'discharge' in the Tayside Pain Service as they use an open appointment system where patients have a 6 month window to request another appointment.

A decision has been taken to prioritise certain questions on the BPI (Q5 and Q9a-f) as other questions are already covered in their standard questionnaire. This can present difficulties when analysing the data (cannot calculate a score for the patient). Inputting EQ-5D-5L scores is responsibility of administrator, input has ceased as of 14/2/17 as EQ-5D-5L scores are only collected at the initial appointment resulting in data that was not very meaningful (could not assess whether the patient's quality of life was improving). The EQ-5D-5L data does not appear to be linked to the rest of the patient's records and is not administered at follow-up reducing the usefulness of the data. The focus of data collection, in general, is on the initial assessment, not follow-up.

More information can be found in Appendix 2.

NHS Fife Pain Service

i. Key Findings

Good Practice Points

1. Follow-up data was collected for each outcome measure which was generally well completed (apart from the Visual Analogue Scale).
2. Provides a well-rounded overview of the patient (from their referral to their outcomes).
3. Separate columns for Body Part, Outcome and Onwards Referrals with True/False answers led to a full completion rate for these sections.

Potential Areas of Improvement

1. Only total score is listed for each outcome measure, there is no way of determining how missing scores were dealt with.
2. For many columns there are no standard answer lists leading to several different answers which have the same or similar meaning and data that cannot be coded.
3. Physiotherapy outcome did not appear to be used as there was missing data at a rate of 99.8%.
4. Referrals to secondary care departments had a considerable amount of missing data (29%), also the free-text feature led to confusing data analysis (some entries were just phone numbers or names of clinicians).
5. The Visual Analogue Scale (VAS) had a high percentage of missing data at pre-assessment (59%) and at follow-up (79%).
6. Pain type and Employment/Work Status are not recorded.

ii. Clinician Questionnaire

13 members of staff returned questionnaires (22 distributed).

Lack of clarity on the usefulness/utility of the data was a main barrier to inputting the data itself.

9 members of staff knew that Oasis was going to be replaced by Trak and/or Tiara in the near future.

IT System Features (Rated 0-10)	Mean Rating	Standard Deviation
Speed	4.22	2.13
Dropdown	4.56	1.96
Interface	4.67	1.71
Free-text	4.56	2.25
Responsiveness	5.29	2.20

IT Issues	Number of Participants	Percentage of Participants
Lack of clarity on usefulness/utility of the data	9	69%
Lack of time	6	46%
Poor Access to IT	4	33%
Lack of consensus on data input responsibilities	1	8%

iii. Additional Comments from Clinicians

"Pain Management Psychology in Fife is organisationally situated in the Psychology Dept. The whole dept. has recently moved from an old fashioned excel data base to TIARA. It is therefore early days at present to judge how effective this new system is for us. Primarily this shift has occurred to allow better reporting for psychological therapies HEAT Target, but Tiara does have capacity to collect outcome data. It is not clear to me how work progressing with the National Pain Group to look at outcome measures will map onto work being completed nationally in mental health around outcomes measures".

See Appendix 3 for more information.

NHS Lothian Pain Service

After successful installation of a Secure Global Desktop to analyse Lothian data remotely, the PAs are currently waiting authorisation to gain access to the shared T Drive, where the Chronic Pain Service data is stored. Presented below are the results and comments from the staff questionnaire, disseminated by the PAs to gain clinician perspectives on current data collection procedures.

i. Clinician Questionnaire

15 members of staff returned questionnaires (20 were distributed).

Trakcare is used in this health board. One clinician indicated that their service is moving over to "SCI Clinical Portal".

IT System Features (Rated 0-10)	Mean Rating	Standard Deviation
Interface	5.54	1.98
Responsiveness	6.87	2.17
Dropdown	5.21	1.97
Free-text	5.42	2.22
Speed	4.74	2.12

IT Issues	Number of Participants	Percentage of Participants
Lack of time	11	73%
Lack of clarity on usefulness/utility of the data	6	40%
Poor access to IT	5	33%
Lack of consensus on data input responsibilities	2	13%

ii. Additional Comments from Clinicians

"We also have access to SCi-Store which is linked to Trak. There are huge amounts of Trak data that we ignore as it is irrelevant but may have to wade through."

"Processing speed variable

TRAK – no back button – not the most intuitive system"

"We do not enter our data into trak. It is entered into excel / SPSS. Data is entered by an asst, not by clinicians."

