Consultation exercise:

The consultation periods ran from 27th of October to 23rd of November 2017 and from 17th of July to 9th of October 2018. We would like to thank everyone from NHS and Third Sector organizations who took the time to respond to this consultation exercise. We appreciate the many insightful comments received that have helped us to develop and improve our Core Minimum Dataset (CMD) and Quality Performance Indicators (QPIs). The consultation responses have been analysed carefully and as a result of this consultation, changes have been made to the core minimum dataset and QPIs. We have attached the consultation tables with our responses to each comment received on the CMD and QPIs.

Attachment 1 – consultation table

Individual/Organisation	Comments	Response
Glasgow City Council	Dataset Are these the right questions? No – "Can you add a question about sleep and sleep quality? I find if my pain is bad then not getting enough sleep is a huge barrier to functioning properly and also tends to make my pain even worse."	Might be suitable for larger dataset, but not CMD
	How do you see yourself collecting it? Computer, paper, administered by clinician – "could the questions be adapted for a phone app and done by the patient and submitted that way?"	Will be collected to fit with local practice e.g. some clinics post out questionnaires in advance of appointments, other administer on the day of attendance. Worth considering for future, and discussing with eHealth now
	Which IT system (if any) would you use to collect this data? Other: google analytics or similar Explain: "most analytics packages attached to google or similar tools can create a dashboard or a series of pivot tables for a specific set of questions. Also gives exact numbers for amount of people using web and/or phone app. As long as the correct parameters at set then the data collected is very accurate."	This question was intended to refer to NHS systems
	Is there anything here that we do not need?	See above. This is only CMD at

	I think this is a really good minimum ask but as mentioned above – something about sleep quality is vital as lack of sleep has a huge effect on both your mood and pain level.	present
	QPIs Are the targets reasonable? QPI3 – Pharmacy Review Too high – "I personally, do not receive an annual review and I have suffered from chronic pain for over 20 years and have been on my current medication for about 10 years with no review!! So I suspect if there are not the resources to do these reviews then this target is way too high."	Thank you. This is why we need this QPI!
	QPI5 – Exercise and Exercise Therapies Too high – "This will vary greatly from one NHS area to another. A lot of the alternative therapies suggested by pain clinics are expensive, which often rules these out for a number of pain patients. Physio tends to be online access – again ruling out some pain patients. Need to be careful that options offered are not creating inequalities and it is just people who can afford to access alternatives are the only patients catered for. As far as I am concerned equal access to all has to be the only option under this indicator."	We are aiming this QPI as a minimum standard of a cheap, safe and effective intervention. We have not specified what exercise needs to consist of, and most people have access to some form of physical activity
	Are the specifications reasonable? QPI1 – Pain Education Too low – "Counting the number of people is fine as the very minimum – but surely there has to be a qualitative element incorporated? If not, How are you improving the Quality of Life of every chronic pain patient in Scotland? If you just count things you never improve quality of life."	This QPI is about providing information, rather than measuring QoL, which will be measured by CMD
	QPI4 – Service Evaluation and Audit About right – "This should not be about 'Doing things to Patients' but more about 'Doing things with Patients' – not everyone is the same and whilst it is fantastic that a multidisciplinary approach is the best way forward, it is really important to remember you are dealing with people and all anyone wants is a better quality of life."	Good point. We have changed the wording to "with patients"
	QPI5 – Exercise and Exercise Therapies Too low – "use the existing health inequalities information available about how accessing green space increase mental wellbeing by X% or that	This QPI is intended for clinicians, and will be accompanied by education (above)

	walking for 20 minutes a day can help reduce your pain by X% as well as make you feel happier. Have to make easier to understand why exercise and activity can improve quality of life and reduce pain levels. What is there is fine bur only if you are a clinician!! This section is really important and should not be underestimated as it is the area where the biggest difference can be made in terms of improving patient's quality of life. Signposting is OK but giving a reason why would be even better."	
	Any other comments? "I am not a clinician but my day job and passion is about addressing health inequalities around the impact of where you stay on your health and wellbeing. Place has the biggest impact on your health and wellbeing – everyone stays somewhere. I included the comments about doing things with patients because for the last 20+ years I have suffered with chronic pain and have felt that I am a number not a person and the NHS has done things to me. I think explaining why chronic pain has happened to you is really important. Also simple signposting to other activities doesn't work, especially leaflets and online physio – I have spoken to hundreds of pain patients over the years, who are fearful of doing physio this way because they might harm themselves or make the pain worse. Having chronic pain, especially just after diagnosis makes most people fearful of doing something that might make the pain worse. Ongoing face to face human contact is vital for pain patients – especially long-term. I personally only have contact with a pain clinician when I go once every 3-6 months for my treatment. I have no access to anyone else – I pay for all my physio, exercise, etc. I know that I am not the only person in this position and it is not ideal, especially when you have a really bad pain flare-up."	Thank you. This comment explains why we need the above QPIs.
NHS Greater Glasgow & Clyde	Dataset\n\nIs this dataset sufficient, as a bare minimum? Yes - But? duplicate functional question to separate into home/recreation and work impact as some patients still working and would be good to know specifically how much work related impact.	Good point, but maybe for larger dataset, not for CMD. Many patients are not working, so this would lead to redundant question
	Any other comments? It would be good for the outcomes of this to work	We use and have validated the CPG questionnaire extensively. It

	towards a grading for chronic pain – along the lines of the CPGS (Pain Volume 50, Issue 2, August 1992, Pages 133-149 Von Kroff et al,) I think this would help to stratify patient complexity and direct resources regionally and nationally; whatever is decided it would be useful to output a report with a grading summary for regional analysis.	includes 7 questions, and is thus not suitable for CMD, but maybe larger dataset
	QPIs Are the targets reasonable? QPI4 – Service Evaluation and Audit Expand this to capture return waiting times for medical, nurse, physio and psych clinics within each service and regionally – this is a big issue which is being worsened by the focus on new appointment times.	Good point. There are numerous complexities around capturing and interpreting data relating to return appointments. ISD are examining this at present, with a view to reporting soon
	Are the specifications reasonable? QPI1 – Pain Education Too low - Seems to be measuring passive availability of education as opposed to targeted education – I would have thought the latter would be better quality and more useful to patients. If only looking at the former then I think you will easily get target (via website and signposting) but will not capture any qualitative info on the uptake or utility of this info.	How would we specify targeted education, while also including Level 1 and 2 services? We hope to start low and work up from there, but this point is well made
	QPI2 – Outcome Measures About right - How will you ensure the denominator is accurate with regard to excluding stable patients?	Our view is that stable patients should still be reviewed/assessed regularly
	QPI3 – Pharmacy Review About right - Needs to be a specific pain med review and not ticked by general asthma/diabetic review.	Agreed – and recorded as such, or as part of polypharmacy review (including pain meds).
	QPI4 – Service Evaluation and Audit About right - A lot of this info will be static (WTE etc) so could review annually, or at points of service change or staff change.	Yes. Annual review would be the plan.
	QPI5 – Exercise and Exercise Therapies About right - Again, how passive is this info vs directed guidance and activity. Might get artificially high success rate from sign-posting only without a corresponding change in patient behaviour.	Again, start low, work up. This QPI aims to raise awareness, but it is right that exercise advice alone is not sufficient to effect changes
	What other areas might additional QPIs cover? Work impact and return waits as mentioned above.	See above
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable?	We are liaising with I.T. to assess the capacity of TRAK to embed the core dataset within this

	If not, do you have any other suggestions? No - Coded appointment/review focus (i.e. med review, education etc.) and national outcome data should be imbedded in compatible IT system and recorded continuously where possible to allow more frequent reporting and feedback to clinicians to encourage and highlight improvement, unless this type of measurement is built into the NHS the way QoF was for primary care it won't happen effectively – needs to be adopted as a core system in a manner that doesn't overburden – I think you need a coordinated IT system to record and pool the data. This might be difficult/costly to implement across secondary care without government pressure, but systems do exist from GP processes which helped to identify and target QoF criteria which might be adaptable to this dataset.	system. We are also working with ISD and Scottish Government, towards a data collection and management system to facilitate all of this, aiming, as this comment suggests, to maximise the use of routinely captured data.
	Any other comments? I think this is a good development, but needs to be built into clinical systems and time to work, it will fail as a process/results will be too patchy without this commitment. The rationale for education seems to have been drawn from back pain work and PMP delivered education which is more hands on that simple sign-posting. The education and physical exercise info might be best assessed by patient survey rather than service assessment as I suspect there are sufficient loopholes in the signposting of information for a service to achieve the indicator without actually impacting on the patient to the level you are seeking. Alternatively stratifying the level of education or exercise might allow you to analyse this better. Recording the access to this by the patient is also relevant – could they attend the session/is the info in a format appropriate to their needs/understanding – asylum groups and non-English speakers may be disadvantaged by one stop shop education processes.	Thanks, and agreed. Thanks. See above. Good point about the language of materials provided.
NHS Greater Glasgow & Clyde	Dataset How feasible is this dataset to collect? 5 - The Glasgow Pain Management Programme already measures all of these variables (with the exception of HRQoL) and in more detail than is proposed.	Good. This ensures compatibility with this existing service

