Appendix 1

Data Collection
At the time of the study, Islington CCG comprised 36 general practices, 34 of which agreed to participate in the PAM pilot collection. PAM questionnaires were sent out to patients twice, via a third party provider, first in November 2014 and then 12 months later, in November 2015.

PAM questionnaires were sent to all patients registered at the participating general practices, and who were aged 18 years or over and identified as having one or more of the following long-term conditions: acute mental health conditions (including schizophrenic disorders, bipolar affective disorder, psychosis, manic disorder), asthma, cancer (from 2003), chronic depression, chronic heart disease (including ischaemic heart disease and other current complications following acute myocardial infarction), chronic kidney disease (stage 3-5), chronic obstructive pulmonary disease (including all stage chronic obstructive pulmonary disease, emphysema, or other chronic obstructive airways disease), chronic liver disease, dementia, diabetes, heart failure, hypertension, stroke (or transient ischemic attack).

Patients were identified by their general practice team, which generated patient lists for each condition through searching the EMIS electronic health records using standard READ codes for long term conditions eligible for quality and outcomes framework.[1] Patients were not excluded from lists the basis of cognitive capacity or multi-morbidity. The lookback period available to the practice was the full period of patient registration, however the condition had to be listed as currently 'unresolved' for a patient to qualify for inclusion on the list.

For the second set of questionnaires, patient were re-identified using the search criteria so as to include patients who had been diagnosed with a long-term condition between November 2014 and November 2015, and to exclude patients who had died, deregistered or recovered in that period. Patients were asked to complete the questionnaires and return them using the pre-addressed and pre-paid envelope that was supplied, within six weeks. General practices were financially incentivised (£2.50 per patient) by Islington CCG to calculate PAM scores from the patient responses, and to upload the PAM score to the electronic medical record.[2]

Our dataset was processed by the clinical support unit, using the same QOF READ codes as described above and so patients were flagged as having an unresolved long term condition, as used in the general practice. Patients could have multiple long-term condition flags; though all conditions were active within the dataset.

Patient Activation Measure
'Patient activation' comprises individuals' knowledge, skills, and confidence in managing their health and healthcare [3]. The Patient Activation Measure (PAM), is a commercially licensed questionnaire has been developed to measure activation as part of clinical care[4]. The PAM questionnaire contains questions and statements associated with activation about beliefs, confidence in managing health-related tasks, and self-assessed knowledge about their own conditions, and their ability to discuss their condition with their clinical team. The score incorporates responses to thirteen statements about beliefs, confidence in managing health-related tasks, and self-assessed knowledge. Examples of such statements include - "I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself"; "I know what treatments are available for my health problems"; and "I am confident that I can tell a doctor my concerns, even when he or she does not ask."[5] Using the questionnaire patients rate the degree to which they agree with each statement. Results are weighted and a score calculated. The result is a scale score between 0 and 100 which places patients at an activation level between 1 (low) and 4 (high) [3].
Level 1: Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.

Level 2: Individuals may lack the knowledge and confidence to manage their health.
Level 3: Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.

Level 4: Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.[2]

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