"I am a medical secretary and have only just started an honorary assistant psychologist contract so my results may not necessarily represent those given by clinicians. Overall, trak is very efficient and very good compared to NHS IT systems I have used in England."

"The NHS computers I have access to tend to be older models and slow. I find Trak to be a user friendly system on the whole however the dropdown menus can offer limited choices (for example when outcoming appointments). The only free text I use are the progress notes section and this is adequate for my requirements."

"The main problems occur with the Sunray system that Lothian use – this can at times be extremely slow to load and often has login issues requiring phone calls to IT support. TRAK itself appears to run smoothly once the computer is up and running so to speak."

"We don't input any data onto TRAK currently so I've left questions 7 & 8 blank as presume these are to do with outcome measure input rather than case notes?"

Quality Performance Indicators (QPIs)

In accordance with the objectives of the original proposal, collated information from the three health boards were utilised to develop recommendations for service improvement.

The PAs have begun drafting **Quality Performance Indicators** (QPIs) for chronic pain services in Scotland, with each QPI corresponding to one of the four levels of the Scottish Service Model (Appendix 4). A draft QPI is displayed below, with references.

QPI Title:	Patients with chronic pain should have their medication reviewed regularly by their GP or Pharmacist.
Description:	A review of the medication a patient is prescribed, for pain, should be undertaken, in person with their designated clinician at least annually.
Rationale and Evidence:	Despite a lack of strong evidence, it has been found that involving patients in their medication review can improve patient's knowledge, satisfaction and the identification of drug related problems [1]. SIGN 136 [2] states that an individual's success in pharmacological treatments is dependent on regular, scheduled re-assessment of pain relief and side effects. It has also been found that if an individual has not responded to treatment after two to four weeks after titration to an adequate dose, then they are unlikely to develop a response thereafter [2] which is why a regular review is important.
Specifications:	Numerator: Number of chronic pain patients prescribed mediation having at least one review annually Denominator: All patients with chronic pain who are prescribed medications. Exclusions: Patients with chronic pain who are not prescribed medications.
Target:	[90%] patients who are being prescribed medication to manage their pain should receive an annual medication review.
References:	1. Willeboordse, F., et al., *Patient participation in medication reviews is desirable but not evidence-based: a systematic literature review.* Br J Clin Pharmacol, 2014. **78**(6): p. 1201-16. 2. SIGN 136, *Management of chronic pain.* Scottish Intercollegiate Guidelines Network, 2013.

Improving Data Collection – Examples of Good Practice across the World

Australia and New Zealand- ePPOC (electronic Persistent Pain Outcomes Collaboration)

ePPOC (electronic Persistent Pain Outcomes Collaboration) is a new program which aims to help improve services and outcomes for chronic pain patients through standardisation of care and treatment. ePPOC is an initiative of the Faculty of Pain Medicine, and has been further developed in recent years by the Faculty, the Australian Pain Society and the wider pain sector.

ePPOC involves the collection of a standardised dataset and assessment tools by specialist pain services throughout Australia and New Zealand to measure treatment outcomes for their patients. This information will be used to develop a national standardised system for the pain sector, which will lead to better outcomes and best practice interventions for patients in chronic pain. The information will also enable development of a coordinated approach to research into the management of pain in Australasia.

The first phase of ePPOC began in 2013, with eight adult pain services in NSW trialling the measures, process and software for collection of the information. ePPOC is now being progressively rolled out to adult and paediatric specialist pain services throughout Australia and New Zealand.

The ePPOC dataset includes the following outcome measures:

- Brief Pain Inventory (BPI)
- Depression, Anxiety and Stress Scale (DASS)
- Pain Self-Efficacy Questionnaire (PSEQ)
- Pain Catastrophising Scale (PCS)

The Annual Report from 2016 demonstrated that 46 services provided information on 16,790 patients and, in total, these patients had 12,624 episodes of care and 8,673 pain management pathways in this reporting period (1st of January 2016 to 31st December 2016) [3]. Number of recorded questionnaires in this period are also noted with 11,763 questionnaires received from all services at referral with 212 at the beginning of the programme and 221 at programme end.

The two PAs have established correspondence with Dr Hilarie Tardif, ePPOC Manager at the Australian Health Services Research Institute (AHSRI).

Germany- VAPAIN (Validation and Application of a patient relevant core outcome set to assess effectiveness of multimodal PAIN therapy)

The aim of this project is to determine interdisciplinary consensus recommendations to define relevant areas of the disease experience as well as a core set of outcome measures in order to reliably measure the treatments for chronic pain. This project is led by Principal Investigator Dr Ulrike Kaiser at the University Hospital Carl Gustav Carus, Dresden.