	Is this dataset sufficient, as a bare minimum? No - If this was to be completed at the end of treatment, it should probably include the friends and family question (Would you recommend this service to friends and family?) as it can influence policy makers.	Worth thinking about, as a type of PROM, but maybe not as CMD for every visit.
	Are these the right questions? No - I'm unsure if an NRS that asks patients to reflect back on the past 6 months is that valid, it certainly isn't a standard measure. In the list of pain sites, I thought that differentiating between L and R limbs was unnecessary and using cervical, instead of neck, was potentially confusing, particularly if completed by patients. I also have a concern about the Underlying diagnosis question. I see that it is the proposed ICD-11 classification and that there are definitions, but there are some obvious problems with the definitions and the list. Firstly, it doesn't allow for multiple diagnoses (Respondents are asked to "tick the option that applies") and MSK and neuropathic pain often co-occur, e.g. back pain with radiating leg pain. Secondly, there's also no Central Pain diagnosis, and whilst that might be covered by a neuropathic pain diagnosis, this isn't helpful as most clinicians would want to discriminate between them. Thirdly, I'd also dispute that chronic neuropathic pain is always related to a lesion or disease of the somatosensory nervous system as this leaves out dysfunctions of the nervous system. Finally, Chronic Primary Pain is not a diagnostic term that many (clinicians or patients) would recognize and it has doubtful validity, particularly as it's the only diagnosis that mentions distress or disability. I think all of these concerns reflect the problems in diagnosis, more broadly.	NRS (6 months) is drawn from the CPG Including L and R limbs allows identification of symmetrical neuropathies, e.g. Diabetic. We intend for this question to be completed by clinicians Our view is that we need to be consistent with ICD-11, which has undergone rigorous development, and international testing, and is about to be formally launched. We have changed the question to allow more than one tick. This is THE definition of neuropathic pain – IASP, validated, and recently updated. Chronic Primary Pain is a new term in ICD-11, which is about to be launched and publicised
	How do you see yourself collecting it? Computer, paper, administered by clinician and patient completed - I've selected all as I think that there are two separate parts, some of which can only be answered by the patients (e.g. self-rated health QoL) and some by the clinician (e.g. diagnosis).	Thank you
	Which I.T. system (if any) would you use to collect this data? Bespoke database - We have a bespoke database that we use currently.	Thanks. We are also working with ISD and Scottish Government, towards a data collection and management system.

	Any other comments? I appreciate the tight physical space, but employment and marital status are important health variables at a population level, as is postcode (SMID), and they don't take up much space.	We are planning to include both of these variables (employment status and marital status) in the optimal dataset. These two variables don't have a direct influence on the outcomes and therefore may be more relevant for the research purposes. Thank you for your suggestion. We have now added postcode to the CMD.
	QPIs Are the targets reasonable? QPI1 – Pain Education About right - It doesn't specify that the target is 100%, although it does say each service should provide information.	Thank you. We have changed the target description to the following: 100 % Each service provides educational information about chronic pain.
	QPI2 – Outcome Measures Too low - Needs to be apparent that age, gender, diagnosis, etc don't need repeating and I would suggest that the target of 50% records 50% of the data at least twice is too low.	As a result of this exercise, the target for this QPI has been changed to the following: 1) 90% of patients have partially completed questionnaires. 2) 75% of patients have fully completed questionnaires.
	QPI4 – Service Evaluation and Audit Too low - I think that all patients should have access to a local (where geographically possible), group-based, psychology-led, rehabilitation programme (i.e. PMP) and that this should be a service standard.	Thank you for your comments. The provision of pain management programmes is a potential future QPI.
	QPI5 – Exercise and Exercise Therapies Too high - Some patients don't require advice and support to exercise so the target might be too high.	We disagree. Even those who are exercising need to have the benefits of these emphasised
	Are the specifications reasonable? QPI 2 – Outcome Measures About right - Although I think that it is both the numerator and the denominator that should	To be discussed Thank you. Our ultimate aim is to include all people whose chronic pain is managed in Level 2 services in the numerator. As we

	include the specification that this only applies to services at level 3 and 4.	work towards this, we will review this statement in the QPI
	QPI3 – Pharmacy Review About right - In the specifications list, isn't the second specification subsumed under the first?	We have changed it to the following: 1) 80% of patients using analgesics to manage chronic pain receive an annual review. 2) 90% of patients using strong opioids and gabapentinoids receive an annual review of their medications.
	QPI4 – Service Evaluation and Audit About right – Maraim Torkamani (trainee clinical psychologist) has developed a tool with which to audit pain management programmes, which was derived from the Faculty of Pain Medicine Standards. Perhaps some of this could be adopted.	Thank you. We have found this tool, and will look to adapt the relevant components for reporting on this QPI
	What other areas might additional QPIs cover? Provision of pain management programmes	Yes – agreed that all should have access to some form of PMP. This is not specified in the FPM Standards which we used in this QPI, but we have now added access to a multi-disciplinary QPI as an additional Key Standard
NHS Fife Pain Management Service	Dataset How feasible is this to collect? - It is unclear who is to complete the questionnaire. Some questions could be answered by the patients but others do not. I do not like the question about diagnosis as we are mostly in the realm of chronic pain as a medically unexplained symptom/central sensitization syndrome. There is no objectivity to the questions.	We would like the patient to complete questions 1-10 and the clinician to complete questions 11 and 12. Please see above. This diagnosis follows the new ICD-11 coding, which has been extensively and internationally tested and validated, and is about to be launched and publicised.

	Are these the right questions? No - Some questions are appropriate e.g. demographics and duration/site, but there is a general lack of objectivity when assessing impact and function. Rating scales give fairly meaningless data on pain intensity. I do not like the question about diagnosis.	See above. Diagnosis is based on the new ICD-11. Being consistent with this rigorously developed system allows comparison internationally. More detailed questions about impact, function and intensity would require more questions. These scales are all validated
	Is there anything here that we do not need? Question about underlying diagnosis is not relevant. It could be simplified to cancer pain or persistent non-cancer pain.	We disagree. A deeper understanding of presenting diagnoses allows identification of resource requirements. There is much greater complexity than simply cancer and non-cancer pain, and even the distinction between these is not absolute
	QPIs QPI4 – Service Evaluation and Audit Too high - Annual audit/ review represents a significant administrative burden for busy services trying to meet clinical targets. A 5 yearly rolling cycle is probably more realistic and achievable.	Our initial intention is to conduct a yearly evaluation, using as much routinely recorded data as possible. We consider that five years will be too great an interval if the first return showed under-provision. This QPI is intended to ensure adequate resourcing. We will review the frequency according to responses and perceived benefit.
	What other areas might QPIs cover? Is there a need to cover psychological therapies and pain management programmes?	Yes, with separate QPIs, in due course.
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions? Yes - But only if the self-reporting questionnaire is short and easy to complete so as not to add to the (already enormous) administrative burdens.	Agreed. We are developing this questionnaire.
Lothian Chronic Pain Service	Core Dataset How feasible is this dataset to collect? 4 - It is a fairly basic set that would be relatively easy to collect but it sometimes difficult to get	Agreed – so we need an embedded system, as discussed

	clinicians to fill these things in	above.
	Is this dataset sufficient as a bare minimum? Yes - As a bare minimum yes but 4 questions are just demographics and the other 5 are just collecting small snippets of information and so hard to say whether they will provide useful information.	We will evaluate the value and validity as we roll this out.
	Are these the right questions? No - Perhaps to a point – it may be useful to collect data on co-morbidity, previous drug use etc.	These will form part of the larger optimum dataset, though we would need standardised questions with standardised answers
	How do you see yourself collecting it? Computer, paper and patient completed It might need to be a mixture of all of the above. I can't see clinicians feeling inclined to regularly collect this data. One suggestion is to explore ways of getting clinician buy in – one thought might be to ensure clinicians can easily get data back regarding themselves and their patients which then can be used for their own revalidation, appraisal etc.	Thank you for your comments. We are currently liaising with eHealth and ISD to assess the capacity of clinical systems to collect the core minimum dataset.
	Which I.T. system (if any) would you use to collect this data? TRAK - TRAK would be best as it is (I think) nationally based. There will be no support locally for any other data collection unless funded centrally.	Note that TRAK is only used in 7/14 NHS Boards. We are discussing this with eHealth and ISD.
	Any other comments? This is an admirable project and I hope we can get something from it. It will need resourced otherwise I suspect that it will struggle. There are successful national projects such as the Scottish arthroplasty register – it might be worth looking at how they are funded and how they capture their data set.	Thank you for your suggestions.
	QPIs Are the targets reasonable? QPI1 – Pain Education About right - It is a basic service requirement that we routinely signpost patients to information regarding chronic pain and physical activity / exercise. One question raised was Are they reliable indicators of performance? Will this will discriminate between a service that excels and one that underperforms.	Thank you. We will start at a low level, but not currently aiming to compare services who reach beyond the QPI. We should consider this for the future, and also about how to raise minimum standards

