

³ 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.

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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.

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.