Part A: The recommendations will be developed by an interdisciplinary team in the context of a Delphi process consisting of representatives of medicine, psychotherapy, physiotherapy, care research and patients. In addition to the defined areas, reliable and sensitive measuring instruments should be discussed. The aim of this process is to provide an overview of current research on instruments and a data set of patients with chronic pain retrospectively analysed.

Part B: A questionnaire set is produced from the resulting recommendations which will be administered in four multimodal facilities regarding their quality criteria and significance for the effectiveness of the therapy.

Universitätsklinikum Carl Gustav Carus
DIE DRESDNER.

B. Management of Chronic Pain in Children and Young People: A National Clinical Guideline

PA Contribution

The PAs attended the multidisciplinary meeting of the Short Life Working Group (SLWG) for Paediatric Pain on the 2nd of September 2016 in Edinburgh. This meeting concerned the development of a Scottish Medical and Scientific Advisory Committee (SMASAC) guideline for children and young people with chronic pain. The key objective: to provide a useful practical resource for managing this complex condition, thereby improving quality of life and reducing longer term harms. This guideline was developed in collaboration with the Scottish Intercollegiate Guidelines Network (SIGN).

The PAs participated in multidisciplinary discussions regarding the levels of evidence and quality of the studies to be included in the guideline. The main responsibility of the PAs was synthesising evidence and writing up the guideline itself, by incorporating and updating literature highlighted by the specialist SLWG pain clinicians.

The PAs, in collaboration with [redacted] launched the guideline's consultation process at the Scottish Pain Research Community 7th Annual Scientific Meeting on the 24th of March 2017. This comprised of a poster (see Appendix 7) and oral presentation (delivered by Professor Lesley Colvin). Through correspondence with the SLWG, the PAs identified other specialist organisations/individuals invited to comment. The guideline went 'live' on the 17th of March 2017, with PAs disseminating the final draft to reviewers. The consultation period currently has a deadline of the 5th of May 2017 for comment.

The final version of the SMASAC guideline is available upon request.

NEXT STEPS:

- Following the end of the consultation period, the official document, 'Management of Chronic Pain in Children: A National Clinical Guideline' will be uploaded and published on the Scottish Government website.
- A link to the final version of the guideline will be made public on the SIGN website.

C. Interventions to support patients in reducing or stopping strong opioids

PA Contribution

The PAs were involved in a systematic review investigating opioid reduction strategies utilised in chronic pain populations. The PAs were responsible for conducting the literature searches (from 2013 onwards) across several databases, in accordance with strategies outlined in an earlier Cochrane review [4].

The PAs completed these searches as independent reviewers, with the inclusion of papers decided only after extensive review and discussion of the abstracts with Prof. Colvin. The PAs authored the Results section of the paper (see attached draft). A snapshot of the review's protocol is presented in Appendix 3 and can also be found at the link below: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015017480).

NEXT STEPS

- The review will be submitted to the British Journal of Anaesthesia with the aim of publication in a peer-reviewed journal.

D. SPaRC Annual Scientific Meeting, Project Management

PA Contribution

A substantial contribution to project management was provided by the PAs by supporting the conference organization, contributing to a very successful meeting a (see Appendix 6 for the 2017 programme).

Online publicity, delegate bookings, correspondence with the keynote, oral and poster presenters, development of abstract and biography booklets, venue arrangements and catering were among some of the PA responsibilities.

Formal evaluation of the meeting is currently being conducted by the PAs through an online survey.

See Appendix 6 for the programme from SPaRC ASM 2017.

NEXT STEPS:

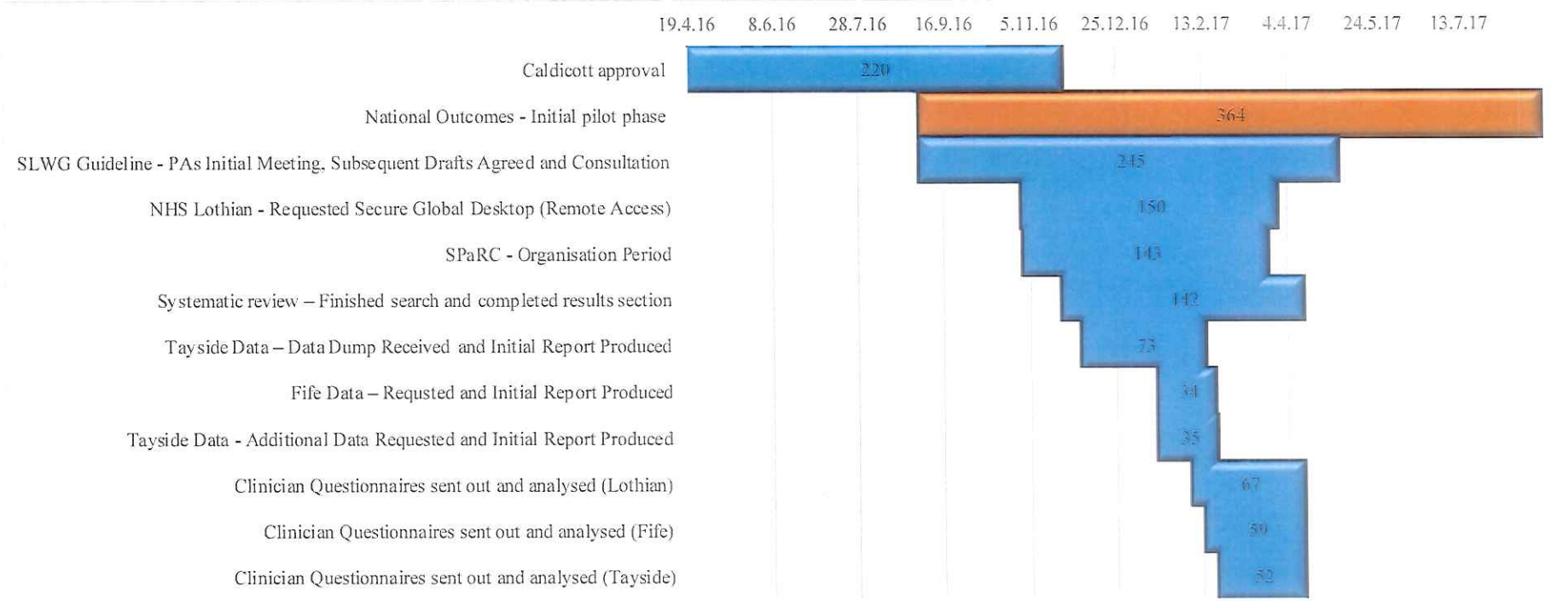
- PAs will author a report on the delegate survey results from the 7th ASM, with a view to informing the planning of the 8th ASM next year.

References

1. Willeboordse, F., et al., *Patient participation in medication reviews is desirable but not evidence-based: a systematic literature review.* Br J Clin Pharmacol, 2014. 78(6): p. 1201-16.
2. SIGN 136, *Management of chronic pain.* Scottish Intercollegiate Guidelines Network, 2013.
3. Electronic Persistent Pain Outcomes Collaboration, *Patient Outcomes in Pain Management: 2016 Annual Report.* University of Wollongong, 2016.
4. Windmill, J., et al., *Interventions for the reduction of prescribed opioid use in chronic non-cancer pain.* Cochrane Database Syst Rev, 2013(9): p. CD010323.

Appendices

Appendix 1: Progress (to date)



Appendix 2: NHS Tayside Pain Service Data

Pain Site and Duration

Site of Pain (not mutually exclusive)	Number of Patients	Percentage of Recorded Patients
Low Back	262	30.54%
Widespread Pain	190	22.14%
Hip, Buttock, Groin or Thigh	79	9.21%
Knee or Foreleg	54	6.29%
Upper Back or Neck	47	5.48%
Shoulder or Upper Arm	38	4.43%
Foot/Ankle	36	4.20%
Abdomen (Non-Spinal)	33	3.85%
Head and Neck (Non-Spinal)	32	3.73%
Other	27	3.15%
Elbow or Forearm	21	2.45%
Pelvis (including gynaecological)	16	1.86%
Thorax (Non-Spinal)	13	1.52%

Duration of Symptoms	Number of Patients	Percentage of Recorded Patients
< 3 months	[redacted]	[redacted]
3-6 months	23	2.68%
6-12 months	67	7.81%
1-2 years	105	12.24%
2-5 years	213	24.83%
5-10 years	194	22.61%
> 10 years	211	24.59%

Number of Pain Sites	Number of Patients	Percentage of Recorded Patients
1 site	258	30.07%
2 sites	156	18.18%
3 sites	95	11.07%
4 sites	35	4.08%
5 sites	13	1.52%