	QPI2 – Outcome Measures About right - The challenge will be data collection.	Thank you. Agreed
	QPI3 – Pharmacy Review Too high - This makes perfect sense but this will require considerable resource to do. I don't believe we could do this for all patients in secondary care and I suspect that it will be difficult for primary care. I don't think that 90% compliance with this will ever happen in a clinically meaningful way.	Nonetheless medication review is essential for all patients. After careful consideration of all feedback provided we intend to retain the 90% target for now.
	QPI4 – Service Evaluation and Audit About right – I think that this could be achieved.	Thank you
	QPI5 – Exercise and Activity Therapies About right - I think that this is a reasonable aspiration.	Thank you
	Are the specifications reasonable? QPI1 – Pain Education About right - I think that this could be achieved on some form.	Thank you
	QPI2 – Outcome Measures This will be the most challenging part of the project and will need to get quite a lot of buy in.	Agreed
	QPI3 – Pharmacy Review Too high - A very ambitious target - who will ensure a patient will receive annual analgesic review with the responsibility seemingly divided between 1° and 2° care?	The responsibility will lie with the prescriber – i.e. primary care. This is already part of routine primary care provision, though the extent of the review is variable
	QPI4 – Service Evaluation and Audit About right - It is based on good quality standards and therefore very reasonable - What happens if a service falls below a particular standard in a particular domain?	Thank you. If this happens, the QPI would not have been met. It is likely that this would indicate insufficient resourcing, and an opportunity to address this will have been presented. It remains to be determined how this will be reviewed at national level.
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions? No - I think it depends a lot on how data is collected. If it is embedded in TRAK it may be possible to pull data remotely	Some information will be difficult to collect by TRAK, but we will aim for maximum collection through routine means
Lothian Pain Service	Dataset	We are aiming for this as the minimum, then to provide a

	This exercise seems to sit uncomfortably between two competing and opposite pressures 1. The limitless number of measurable variables concerning pain, mood and function, because no two patients are the same 2. The need to minimise the work of gathering, uploading, storing, retrieving and analysing data Big data is needed to satisfy the first point, to find important correlations in outcome. But here the core dataset uses tiny fragments of questionnaires to satisfy the second point.	larger optimum dataset. Use of ICD-11 consistent codes and Read codes will allow data linkage with routine datasets
	There are ten measures, five of which are demographic data (age, site, diagnosis etc.). So there are only five questions that tackle outcomes which can change after pain service intervention. This dataset is so small that outcomes could reflect random variation, or resolution to the mean, rather than anything a pain service had achieved	One of our current projects aims is to validate the CMD against the standard measures that are currently used in three different NHS Boards. This exercise will help us to test the validity, reliability and sensitivity to change of the CMD.
	Also some explanation might be needed as to why particular outcome questions were chosen. Is it a coincidence that three of those five questions belong to a committee member's questionnaire? I understand the desire to avoid the cost of publication rights, but that seems to be at the cost of appearing to create a conflict of interest	This is available in the Full Report (Richardson, C., Laskawska, M., Berlouis, K., Cameron, P., Colvin, L., & Smith B. H. (2017). Executive summary. Data and Measurement for Chronic Pain Services. A Project to Inform National Pain Service improvement, 1-36). No questions "belong" to anybody. Members of the group have been involved in validating outcome measures that others have developed, but have not originated any of those included here. We do not perceive a conflict of interest. All questionnaire items are validated, or part of larger validated measures. Core minimum dataset (CMD) is

			based on:
			1.Validated questionnaires 2.Best available evidence 3.Balancing the need for detail with the need for feasibility of collection 4. Other issues such as licensing costs and burden of administration were also taken into consideration when developing this dataset.
		We have faced barriers to data collection since the year dot: negligible clinician time (and inclination?) to fill in and analyse the data. I think clinician buy in is needed, but what will we get in return for our labours? Who will ensure a second dataset is collected and when?	Agreed – we will aim to embed the CMD in routine care and systems as much as possible.
		I know that some or all of these documents are at draft stage but the outcome data collection targets are nonsensical. Who is going to measure record targets and calculate whether they are the quoted 90% vs 50 vs% 75% vs 100%? Who will act if a service falls below the targets? Why does that target have an 18 month window when second outcomes are supposed to be recorded between 6 weeks and a year? What use is 50% of data in 50% of patients?	Our intention with this consultation exercise is to seek views on what these targets should be, with a view to amending them in light of suggestions. This comment does not provide such a suggestions. As a result of the consultation exercise, the target for the QPI 2 has been changed to the following: 1) 90% of patients have partially completed questionnaires. 2) 75% of patients have fully completed questionnaires.
		QPIs 1. Who will ensure a patient will receive annual analgesic review with the responsibility seemingly divided between 1° and 2° care?	Responsibility lies with the prescriber – primary care, though secondary care can advise (and be consulted)
		2. Who will carry out service audit and evaluation? Where does that information go? What happens if a service falls below a particular standard in a particular domain?	Please see above

	3. Exercise and Activity Therapies ... how do we 'support' 90% of patients in their proposed exercise programme?	There are many approaches to this, including education, physio, classes, gym referrals. This QPI should be about providing advice, and signposting as appropriate. Thank you for pointing out this inconsistency between the Title/Description and the Standard. We have removed "support" from the Target. As we progress, we might expect to increase the standards in this QPI to include support.
Completed on behalf of ScotPHN	Dataset How feasible is this dataset to collect? ScotPHN is not answering this question as we would not be directly involved in collecting them. However from the 2014 HIS 'where are we now' report, one of the feedback points was around patients already having several questionnaires to complete, and being asked for the same data multiple times. Is it possible to work this into systems already in use? It would also be beneficial to provide assurance that the results would be fed back to the service, and have mechanisms in place that would ensure these reports were sent annually to the services.	We are currently liaising with eHealth to assess the capacity of TRAK to collect this data. We agree that robust and effective mechanisms are required to feed back the results and respond to them. We will develop these with DCMO and NACCP
	Is this dataset sufficient as a bare minimum? No - We would advise including patient's postcode to enable to see the data by SIMD. This would enable you to be able to see how service provision varies by deprivation. Add in 'date of completion' so that you can compare start of treatment with after treatment. Which services would the questionnaire be asked in? If only secondary care, would it be helpful to ask if they had already self-management tools?	Thank you - We have added this in. Good point. We have added this in. Ultimately, we would like the CMD to form part of Level 2 services. To begin with, it will only be collected in Levels 3 and 4. It is difficult to see how this question can be asked meaningfully
	Are these the right questions? No - Examining the questionnaire there are some questions phrased as if the patient answering, but	We would like the patient to complete questions 1-10 and the clinician to complete questions

	others that might be unclear for the patient, i.e. 8&9 –patients might not have sufficient medical vocabulary to answer these, i.e. thoracic. If they were completed by clinicians, much of the data they would already have, but questions 4-7 might be asked in rather different ways during their consultations, meaning they'd have to ask these in addition, and could result in providing the best guess based on the consultation, for these answers.	11 and 12. This will be clarified.
	I was unclear in the ordering of the pain sites, is this in line with what clinicians usually use, otherwise perhaps there is a more intuitive order i.e. going from the head down?	Fair point. We have changed this.
	What I.T. system (if any) would you use to collect this data? Would be worth consulting with eHealth services about how best it would be for them to pull this data to pass onto ISD /whomever is going to compile the data and do cross-board comparisons. As a basic requirement, the data needs to be collected in a way which allows it to be merged into a national core dataset.	Agreed. We are discussing this with eHealth and ISD. We agree that it must be compatible with existing datasets. Please also see above responses.
	Any other comments? If this is going to be collected as a self-completion survey, it will need to be checked for patient readability? Question 9 in particular will be lost on the majority of people, but others may also require significant reading and comprehension skills.	See above
	QPIs Are the targets reasonable? QPI1 – Pain Education About right - The description was good, but might not be captured in the specification. It may be that it needs to be more specific, i.e. the number of services (and levels) providing information on self-management tools and/or education sessions. This QPI presumes that we know what type of patient information/education is appropriate for the differing levels of service. Have these been agreed?	Thank you. No, we haven't agreed on standard educational materials. At this stage, we just need there to be something rather than nothing
	QPI2 – Outcome Measures Not sure what target services at the differing levels would find realistic.	The feedback obtained from this exercise is being used to refine the specifications and targets for the QPIs.
	QPI3 – Pharmacy Review	This should be feasible, in

