Patient Health Questionnaire (PHQ-9)		
SCORE	Initial Assessment	Follow-Up Assessment
Mean	13.3	1.8
Minimum	0	0
Maximum	31	27
SD	7.2	4.0
Missing Data	1	1

Generalised Anxiety Disorder Questionnaire (GAD-7)		
SCORE	Initial Assessment	Follow-Up Assessment
Mean	9.2	1.5
Minimum	0	0
Maximum	21	21
SD	6.5	3.7
Missing Data	0	3

4) Conclusions

The NHS Fife Integrated Pain Management Service provides an extensive overview of the patient, including age, pain site/duration, referral and outcome measures. The questionnaires are generally well completed and administered pre and post programme. In future, it may be useful to include pain type, gender and work status to the database for a more extensive profile of the patient.

Appendix 3 - NHS Lothian Pain Service and Pain Management Programme

About the Service

Clinicians currently collect detailed information on paper questionnaires, from all patients attending specialist pain services. Measures include basic demographic data, plus validated self-report tools to assess different aspects of chronic pain and its impact (e.g. Brief Pain Inventory (BPI), Hospital Anxiety and Depression Scale (HADS), Self-completed Leeds Assessment of Neuropathic Symptoms and Signs (S-LANSS), Tampa Scale for Kinesiophobia (TSK), Patient Self Efficacy Questionnaire (PSEQ), Patient Catastrophizing Scale (PCS), and EuroQol 5 Dimensions Questionnaire (EQ-5D). These are currently used to inform individual care planning. The core dataset used at all points is the BPI and HADS, additional measures are added for research purposes.

Pain Management Programme

The Pain Management Programme is part of the Lothian Pain Service and comes under Clinical Health Psychology Services. It is based at Astley Ainslie Hospital, Edinburgh. The aim of the programme is through psychological principles, based on cognitive behavioural therapy, to offer specialist intervention and treatment to reduce the effect pain is having on an individual's mood, activity and quality of life through specialist intervention in a predominantly group based environment. The team is comprised of Clinical, Counselling and Assistant Psychologists as well as Physiotherapists. Data entry responsibilities are assigned to Assistant Psychologists and Trainee Physiotherapists.

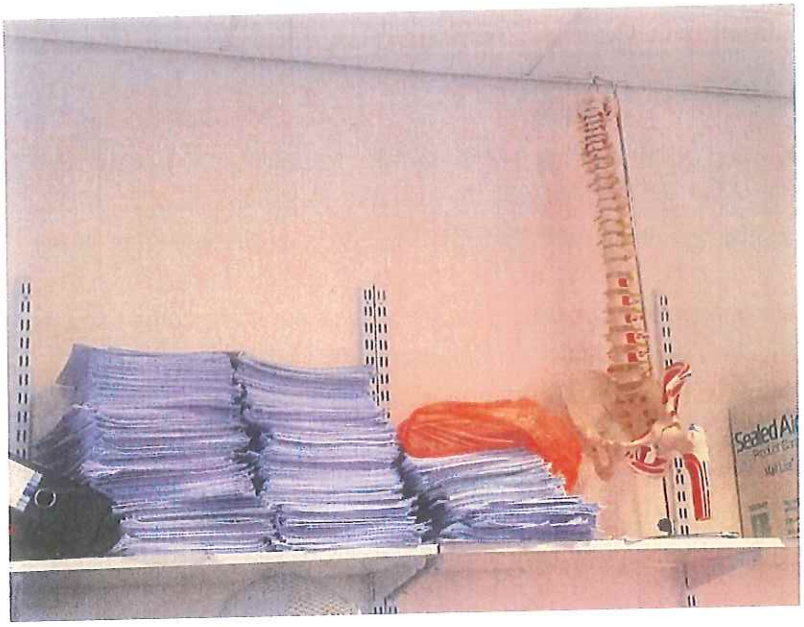
Pain Service

The PAs visited Leith Community Treatment Centre (LCTC) on the 2nd and 3rd of June to input paper questionnaires administered by clinicians in the Pain Service. The purpose of this exercise was to determine the number of questionnaires that could be inputted by two individuals over a

two day period, taking into consideration configuring and setting up the databases. The PAs were able to input 158 questionnaires overall.