Pain Type	Number of Patients	Percentage of Recorded Patients
Mixed neuropathic/nociceptive	499	58.16%
Neuropathic	183	21.33%
Nociceptive - somatic	106	12.35%
Other	23	2.68%
Nociceptive - visceral	[redacted]	[redacted]
CRPS		

Management

TCPS Investigations	Number of Patients	Percentage of Recorded Patients
Blood test	1	0.11%
MRI	10	1.17%
X-Ray	3	0.35%

Management	First	Second	Third	Fourth
Acupuncture	6	17	19	14
Advice Only	7	3	1	2
Anticonvulsant	139	62	25	7
Antidepressant	83	69	29	12
Benzodiazepine	0	0	1	1
Hypnosis	0	0	1	0
List for Procedure	13	4	3	1
N/A	146	238	446	673
Non-Opioid Analgesic	5	6	7	4
NSAID	11	23	12	8
Other	6	10	9	2
Pain Management Programme	17	26	6	5
Physiotherapy	20	25	25	17
Psychology	4	8	6	8
Referral to Other Specialist	1	7	6	0
Relaxation	7	17	12	9
Self-Management	179	90	82	47
Strong Opioid Analgesic	9	9	5	4
Systemic L.A's	6	2	0	0
TENS	34	77	63	18
Topical Agents	154	146	79	15
Weak Opioid Analgesic	11	19	21	10

Employment Status

Employment Status	Number of Patients	Percentage of Recorded Patients
Employed	277	32.28%
Unemployed	254	29.60%
Retired	228	26.57%
Houseperson	52	6.06%
Student	23	2.68%
Registered Disabled	15	1.75%

Work Status	Number of Patients	Percentage of Recorded Patients
Absent from work due to health problem	234	27.27%
Retired	186	21.68%
Remains at work	128	14.92%
Remains at work with difficulty	112	13.05%
Other	75	8.74%
Absent from work due to another health problem	30	3.50%

Referral Source

Referral Source	Number of Patients	Percentage of Recorded Patients
GP	519	60.49%
Hospital Doctor	255	29.72%
AHP	57	6.64%
Nurse	14	1.63%
Other	12	1.40%
Self	[redacted]	[redacted]

Outcome Measures

Brief Pain Inventory (BPI)						
Questions	Mean	SD	Minimum Score	Maximum Score	Outliers	Missing Data
Average Pain (Q5)	6.96	1.68	0	10	0	217
General Activity (Q9a)	7.62	2.22	0	10	0	243
Mood (Q9b)	6.75	2.73	0	10	0	250
Walking Ability (Q9c)	6.95	2.94	0	10	0	246
Normal Work i.e. working outside the home and housework (Q9d)	7.74	2.29	0	10	0	250
Relations with Other People (Q9e)	5.68	3.21	0	10	0	252
Sleep (Q9f)	7.43	2.82	0	10	0	241
Enjoyment of Life (Q9g)	7.54	2.56	0	10	0	241

EQ-5D-5L Pre-Treatment Data (Data from Oct & Nov 2013 and Feb-Nov 2015) *One record from Oct 2013							
	Mobility	Self-Care	Usual Activities	Pain/ Discomfort	Anxiety/ Depression	EQ-5D-5L Health State	EQ-5D-5L Index
Median	3	2	3	4	2	Median	0.3262
Mode	3	1	3	4	2	Mean	0.3110536
No. of patients	500	500	500	500	500		500

EQ-5D-5L Pre-Treatment Data (Data from Nov & Dec 2015 and Jan-Nov 2016)							
	Mobility	Self-Care	Usual Activities	Pain/ Discomfort	Anxiety/ Depression	EQ-5D-5L Health State	EQ-5D-5L Index
Median	3	2	3	4	2	Median	0.33925
Mode	3	1	3	4	3	Mean	0.3481372
No. of patients	500	500	500	500	500		500

EQ-5D-5L Pre-Treatment Data (Data from Nov-Dec 2016 and Jan-Feb 2017) *One record from Feb 2017							
	Mobility	**Self-Care**	**Usual Activities**	**Pain/ Discomfort**	**Anxiety/ Depression**	**EQ-5D-5L Health State**	**EQ-5D-5L Index**
Median	3	2	3	4	2.5	Median	0.3437
Mode	2	1	3	4	3	Mean	0.35640893
No. of patients	112	112	112	112	112		112

*Incomplete EQ-5D-5L forms were not inputted into the database