	About right - Sounds valuable. However, it will be difficult to ensure that patients had an appointment ~6wks after starting a new treatment to see if it had been effective?	primary care (where most new treatments are initiated), pharmacy and/or by telephone review
	QPI4 – Service Evaluation and Audit It is likely that there will be initial challenges with the definition of a service having at least two consultants – this could be particularly difficult for rural areas and could result in access issues. Would support be available to assist with telehealth opportunities for smaller services to join up? Are there sufficiently trained consultants to fulfil the 'two consultants who have achieve competencies and experience in advanced pain medicine', if not do extra courses/other support need to be put in place to help build up the workforce? Would be worth linking in with the Faculty of Pain Medicine to ensure this is possible. It would be helpful to have data on the number of people who have contacted the third sector for assistance, i.e. the Pain Association.	These criteria come from FPM. One reason for setting this QPI is to identify areas that are unable to meet these minimum standards, with a view to rectifying this. There is a parallel piece of work going on nationally to examine workforce needs for managing pain.
	QPI5 – Exercise and Exercise Therapies About right - As mentioned in the rationale, the provision of information about exercising is not sufficient, there is also likely to be inequality in relation to accessing activity sessions. The target mentions both information and support, the emphasis should be put in place in relation to supporting people into exercise, and could also monitor how many are doing/take up exercise.	As above, we have removed "support" from the Target, though will work towards introducing this in the future. We believe that both of these elements are important in improving patients' outcomes. However, it would not be feasible to measure how many people are engaging in exercise at present. Instead we are planning to measure the total number of new patients with chronic pain that were offered information and signposting to increase or maintain their physical activity and exercise.
	Are these specifications reasonable? QPI2 – Outcome Measures How would you know who declined to complete relevant measures? There isn't a 'not answering' option for most of the questions. In terms of primary care, to be able to answer the	Patients who decline will still have elements of the CMD collected through their routine data. This will provide an indication of those who did not complete the full questionnaire.

	questions they may have to make chronic pain patient registers, possibly based on prescriptions patients received, the definition of these should be clear, so that there can be consistency between practices – perhaps linked with categories for the pharmacy review.	Good point. We are working on this with SPIRE
	QPI3 – Pharmacy Review About right - Please clarify - there seems a disparity between the 'daily morphine equivalent doses of 50mg or above' in the rational and the '>180mg/day' mentioned in the target?	We have reviewed this and updated the figure in the rationale (which is a national statistic, rather than a recommendation), while noting that the '>180mg/day' figure is also currently under review (by SIGN).
	QPI4 – Service Evaluation and Audit Suggest adding the date when the patient entered the pain service and the postcode for SIMD.	Yes, agreed. Both of these variables have now been added.
	What other areas might additional QPIs cover? Use of level 1 (supporting self-management) services – if not covered by QPI 4	This will be a challenging QPI to develop, but we will consider it.
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions? Yes - Though this would need to take into account the comments made above about the reading and comprehension levels needed for survey completion.	Thank you. See above.
NHS Greater Glasgow & Clyde Pain Management Service	Dataset How feasible is this dataset to collect? 3 - There are 2 factors within the feasibility- collection and collation. If the dataset is only patient self-report it is feasible. However it becomes less feasible depending on questions related to clinician's input (8&9). Collation will not be possible without additional funding to assist with data input and analysis. Within GGC this is not something we could take on without central assistance.	Thank you. We note this, and will aim for a system that is embedded within routine care
	How sufficient is this dataset, as a bare minimum? No - GGC felt it would be appropriate to also collect- postcode, marital status and employment	We are planning to include both of these variables (employment status and marital status) in the

	status.	optimal dataset, but consider that they are less essential for the core dataset, as their influence on outcomes is less direct than other factors. We have added postcode to the CMD.
	Are these the right questions? No - Some additional questions required as above and see below for questions not required.	See above
	Which I.T. system (if any) would you use to collect this data? TRAK, Bespoke Database and Other: Paper - Clarity required around patient self-report only or clinician to complete? Questions 8 & 9 require clinician's input. Unsure about database and how the data would be collected and subsequently collated.	Thanks. We are working on this We would like the patient to complete questions 1-10 and the clinician to complete questions 11 and 12 (formerly 8 and 9).
	Is there anything here that we do not need? Pain site- possibly too many options? Fewer categories for pain duration- overlapping years Pain severity- is this required? Time over 6 months is too broad and unsure if relevant.	We have changed the structure of this question. However, we have decided to keep all of the pain sites, knowing this is important in improving our understanding of the prevalence of the individual types of pain diagnosis in adults in Scotland. We have changed these categories to reflect the feedback. Pain severity is a core indicator of health and response. This question is drawn from a validated questionnaire (CGP). We need to balance a duration that is meaningful in terms of chronicity with one that is meaningful in terms of recency. We consider that 3 months achieves this.
	Any other comments? Mixture of self-report and requiring clinician's input.	Yes
	Question 5- This is a screening measure and the group felt that	We need to consider the governance issue. But this type

	there would be a governance issue around this (ie identify someone is down depressed and hopeless but then not acting on that information) in terms of alerting GP and referring to crisis service etc. The group also felt it was a good question.	of question should be routine in any pain assessment, so the issue will face any assessing clinician
	Question 6 Good to have a functional measure but felt 6 months was too broad and perhaps 4-6 weeks would be more relevant?	This question is drawn from the validated questionnaire (CPG). Please see above. We have changed this to 3 months, which keeps it within a validated version of the CPG.
	Question 7- Health-Related Quality of Life Is this general health or pain health? The group question was also around can we influence general health and it was felt the question was open to interpretation.	This is general health, and is one of the core IMMPACT outcomes. Patients are free to interpret as they wish, but their QoL is what is important
	QPIs Are the targets reasonable? QPI2 - Outcome Measures Unsure- targets unclear and require further clarification.	As a result of this exercise the target for the QPI 2 have been changed to the following: 1. 90% of patients have partially completed questionnaires. 2. 75% of patients have fully completed questionnaires.
	QPI3 – Pharmacy Review About right - We would expect most the regular pharmacy reviews to take place in primary care. Secondary care would not always offer an annual pharmacy review depending on the patient's treatment plan.	Agreed.
	Are the specifications reasonable? QPI4 – Service Evaluation and Audit About right - GGC staffing with the exception of occupational therapist within the secondary pain setting. Currently not meeting 18 week standard but working towards this. Diagnosis and treatment coding- do not agree with this classification- review group felt categories were unclear with some omissions and overlap. Post-traumatic pain was misleading. Often patients may fit into a few categories. Also some categories missing eg SSD, etc.	Thank you QPIs should allow these things to be identified and then resourced! Please see above. We are using new ICD-11 codes, and would not like to deviate. We have amended the questionnaire to

		allow more than one diagnosis to be selected
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions? Unsure further clarification required around the collation and self-report versus clinician's completion.	See above
	Any other comments? NHSGGC chronic pain MCN are nearing final completion of our own Standards within the Pain Management Service. Many of the suggestions are included within our own Standards document.	Thank you. It is good to be compatible with existing systems and datasets
NHS Ayrshire and Arran Pain Management Team	Dataset How feasible is this dataset to collect? 5 - We currently collect more data in form of a pre clinic questionnaire which patient return prior to their first appointment. Our questionnaires could be altered to mirror this dataset for collection. Questionnaire paperwork and current database would need to be altered.	Thank you
	Is this dataset sufficient as a bare minimum? Yes - Dataset covers main demographics and impact factors	Thank you
	Are these the right questions? Yes – A good starting point.	Thank you. That is our intention
	How do you see yourself collecting it? Paper and patient completed - we would send as a pre-clinic questionnaire for patients to complete and this data would be uploaded to a database by admin staff as per current practice.	Thank you
	Which I.T. system (if any) would you use to collect this data? Bespoke database – current database system.	Thank you. We are discussing this with eHealth and ISD.
	Any other comments? We also currently ask about expectations to the service and also information regarding work status, physical activity and healthcare utilization. From a psychological perspective, the 'emotional impact' measure is very limited to depressive symptoms on both items. There's nothing that would reflect intervention to improve acceptance of persistent pain or increase self-efficacy. Also doesn't specify distress related to pain, so on its	Thank you these are good points. We will address these in our larger optimum dataset.

	own could easily be contaminated where long-standing mental health history.	
	QPIs

Are the targets reasonable?