The figure below is a visual demonstration of the number of questionnaires that have not been inputted into the NHS Lothian IT system.

Figure 2: NHS Lothian Pain Service Paper Questionnaires



The estimated time to input all of these questionnaires is 16 full working days for one data entry clerk, which has significant costs associated.

1) Key Findings from NHS Lothian

Good Practice Points

1. A wide range of outcome measures are used which provides a well-rounded account of the patient.
2. Information is collected on visits to the GP or hospital which highlights how the patient is coping with their pain, any problems they have been experiencing.
3. Work status is recorded which is also an indicator of how the patient is coping with their pain and the severity of pain.

Areas of Improvement

1. More guidance is needed when administering questionnaires to patients, it is clear that some patients did not understand some questions for example in the S-LANSS patients wrote "sometimes" next to the yes or no answers. This leads to the questionnaire being spoiled.
2. The large number of questionnaires leads to attrition towards the end, with some patients missing out entire questionnaire instruments or missing out questions.
3. Pain type is not well recorded, which is an important area to cover.
4. Patient information (CHI number, date of birth etc.) is often not matched with the questionnaire pack which highlights an issue of usefulness of this data.
5. The body map where patients indicated the site of pain was difficult to interpret as this does not appear to have been verified by the clinician.

2) Clinician Questionnaire

After successful installation of a Secure Global Desktop, the RAs gained access to the online shared Drive, where the Lothian Pain Service data are 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.

Across both the Pain Management Programme and Pain Service 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	5.5	2.0
Responsiveness	6.9	2.2
Dropdown	5.2	2.0
Free-text	5.4	2.2
Speed	4.7	2.1

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%

i) Additional Comments from Lothian 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 assistant, 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?"

3) NHS Lothian Pain Management Programme Data

Assessment Stage (n = 1,020)

Lothian Pain Management Programme Data	
Years	**Number of Patients**
2014	162
2015	460
2016	403
Total Number of Patients	1025

Assessor	Number of Patients
Physiotherapy	576
Psychology	366

Referral	Number of Patients
Pain Consultant	511
Blank	417
General Practitioner	213
Other	75
Psychology	[redacted]

Answer	Asst oc/c1	Asst oc/c2	Asst oc/c3
Intro	551	0	0
1:1 Treatment	177	24	0
Discharge (External Referral)	18	0	0
Discharge	80	0	0
Did Not Attend & Discharge	1	0	0
Internal Referral	24	4	0
Treatment and Discharge	3	0	0
N/A	0	0	2
Blank	363	1189	1215

Answer	Mean	Standard Deviation
Aetiology	4.1	3.4
Quality of Life (0-10)	3.6	2.2
Visits to GP	3.4	3.2
ECO	0.4	1.3
Hospital Admissions	0.3	1.1

Pain Type	Number of Patients
Blank	1041
MSK	91
Mixed	65
Neuro	12
Visceral	[redacted]

Pain Type ("Other" Responses)	Number of Patients
Abdominal	[redacted]
Chronic Pelvic Pain	[redacted]
Migraines	[redacted]
Myelitis	[redacted]
Phantom Limb Pain	[redacted]
Post-Chemotherapy Neuropathy	[redacted]
Post-Stroke Headache	[redacted]
Psoriatic Arthroplasty	[redacted]
Shoulder Impingement	[redacted]
Trigeminal Neuralgia	[redacted]
Visceral	[redacted]
Unknown	[redacted]
Blank	1199

