

Population Name	Edinburgh and NHS Lothian
Population Size	897,059
Report for 12 months ending	September 2013
Number of practices in the population	125
Participating practices - number (%)	125
Total number of patients from participating practices	897,059
Total number of patients diagnosed with CPP	Does this mean over the course of the year? We're not sure how we would gather this info for our clinic as we don't record the number 'diagnosed with CPP'. Would giving the number of first assessments give a ball park figure (140-150)? Although obviously some patients are diagnosed with CPP before they attend the clinic for the first time.
% of total patients diagnosed with CPP:	% of what? Total number of gynae referrals? Lothian patients in total? Number of patient assessed by the clinic?
% of CPP patients for which the IPPS has been filled out by the GP	0%. This is not a part of the pelvic pain pathway GPs are asked to follow. Patients are asked to fill out a PDQ and PHQ-9.
% of CPP patients receiving a diagnosis in primary care	Again - difficult to answer. Our sense is that they refer on rather than give a diagnosis in primary care. Not sure how we would determine this.
% of urgent or semi-urgent patients referred within one month of presentation by their GP (urgent/semi urgent patients=severe undiagnosed or progressive pain with the risk of increasing functional impairment, generally of 6 months duration or less)	We act as a tertiary referral service. We only accept referrals from secondary care.
% of routine or regular patients referred with 8 weeks of presentation by their GP (routine=persistent long term pain without significant progression)	See above.
Number of referrals to secondary care including number of new patients in gynaecology/urology with CPP	Information not available.
Number of follow up CPP patients in gynaecology	Information not available.
% of CPP patients for whom an IPPS questionnaire was completed prior to attendance in gynaecology clinic	The IPPS questionnaire is not completed by the service however a similar measure developed for pre-screening patients prior to attending the pelvic pain clinic (PDQ and PHQ-9).
% of CPP patients for whom an IPPS questionnaire was completed prior to attendance in pelvic pain clinic	See above.
% of CPP patients for whom a multidisciplinary meetings was held	Is this a helpful outcome measure? Surely what is important is that key patients are discussed by MDT in relation to a relevant issue rather than all patients per se? Given the number of patients seen it would not be feasible to discuss each one. We hold an hour long MDT on alternate weeks.
Time from presentation to multidisciplinary meeting being held	Again we're not sure this is necessarily an indicator of a quality service? At present this is variable however following the introduction of new clinic setup 100% of patients will be discussed by the MDT following

	assessment.
% of CPP patients with a named co-ordinator of care	100%
% of CPP patients for whom patient outcomes are reviewed every 6 months	This is not routinely completed by the service at present on a time contingent basis. Regular reviews of patient outcomes are completed by the clinicians involved in their care.
% of CPP patients who report their pain is under control	Is this a valid outcome measure? Control has connotations of being pain free. We think % who report feeling confident they have methods to manage their pain would be a more valid measure. However, this is unknown for our service at present.
% of CPP patients satisfied with their care	A recent patient satisfaction audit carried out within the department reported that patients have high levels of satisfaction with the service provided by the team. In particular, the compassion of the staff was praised by respondents as well as the helpful nature of their work to increase patient understanding of pain. The multidisciplinary nature of the clinic was mentioned as a key benefit by many respondents. In addition, our service has been selected as a finalist in the 'Services to Women and Children Award' at the '2013 Scottish Health Awards' (in association with the Scottish Government and Daily Record).
% of CPP patients with high psychological distress in line with NICE CG 91 who have early access to CBT	Our thoughts - Could this be changed to a yes/ no question rather than %. Patient choice comes into it - may have high distress, be offered therapy but decline for various reasons. 100% patients have the potential to early access to CBT in keeping with a stepped model of care as specified in the NICE CG 91 guidance. Individuals presenting with mild depression are offered relevant self help materials and those with moderate to severe symptoms are offered individual therapy with a psychologist trained in CBT. (We also think it is a bit narrow as CBT is not the only therapy shown to be helpful for pain patients - Acceptance and Commitment Therapy and Interpersonal Therapy are also evidence based therapies however are not specified in the NICE guidelines so perhaps this is why they are not mentioned)
% of CPP patients receiving copies of referral letters	This is not routinely completed by service at present although is to be introduced shortly.
% of CPP patients give access to decision support tools easily accessible eg map of medicine wide range of search terms to access the map and visible to patients	We have a dedicated website for patients (and clinicians) - www.crh.ed.ac.uk/pelvicpain . 100% of patients have access as a link to the map of medicine pelvic pain pathway is given on the website of the service. All patients receive the pelvic pain website link.
% of CPP patients who report that the information they need is readily available	This information is not routinely collected by the service.
% of CPP patients informed about local buddying, peer support groups	Women with endometriosis are provided with information regarding Endometriosis UK and the local support group. There is no local support group for women with chronic pelvic pain with no diagnosis of endometriosis. Our patients are given links to the pelvic pain support network and other relevant resources.
% of CPP patients utilising local buddying, peer support groups	Unknown

% of CPP patients using self management resources	Unknown. We think the wording is important here, perhaps phrased as 'pain management strategies besides medical procedures/ operations'? We're not sure that the majority of patients are familiar with the term self-management.
% of CPP patients who find available self management resources to be useful	Unknown
% of CPP patients for whom patient experience is monitored	Patient satisfaction audit was completed for a subsample of attendees (see above).
% of local support groups or materials (i.e. shared decision aids, you tube videos, leaflets, etc.) which have had CPP patient/carer involvement in production and implementation	The Endometriosis UK support group co-ordinator is in regular contact with the service. We are currently developing the service website further with input from patients.
% of CPP patients using a diary	Unknown
% of CPP patients monitoring their pain: Dolotest, SF 12 online	Unknown
% of CPP patients who have taken charge of their own medical records	None- not offered by the service as an option at present
% of CPP patients for whom a Patient Activation Measure (PAM) has been completed - this should be noted in patient records	None - not used in the service.
% of CPP patients for whom a Patient Activation Measure (PAM) >8	None - not used in the service.
% of CPP patients who know about Map of Medicine	This is on the service website, link to website given regularly in clinic.
% of CPP patients who have accessed Map of Medicine	Unknown
% of gynaecologists in training that have completed RCOG training modules	Staff from team involved in medical student and other healthcare professional teaching. Healthcare prof pathway devised and available on website. It is not known how many gynaecologists in training have completed the RCOG training modules.
Number of research uncertainties uploaded to DUETS and flagged to NETSCC	Trial application submitted to EME chronic pain call.
Contact person	Andrew Horne
Contact email	andrew.horne@ed.ac.uk