QPI1 - Pain Education
About right - we feel we should be offering pain education at all levels of the service model. This also helps support our business case for increased nursing sessions to support pain education. | Agreed. That is why we include it here. |
| | QPI2 – Outcome Measures
About right - We currently collect larger questionnaires on these areas which can be time consuming and not completed by individuals. This would hopefully allow easier completion by patients and not time consuming if needed to be completed in clinic. | Thank you |
| | QPI3 – Pharmacy Review
About right - We are currently unsure how we would collect this data. We have limited pharmacy support in the service and unsure if this data could be yielded in primary care. Would need to be further explored. Pharmacy provision in pain management service is currently under discussions. | Thank you. We hope this QPI will support these discussions and subsequent resourcing |
| | QPI4 – Service Evaluation and Audit
About right - We currently would not comply with the minimum standards as do not have OT and formal links with other services such as psychiatry but this would also support developments we would wish to look at in the future. | Thank you. This is why we are setting this QPI |
| | QPI5 – Exercise and Activity Therapies
About right - It may be difficult to report on community sessions but links with MSK services would support this. | Thank you |
| | We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions?
Yes - This previously worked well with data collection snapshots and could be submitted annually but working group locally would need to be established. | Thank you |
| NHS Borders | Are these the right questions?
No - Is there a definition of primary pain? | We have amended this and the definition has been added to the new CMD from. |
| | No question about work/employment status | All of these questions will be |

	Any merit in asking about health economics questions e.g. number of GP visits, number of pain clinic referrals	considered for the optimum dataset.
	QPIs Are these targets reasonable? QPI2 – Outcome Measures Too high - Patients often fail to attend/engage at follow up	Others have suggested this was too low and as a result of this consultation exercise, the target for this QPI has been changed to the following: 1) 90% of patients have partially completed questionnaires. 2) 75% of patients have fully completed questionnaires.
	QPI3 – Pharmacy Review About right - Ought to be prescriber as it is their responsibility. GP is most often the prescriber	Agreed
	QPI4 – Service Evaluation and Audit About right - Need to define 'effectiveness' in chronic pain. What is often effective for the patient is not an black and white/binary response	Our intention is that the specifications set out in this QPI will contribute to the assessment of 'effectiveness'
	QPI5 – Exercise and Activity Therapies About right - Does this apply to paraplegics and tetraplegics?	Thank you. Yes, this information should be available to all patients. This QPI does not specify what information and advice is to be available. Clinical experience and skill will determine the nature/extent of activity that can be individually recommended.
	Are the specifications reasonable? QPI3 – Pharmacy Review About right - Think this is a good target but is it achievable? What are the incentives for primary care?	Thank you. We will discuss targets, but really it should be 100%. The main incentive for primary care is long-term reduction in health service use, as well as the wellbeing of their patients. Review of repeat prescriptions already forms a routine part of primary care practice.
	QPI4 – Service Evaluation and Audit Too low - Further specification on self-management would be helpful	We have now added this in. Please see below: Information about managing pain

		may take the format of: - verbal advice - signposting and referring to relevant services - or both. Patients should be provided with information about: - Types of pain - Coping mechanisms - Dealing with sleep and anxiety - Origins of pain.
NHS Borders Community Pharmacy Network	QPIs Are the targets reasonable? QPI2 – Outcome Measures Too high - These outcome measures may result in the clinician dictating the consultation content and not providing patient centred care.	We do need to be aware of this. The opposite may also happen – through self-completion of the questionnaire, the patient may recognize issues that she had not previously been aware of. They might also stimulate a wider review, and/or be part of pharmacy review.
	QPI3 – Pharmacy Review Too low - The outcome measure is too vague. Need a clear description of appropriate HCP what review entails i.e. is review face to face.	We have amended this. The document contains information relating to: a) what should be included in the review and b) what the review entails
	QPI5 – Exercise and Activity Therapies Too high - If this action is done according to guidance, it seems like a large piece of work and it is not clear who does it presently or who will do it.	Others considered it too low. Importantly, we are not specifying the type of exercise/activity, but need to emphasise the need for support
	Are the specifications reasonable? QPI1 – Pain Education Too high - The QPI is too vague. Need a clear definition of what 'NHS Services' means. Does that include community pharmacy? In NHS Borders all community pharmacies have received training in provision of pain education and resources have been provided.	Thank you. We have added text to clarify that this refers to any service in L1-4 under the aegis of NHS; including community pharmacies

	QPI3 – Pharmacy Review About right - Specification not consistent. Is there a difference between annual review and annual review of their medication?	There is no difference – we have changed our specifications and target to make it clearer.
	QPI4 – Service Evaluation and Audit Too low - Rationale lists 'access to dedicated pharmacy input' but pharmacists are not included in the staffing standards.	Thank you for pointing out this inconsistency. We have added pharmacists, as suggested
	QPI5 – Exercise and Activity Therapies Too low – needs clarity	We have amended the description for this QPI (specifically we have added the definition of exercise and physical activity). However, we cannot make specific recommendation as specific exercise will depend on individual needs)
	What other areas might additional QPIs cover? Referral to Pain Association Scotland Training of Support Staff	Referral to PAS may be guided by local agreements, but is not part of a national QPI. It is unclear which Support Staff this comment refers to. Please note that a national exercise is currently underway to identify the needs and availability of specialist workforce and training.
NHS Dumfries and Galloway	Core Dataset Is this dataset sufficient, as a bare minimum? Yes - It seems to be the right balance between ease/difficulty of collecting data and too much/too little information	Thank you
	Are these the right questions? Yes - Easily administrable and includes questions on impact of pain	Thank you
	How do you see yourself collecting it? Computer - Directly filled by patient on a computer/tablet or collected on paper and transferred by admin staff	Thank you
	QPIs Are the specifications reasonable? QPI4 – Service Evaluation and Audit About right – recruitment and retention of staff are challenges	Thank you. These are intended to assist with the identification of resource needs, but we agree this is a challenge
	Any other comments?	Thank you

	Good start to make improvements in Chronic Pain Services	
Lothian Chronic Pain Service	Questions that we feel we need clarity on..... What is the purpose of the dataset?	The purpose of the dataset is to provide a standard set of measures that can be used across Scotland, to allow for a more accurate "picture" of chronic pain nationally. This, and answers to some subsequent questions, is explained fully in the Report that accompanies the CMD and QPIs (please see Appendix C). Richardson, C., Laskawska, M., Berlouis, K., Cameron, P., Colvin, L., & Smith B. H. (2017). Executive summary. Data and Measurement for Chronic Pain Services. A Project to Inform National Pain Service improvement, 1-36.
	What is it designed to provide? What is the "question"?	The data will be used by individual pain services to audit their service and plan patient care and NHS boards/Scottish Government for funding service delivery (Please find attached our summary, (Appendix C)).
	Can we have clarity on who will use the data? Ie is this a fact finding mission for Scottish Government to allow them to scope demographic to allow for funding to follow service delivery?	The data will be used by individual pain services to audit their service and plan patient care and NHS boards/Scottish Government for funding service delivery (Please find attached our report, (Appendix C)).
	Is this a performance Outcome or population and symptom demographic?	The dataset is a mixture of performance outcome and population and symptom demographics (Please find attached our summary report, (Appendix C)).
	Will this be an ongoing data gathering form or will it be a snap shot?	This will be an ongoing data gathering form.