Pain Type 2016	Number of Patients
Spinal Central - with Radicular Upper or Lower Limb	32
Spinal Central	22
FMS	19
Peripheral Joint	[redacted]
PN	[redacted]
Facial	[redacted]
ME/CFS	[redacted]
CRPS	[redacted]
Other	[redacted]
Pelvic	[redacted]
Rheum	[redacted]
1/2 Body Pain	[redacted]
Abdominal	[redacted]
Fibromyalgia	[redacted]
Hypermobility	[redacted]
Other- Thoracic Post- Herpetic Neuralgia	[redacted]
Other - Eye	[redacted]
Peripheral Joint - Spinal Central	[redacted]
Pudendal Nerve	[redacted]
Spinal Central - Lower Back Pain	[redacted]
Stiff Person Syndrome	[redacted]
Trauma	[redacted]

Pain Site(s)	Number of Patients	
	1 site	2 sites
Head	27	N/A
Face	19	N/A
Neck	83	N/A
Neck & 1/2 Arms Below Elbow	32	22
1/2 Shoulders	41	41
1/2 Arms	30	35
1/2 Hands	22	55
Th Spine	61	N/A
Lx Spine	188	N/A
Lx & 1/2 Legs Below Knee	85	38
Pelvis	32	N/A
1/2 Hips/Legs	70	76
1/2 Foot/Feet	46	69
Abdominal/Visceral	20	N/A
Chest	12	N/A
GynaeFemale	[redacted]	N/A
ME/FM	90	N/A

Brief Pain Inventory (BPI)			
Score	Mean	Standard Deviation	Blank
Worst	7.8	1.7	217
Least	5.1	2.3	234
Average	6.7	1.7	234
Now	6.4	2.1	366
Interference with …			
General Activity	7.4	2.3	224
Mood	7.3	2.4	224
Walking Ability	6.9	2.8	220
Normal Work	7.6	2.2	231
Reals	6.6	2.7	232
Sleep	7.6	2.6	217
Enjoyment of Life	7.6	2.3	224

Hospital Anxiety and Depression Scale (HADS)			
Score	Mean	Standard Deviation	Blank
Anxiety	11.5	4.9	221
Depression	10.9	7.4	220

Other Outcome Measures*			
Score	Mean	Standard Deviation	Blank
S-LANSS	13.8	8.4	733
Tampa Scale for Kinesiophobia	31.3	8.8	615
Pain Self-Efficacy Questionnaire	22.7	12.4	240
Work and Social Adjustment Scale (WSAS) (collected 2015-16)	22.3	9.3	1112

Pain Catastrophizing Scale (PCS)			
Score	Mean	Standard Deviation	Blank
Helplessness	13.4	6.5	574
Magnification	5.3	3.4	574
Rumination	9.9	4.8	576

EuroQol Five Dimensions Questionnaire (EQ-5D)			
Score	Mean	Standard Deviation	Blank
Mobility	2.5	1.0	468
Self-Care	2.0	1.0	471
Usual Activities	2.8	1.0	473
Pain/Discomfort	3.3	0.9	470
Anxiety/Depression	2.5	1.1	475

Group Start (n = 412)

Intermittent Visits	Mean	Standard Deviation
General Practice	2.8	2.6
ECOs	0.2	1.0
Hospital Admissions	0.3	1.2

Brief Pain Inventory (BPI)		
Item	Mean	Standard Deviation
Best Pain	4.0	1.8
Worst Pain	7.3	1.7
Least Pain	4.7	2.1
Average Pain	6.2	1.6
Pain Right Now	6.1	2.1
Interference with…		
General Activity	6.1	2.0
Mood	7.1	2.2
Walking Ability	6.6	2.7
Normal Work	7.3	2.2
Relationships with other people	6.4	2.4
Sleep	7.3	2.6
Enjoyment of life	7.3	2.2

Other Outcome Measures	Mean Score	Standard Deviation
HADS Anxiety	11.3	4.4
HADS Depression	10.7	4.1
S-LANSS	14.4	7.5
TSK	30.6	7.7
TSK-17	38.9	8.0
PSEQ	25.4	11.4

PCS	Mean Score	Standard Deviation
Helplessness	12.3	3.0
Magnification	4.6	3.2
Rumination	8.8	4.4