	Who completes dataset patient or therapist?	The patient can complete questions 1-10 and the clinician should complete questions 11 and 12.
	Core Dataset Feedback on content of the questions contained in the Dataset.... 1. Nil 2. Nil	
	3. Pain duration – ambiguity between options i.e. <3, 3-6 months then 6-12 (we would suggest 7-11, 1-3, 4-6,etc)	Thank you. We have amended in order to make it look less ambiguous.
	4. Pain Severity final sentence inn descriptor is confusing = is it necessary?	We have changed it to the following: In the past three months, on average, how intense was your pain rated on a 0-10 grade scale where 0 is "no pain" and 10 is "pain as bad as it could be".
	5.?negatively framed question = bias??	These are validated questions, and would lose validity if we were to change them
	6. Functional impact – inconsistent guidance = scoring 1-10 in text and 0-10 in boxes.	We have amended this.
	7. Health related QoL – we think this will be scored consistently low by patients with Chronic pain therefore? The use of this question?	This is validated in the context of chronic pain. It is usually low, but also sensitive to change. (Torrance et al., 2014) Reference: Torrance, N., Lawson, K. D., Afolabi, E., Bennett, M. I., Serpell, M. G., Dunn, K. M., & Smith, B. H. (2014). Estimating the burden of disease in chronic pain with and without neuropathic characteristics: Does the choice between the EQ-5D and SF-6D matter? *Pain, 155*(10), 1996-2004.
	8. Pain site could be laid out in a "top to toe" format – could it not have proximal and distal UL and LL as an option – why buttocks? (a)We cannot reason why you need peripheral "GHJ"– no other	Agreed – We have amended this.

	peripheral joints listed (b) mixed spinal terms Cx, Thx, Upper back, Lower back??	
	9. Clarity between Chronic Primary Pain and Chronic MSk Pain?	We have amended this and the definitions of the ICD-11 terms have been added.
	QPI's 1. Nil 2.QPI 2 : repetition of Questionnaires pre and post = is the dataset designed as an outcome measure = we don't think that a dual purpose works! 3.confusing how this dataset will achieve this aim – if that is the aim?? + TARGET %'s were confusing to team = we didn't understand = requires clarity.	The CMD will be used as an outcome measure to assist HCP's in assessing patient's progress. We aim to conduct an exercise to test the validity and reliability of the CMD, in comparison with existing measures of known validity. Some elements are known to be sensitive to change (please see previous response). However, we are happy to consider evidence to the contrary. It is difficult to interpret this comment fully. As a result of the consultation exercise, the target for this QPI has been changed to the following: 1)90% of patients have partially completed questionnaires. 2)75% of patients have fully completed questionnaires.
	I hope this will be considered as useful feedback – the basic understanding of what the project aims to achieve is not clearly set out, we find the information very mixed – bottom line is we need clarity on the basic aim of the project and dataset.	This is a fair comment. We should have provided this information more clearly, and apologise. Please see appendix C for more information. Richardson, C., Laskawska, M., Berlouis, K., Cameron, P., Colvin, L., & Smith B. H. (2017). Executive summary. Data and Measurement for Chronic Pain Services. A Project to Inform National Pain Service improvement, 1-36.

Lothian Pain Management Programme	Dataset	
	How feasible is this dataset to collect? 1 - We already collect data via Trak. It would be very difficult to justify asking our patients to complete extra measures as well as taking up clinical and admin time to score and input extra measures. We have spent a lot of time rationalizing our dataset and we will have means of extracting this data via Trak. What makes most sense is for Boards to do this rather than asking for extra data to be collected.	We would expect support for this as the CMD across Scotland. If you are collecting this information already, we should explore methods of extracting this automatically. We are working on this nationally with ISD.
	Is this dataset sufficient, as a bare minimum? No - The PHQ questions have no validity in the form they are presented.	We have used the PHQ-2 in this core dataset which is a valid measure (Kroenke, Spitzel & Williams, 2003). Reference: Kroenke, K., Spitzer, R. L., & Williams, J. B. W., 2003. The Patient Health Questionnaire-2: Validity of a Two-Item Depression Screener. *Medical Care, 41*(11), 1284-1292.
	Are these the right questions? No - The measures suggested are very global and it is unclear what they are measuring. The idea to have measures that can be used throughout the pain pathway is meritable, but in practice not workable and does not really give any meaningful outcomes.	The current questions aim to assess the following domains • **pain severity** • **emotional impact** • **functional impact** • **health - related quality of life**. One of our current projects aims is to validate the CMD against the standard measures that are currently used in three different NHS Boards. This exercise will help us to test the validity, reliability and sensitivity to change of the CMD.
	How do you see yourself collecting it? Please select any/all that apply. We would not be able to collect this as we already have our data systems in place. We would suggest sending you the data we have rather than asking for more.	Please see above comments

	Is there anything here that we do not need? We would suggest using the mean scores from the BPI in terms of pain severity and interference rather than the other pain severity and functional impact measure. We are not sure that the HRQOL score will give you anything useful. In terms of the emotional impact question – we would suggest using a summary score of anxiety and depression and use a measure that has some validity in LTC and medical settings such as the HADS.	Suggested outcome measures from this consultation response include: BPI, HADS or PHQ and GAD, WASAS and TSK. • Both the BPI and HADS have licensing costs. For clinical practice the BPI would cost $100 per clinician. • The PHQ has no licensing costs and we have included the PHQ-2 in the core dataset PHQ-9 in the optimum dataset. • The GAD is in the larger optimum dataset and has no licensing costs attached. • The WSAS is in the optimum dataset and has no licensing costs. • The TSK is not in the core or optimum dataset and has no licensing costs. We do not currently have a section on patient beliefs but this could be included as part of the optimum dataset.
	Any other comments? We discussed this with our pain management team. Our team were not sure what you were trying to measure with this data set i.e. what is the question you are wanting to answer? We were not sure if it was performance/clinical outcome or population and symptom demographic. What will the data be used for? This will guide in what form the data is in, and what amount of data is needed. It is important if you are wanting clinical outcomes to use measures that are validated but also that will show change and are sensitive to change. Our concern with the proposed dataset is that this will not be the case as the measures are quite global and would not be sensitive to the change you would be looking for. We would also find it useful to know whether the	See above responses. We will need a standardised dataset across Scotland, and aim to collect this in an embedded way, consistent with routine systems, and avoiding duplication. If LPMP can work with us to meet this aim, it would be helpful in allowing them to be compared with other services nationally. Please see above comments. Answers to some of these questions are available in the Full Report, which will accompany the next iteration

	data will be collected as a snapshot periodically or whether it is meant to be continuous. We have our own data gathering and analysis work stream in our service and so can supply summary scores etc. but it is not feasible to be sending all of our data plus extra data on an ongoing basis.	
	Specific feedback from physios on the questions as follows: Feedback on content of the questions contained in the Dataset.... 1. Nil 2. Nil 3. Pain duration – ambiguity between options ie<3, 3-6 months then 6-12 (we would suggest 7-11, 1-3, 4-6,etc) 3. Pain Severity final sentence inn descriptor is confusing = is it necessary? 4. ?negatively framed question = bias?? 5. Functional impact – inconsistent guidance = scoring 1-10 in text and 0-10 in boxes. 6. Health related QoL – we think this will be scored consistently low by patients with Chronic pain therefore? The use of this question? 7. Pain site could be laid out in a "top to toe" format – could it not have proximal and distal UL and LL as an option – why buttocks? (a)We cannot reason why you need peripheral "GHJ"– no other peripheral joints listed (b) mixed spinal terms Cx, Thx, Upper back, Lower back?? 8. Clarity between Chronic Primary Pain and	Agreed. We have amended this. We have amended this. It is a validated question. We have Amended this This is validated in the context of chronic pain. It is usually low, but also sensitive to change. (Torrance et al., 2014) Torrance, N., Lawson, K. D., Afolabi, E., Bennett, M. I., Serpell, M. G., Dunn, K. M., & Smith, B. H. (2014). Estimating the burden of disease in chronic pain with and without neuropathic characteristics: Does the choice between the EQ-5D and SF-6D matter? *Pain, 155*(10), 1996-2004. We have amended this

	Chronic MSk Pain?	We have added this in and amended the descriptions.
	In summary if you are asking for demographic data and information about pain duration etc., could this not be requested via Trak quarterly as is done currently with waiting times figures. This would mean there would not be a burden on clinicians or patients.	Yes – that, or another means of harvesting routine data, is the idea, as far as possible
	If you are looking for outcome data, it would make more sense to be clear about what you are looking for specifically from services as per the different tiers of the Scottish Service Model. Our suggestion would be for services offering pain management programmes to submit more comprehensive data if you are trying to benchmark services. Leads of PMP's have already endorsed data sets but I am sure could meet again and agree on a reduced data set. By having very global questions which you have in the minimum data set, you will not get the detail that you would need should you benchmark. We would suggest all services offering PMP's use the BPI and a mood measure such as HADS or PHQ and GAD (both anxiety and depression). On Trak we collect the summary anxiety and depression scores and combined total on the HADS and the mean pain severity and mean pain interference score on the BPI. You could also consider the WASAS which is a nice measure that looks at work and social functioning.	These questions are intended for all pain services, Level 2-4. We accept that PMPs will need more detailed data, and are already collecting these. We plan to follow this with recommendations for a larger optimum dataset, and will be happy to discuss this.

See above responses to the use of these questionnaires, which are beyond the scope of a CMD. |
	We would also ask at what points you wanted to collect the data i.e. would it be pre and post or would it be the change between pre and post? There is evidence and recommendations that PMP's if structured correctly do not need to keep on continuing to be evaluated on an ongoing basis. You could therefore work out how to benchmark a PMP and then ask for evaluation data be done once every 3 years for a 6 month period for example. If this were to be the case, our suggestion would be to be very specific using detailed measures as per the level of the Scottish service model, so that the therapeutic effect can be evaluated correctly. So for level 3 PMP it would be at least BPI, a mood measure and TSK and possibly a functional outcome.	We are not intending to specifically evaluate PMPs, which should be done by the PMPs themselves, who are expert – perhaps with reference to our intended optimum dataset
	Quality Performance Indicators (QPIs)	

	Are the targets reasonable?	
	QPI1 – Pain Education About right - It is important to note that the SIGN guidelines say that information alone is not sufficient, as well as that the local pain management service should advise what the information should be. We think it is very important that there is good governance of materials on chronic pain and so this QPI could have something added that the material along the pathway is reviewed by the specialist service on an annual basis to ensure good governance.	Thank you. This point about information alone is with reference to physical activity/exercise only, in SIGN 136 We have not attempted to specify the educational materials at this stage, though could consider this in due course. It would be a large exercise
	QPI2 – Outcome Measures We do not agree with these measures as explained above and would advise that this QPI is reviewed. We would advocate that outcome measures are identified as per the stage of the Scottish service model, and that there is guidance on how they are measured and analysed. We would recommend that the measures identified are changed (more explanation above)	See above responses
	QPI3 – Pharmacy Review Out with our area of competence to comment specifically, but annual review of meds sounds very reasonable	Thank you
	QPI4 – Service Evaluation and Audit This links into QPI 2. Our recommendation would be for service leads to complete an annual summary of the services being offered. If what is wanted in terms of outcomes is made clearer this could be submitted, but "change in pain and quality of life affected by pain" is a big ask and not very clear. In our service, we would be able to provide data in terms of change from a mood and pain severity and interference perspective, but this should perhaps be in the outcome section? In terms of the faculty of pain medicine standards, this is very medical and mention should be made of the BPS guidelines for pain management programmes and these programmes be audited on this basis. Our suggestion would be to have separate guidelines for staffing/service evaluation for pain clinics and pain management programmes.	Thank you. See above responses. These standards have come from IASP/FPM
	Are the specifications reasonable?	
	QPI1 – Pain Education	Good suggestion about liaising

	Too low - I would suggest a specification would be whether they have liased with local specialist pain management services to ensure the resources are evidence based and recommended, as opposed to number of nhs services etc. An overview of what is recommended could be included	with specialist services to ensure quality and consistency. We have not (yet) attempted to specify particular educational materials
	QPI2 – Outcome Measures Too high - This will be very difficult to do. Previous comments refer.	See above responses
	QPI4 – Service Evaluation and Audit Too high - Outcomes and evaluation confused. Annual overview of services sounds workable, the evaluation not.	See above responses.
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions? Annually may be too frequent – what about every 2 or 3 years?	Please see above responses. We will aim for annual at first, then review. It is important not to leave review for too long if QPIs are not being met.
NHS Tayside Pain Service	Dataset How do you see yourself collecting it? Computer, administered by clinician, patient completed – requires tablet and query funding for IT	Thank you
	QPIs Are the targets reasonable? QPI2 – Outcome Measures About right - Right for level 3 and 4. Cannot comment for level 2 "what constitutes treatment" 75% of patients have 100% of data in past 12 months	Thank you As a result of the consultation exercise, the target for this QPI has been changed to the following: 1) 90% of patients have partially completed questionnaires. 2) 75% of patients have fully completed questionnaires.
	QPI3 – Pharmacy Review Medication needs specified, e.g. moderate to strong opioids plus tricyclic antidepressants plus gabapentanoids.	This QPI is stated and intended to cover all "medication prescribed for chronic pain". We have clarified this in the Numerator, Specifications and Targets
	QPI5 – Exercise and Activity Therapies	Others considered this too low.

	Too high - to achieve 50% would be an achievement	
	Are the specifications reasonable? QPI3 – Pharmacy Review About right - specialist pain clinic to be removed from "description of pharmacy review" this should all be level 2.	We have amended this.
	QPI 5 – Exercise and Activity Therapies About right - take out line four, in the description section "should be provided by pain service", should be all level 1-4	Thank you. We have removed this.
	Any other comments? Concerns about the IT systems, that information will be easily accessible, Concerns about funding Concerns about the time to complete all of above.	We are discussing this with eHealth, ISD and Scottish Government, and aiming for an embedded collection system using routine data where possible
NHS Orkney	Dataset How feasible is this dataset to collect? 2 - Some of the data fields e.g. demographics and pain site could be extracted from Trakcare but a new method/database would have to be created to capture the qualitative elements.	See below
	Are these the right questions? No – Add Dental to Pain Site?	Yes – this is sensible. We have added this in.
	How do you see yourself collecting it? Computer and patient completed - A combination – bespoke database linked to Trak?	Thank you for your comments. We are currently liaising with eHealth and ISD to assess the capacity of TRAK and other systems to collect the core dataset.
	Which I.T. system would you use to collect this data? TRAK - NHS Orkney doesn't have resources currently to develop a bespoke database.	Please see above
	Is there anything here that we do not need? Health related quality of life- this question is already asked in Scottish Health Survey.	Thank you. SHS is not completed by all people, and only once.
	QPIs Are the targets reasonable? QPI1 – Pain Education About right - Who do you suggest would be responsible for ensuring this happens across the many specialties and capture and reporting the	We will be asking each Health Board to identify their own mechanism for reporting on all QPIs. Initially we will only ask

	data?	about Levels 3 and 4, but consider how and when to extend to Levels 1 and 2
	QPI2 – Outcome Measures Too high - Health related quality of life – duplication with Scottish health survey?	SHS is not completed by all people, and completed only once by those who complete it
	QPI3 – Pharmacy Review Too low - Should be more frequent than annually – could this be recorded as part of Prisms?	Agree that it should be more frequent, but we need to start somewhere. Others have considered this too high
	QPI5 – Exercise and Activity Therapies Too high - Who would be responsible for capturing all these parameters? Very difficult to measure/disaggregate data, unless self-reported?	Yes – we are suggesting self-report. Please see above response to QPI 1 comment.
	Any other comments? Who would be responsible for collating the information and who would the Audit visits be to? Orkney doesn't have a dedicated chronic pain service per se – those experiencing chronic pain are dispersed across many specialties and statutory/third sector services.	Yes, we suggest self-report, with occasional audit visits. Please see above responses. We note the comment, though, and will need to tailor expectations and feedback to individual Boards' circumstances.
NHS Orkney	Core Dataset Which I.T. system would you use to collect this data? Other - Primary Care system – using bespoke templates and thus coding directly into patient's records	Thank you. We would aim to work towards a standard system that can be integrated locally
	Is there anything here that we do not need? Whole data set seems reasonable but is OTT for routine use in level 2 where patients may be seen frequently.	It only needs to be collected once, or once per year, to meet the QPI. We note this comment, and will consider it at the point of implementation in Level 2 services.
	Any other comments? As the Venn diagram suggests most chronic pain management is done by GPs. This guidance looks practical and sensible and achievable. Overall I'd welcome this.	Thank you
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable? If not, do you have any other suggestions? No - In primary care the numbers will be larger and	We are working with SPIRE

	the patients multi-morbid. Separating them out 'by hand' for a questionnaire will be time-consuming and prone to error. Automatic collation of coded data would be the best option. It would depend on good coding but the quality of that too can be assessed as part of the data collection and improved. SPiRE was established for exactly this sort of task.	precisely towards this goal
NHS Grampian	Core Dataset Is this dataset sufficient, as a bare minimum? Yes – The dataset should be tailored for different levels of service provision.	Thank you. The main objective of this project is to implement a standardised dataset across all service levels. This is important as it would allow us to compare the outcomes across different services in the future.
	How do you see yourself collecting it? Paper, administered by clinician and patient completed - Currently, 2 questionnaires (BPI 7 EQ-5D) are filled by majority of patients who visit the NHSG services. This gets added to the clinic letters, which is stored in the electronic patient records. Some of the questions in the suggested dataset may not be suitable for this approach.	Thanks. We are also working with ISD and Scottish Government, towards a data collection and management system.
	Any other comments? About 2 to 5% chronic pain populations are seen in level 3 and 4 services. They should not be stationary group. Some of the QPI imply that they stay in level 3 and 4. Also, we are not sure about the usefulness of combining questions from different validated questionnaires in evaluating treatment outcomes. We also wondered about the long term implication of such dataset – help in reducing waiting times or increased funding to match the demands.	We are planning to assess the validity of the CMD. The optimum dataset will provide us with more detailed information on the psychological, emotional and functional impact of chronic pain in Scotland. We hope to achieve several goals with this dataset, including these. There is no current way to accurately measure the

		  • The demographics and needs of the patient group • The effectiveness of any service provision • The resources that will be required to address any areas for improvement • The frequency of pharmacy reviews • The structure and composition of pain services, and gaps that need to be addressed • The use of outcome measures, and responses to them We agree. We would expect support for these activities across Scotland. We are working with ISD and Scottish Government, towards a data collection and management system, and this includes identification of the costs and investment required..
	If there are valid comparisons to be made, the chances of mis-interpretation of data are highly significant as would be the consequences for services. If this is to be done properly there will almost certainly need to be substantial investment in infrastructure to do ensure the accuracy of the data input and the quality of the interpretation.	
	QPIs Are the targets reasonable? QPI 1 – Pain Education About right - In addition to generic information, education about individual drugs and treatments should be available in level 3 and 4 services.	This is good suggestion. The information about medication and other treatment options should be available at all levels. At present, we have not specified what educational information should be available, but we hope to refine this in due course.
	QPI 3 – Pharmacy Review	The responsibility will lie with the

	Too high - More clarity is needed as it suggests that anyone on prescribed analgesics should have ongoing annual review by level 3 or 4 services. It might be that this QPI is primarily aimed at Level 2.	prescriber – i.e. primary care. We have amended the QPI to confirm this
	QPI 4 – Service Evaluation and Audit About right - It is just about right if we consider the service evaluation alone. But introducing the outcome measures complicates the picture. See below the comment about outcome measures in specification.	Thank you.
	Like QPI3 and 4, more QPI can be considered for other treatments offered in these services such as PMP, injections, denervations, spinal cord stimulators and intrathecal drug deliveries.	Thank you. We will consider additional QPIs in due course, but the current Specifications reflect the Standards set out by the FPM, with the addition of access to a PMP. Not all services provide these other interventions.
	QPI 5 – Exercise and Activity Therapies Too high - In level 3 and 4 services, it might be difficult to achieve for people presenting with headache, neuropathic pain, post-cancer pain. They might have the physio input in level 2.	We accept that this might be challenging, but assert that it important to aim for. We are asking for the provision of advice and relevant signposting, rather than for specific therapies or interventions.
	Are the specifications reasonable? QPI 2 – Outcome Measures Too low - The difficulty in achieving this for different service levels of provision has been acknowledged; however, the numerator specifies only one set of data. This is unlikely to provide any useful outcome measure of a given treatment strategy/ service. Specific treatment strategies have been included in other QPIs (3 and 5). So for evaluation of service delivery, administering twice a year such as national audit will be useful. Otherwise, it's likely to generate epidemiological data only.	This will vary from service to service. Some services (level 2 services) will only be able to generate one set of data as they don't aim to test before and after treatment results. However, level 3 and 4 services will often be able to record more than one set of data. We are discussing with ISD how to maximise the clinical value of the CMD.
	QPI 3 – Pharmacy Review Too high - We find it difficult to comment as it is unclear where the specifications will be applied.	Please see the comments above.
	QPI 4 – Service Evaluation and Audit About right - See the comments above; more	Thank you. We have added further specification:

	clarity needed on numbers receiving advice and guidance on managing pain.	Information about managing pain may take the format of: • verbal advice • signposting and referring to relevant services • or both. Patients should be provided with information about: - Types of pain - Coping mechanisms - Dealing with sleep and anxiety - Origins of pain.
	QPI 5 – Exercise and Activity Therapies Too high - It is too wide denominator. It's more appropriate for level 2 services.	Others considered it too low. The denominator is meant to be broad (include people who suffer from different types of pain) as the main objective of this QPI is to promote exercise, regardless of the type of pain experienced by people that suffer from this condition.
	What other areas might additional QPIs cover? 1. QPIs to evaluate the provision and outcome of Pain Management programs 2. QPIs to evaluate the provision and outcomes minimally invasive therapies including RF denervations 3. QPIs to evaluate the provision and outcome of Neuromodulation 4. QPIs to evaluate the provision of inter-disciplinary treatments such as surgical referrals	Thank you. We will certainly consider these in due course.
	We suggest that the information is gathered through self-report questionnaire annually with occasional audit visits, does this seem reasonable?	Thank you -we will consider this, within available resource constraints...

	If not, do you have any other suggestions? Yes - The suggested approach will be useful for majority of QPIs. A national registry for dedicated chronic pain services, or audit methodology employed by RCOA (baseline data for a specified period with follow-up data for those people at later date) might provide more useful information.	
	Any other comments? QPIs are very much needed and should be tailored to current Scottish Service model of provision for chronic pain. Having generic QPIs across all levels of service delivery might not achieve the desired outcomes.	Thank you. We believe that it is important to involve different public organisations (primary, secondary and tertiary services) in the delivery of the same set of QPIs and outcome measurements. This integration is important because as suggested by Burns (which identifies some key principles and recommendations for using and developing targets and indicators), there is a need to examine the performance of the system as a whole. Reference: Burns, H., Targets and Indicators in Health and Social Care in Scotland. A Review. The Scottish Government 2017.
	The current service provision is stretched by itself. Further data collection without additional funding and staffing will be fraught with difficulties. Self-report is very important but by no means the whole story. Without independently verified measures of disability (or even drug-seeking behaviour), the accuracy of data, thereby the quality of information obtained, is open to discussion.	We agree and are discussing support for these activities across Scotland. We agree with this limitation. Self-report measures are reliable and valid. They are widely used to access patients' outcomes by health care professionals. We will be able to link to routinely collected data and other existing NHS datasets
Pain Association Scotland	1. Do you think the development of the Core Minimum Dataset is important in improving patient care? If so why? Yes. The effectiveness of this is dependent on how this is implemented within each Health Board. It is	Thank you.

	therefore imperative that there is continuity across the board.	
	2. Is this dataset sufficient as a bare minimum? If so why? Yes.	Thank you.
	3. Are these the right questions? If so why? Yes	Thank you.
	4. Do you think it is important to develop and introduce the Quality Performance Indicators that measure performance on a range of care aspects? Please specify Yes	Thank you.
	5. Are the proposed indictors relevant and appropriate? Please specify Yes, but within the pharmacy Review there is no mention of self-management and it is vitally important that patients who are having their medication reviewed are referred/signposted to self-management.	Self-management is included in the text of this QPI, and the education which we require from this QPI is about more than self-management. We agree that self-management is essential, and are planning development of a separate QPI on this; identifying quantifiable outcomes will be one of the challenges in doing this.
	6. Are there any indicators that you feel are not relevant/appropriate? No response	-
	7. If you think that any of our proposed indicators are not relevant/appropriate, what alternatives would you suggest? No response	-
	8. Other comments QPI 1 on Educational information about pain should have self-management within the title of this.	This QPI focuses only on pharmaceutical treatment, and review thereof. None of the supporting evidence includes reference to self-management, and there are no measurable outcomes relating to self-management. We agree that self-management is a very important aspect of managing chronic pain.
Pain Concern	Other comments	That's a fair point! We have

	I'm sure I'm not alone in commenting on the use of 'greater than' and 'less than' when asking people about their age. You need to add to one choice, 'equal to or ' in order to cover the age range completely, to make sense and to achieve consistency.	changed this to the following statement: a) 'Please write your age' b) and provided some space for the answer. Thank you. We have simplified the definition of CRPS:
	Quite a fuss is made about explaining the features of CRPS but in my experience Neuropathic Pain is often poorly understood by GPs and secondary care specialists, and could benefit from equal attention.	"CRPS is preceded by a noxious event and is characterized by spontaneous pain or hyperalgesia/hyperaesthesia and other features, not limited to a single nerve territory and disproportionate to the inciting event."