EQ-5D	Mean Score	Standard Deviation
Mobility	2.5	1.0
Self-care	2.0	1.0
Usual Activities	2.8	1.0
Pain/Discomfort	3.3	1.0
Anxiety/Depression	2.5	1.1

N/A = Lack of data

BPI Pain	Number
1Head	N/A
1Face	
1Neck	
1Neck and 1/2arms below elbow	
1/2 Shoulders	
1/2 Arms	
1/2 Hands	
1Th Spine	
1Lx Spine	
Lx and 1/2 Legs below knee	
Pelvis	
1/2 Hips/Legs	
Foot/Feet	
1Chest	
1 Abdo/Visceral	
1GynaeFemale	
1ME/FM	

Group End (n = 306)

Intermittent Visits	Mean	Standard Deviation
General Practice	2.2	2.3
ECOs	0.2	0.8
Hospital Admissions	0.3	1.7

Brief Pain Inventory (BPI)		
Item	Mean	Standard Deviation
Best Pain	5.5	2.1
Worst Pain	6.9	1.9
Least Pain	4.2	2.2
Average Pain	5.7	1.8
Pain Right Now	5.5	2.3
Interference with General Activity	6.0	2.3
Mood	5.7	2.5
Walking Ability	5.8	2.8
Normal Work	6.3	2.3
Relationships with other people	5.6	2.4
Sleep	5.9	2.9
Enjoyment of life	6.0	2.4

Other Outcome Measures	Mean Score	Standard Deviation
HADS Anxiety	9.4	4.7
HADS Depression	8.4	4.0
S-LANSS	14.6	7.5
TSK	28.3	7.9
TSK-17	37.1	8.9
PSEQ	32.2	11.4

PCS	Mean Score	Standard Deviation
Helplessness	8.8	5.5
Magnification	3.7	3.0
Rumination	6.7	4.3

EQ-5D	Mean Score	Standard Deviation
Mobility	2.4	0.9
Self-care	1.9	0.9
Usual Activities	2.6	1.0
Pain/Discomfort	3.1	1.0
Anxiety/Depression	2.1	1.0

BPI Pain	Number
1Head	N/A
1Face	
1Neck	
1Neck and 1/2arms below elbow	
1/2 Shoulders	
1/2 Arms	
1/2 Hands	
1Th Spine	
1Lx Spine	
Lx and 1/2 Legs below knee	
Pelvis	
1/2 Hips/Legs	
Foot/Feet	
1Chest	
1 Abdo/Visceral	
1GynaeFemale	
1ME/FM	

4) NHS Lothian Pain Service Data

Year	Number of Patients
2014	0
2015	100
2016	48
Blank	10
Total	158

Gender	Number of Patients	%
Male	50	32%
Female	106	67%
Blank	2	1%

Age	Number of Patients	%
17-24	[redacted]	2%
25-34	[redacted]	4%
35-44	10	7%
45-64	25	16%
65+	18	12%
Blank	90	59%

Pain Type	Number of Patients
Predominantly musculoskeletal (e.g. LBP + non-radicular referred pain)	[redacted]
Predominantly neuropathic (e.g. brachial plexus injury)	[redacted]
Mixture musculoskeletal and neuropathic (e.g. LBP + radicular)	[redacted]
Musculoskeletal, Neuropathic and Visceral	[redacted]
Visceral	0
Blank	144

Body Part (not mutually exclusive)	Number of Patients
Headache	24
Face	[redacted]
Neck	33
Neck, 1 arm	[redacted]
Neck, 2 arms	[redacted]
1 shoulder	15
2 shoulders	13
1 arm	14
2 arms	14
1 hand	12
2 hands	23
TH Spine	21
Lx Spine	79
Lx 1 leg below knee	35
Lx 2 legs below knee	29
Pelvis (MSK not visceral)	[redacted]
1 hip/leg	35
2 hips/legs	29
1 foot	12
2 feet	31
Chest	[redacted]
Abdo/visceral	11
Gynae Female	[redacted]
ME/FM	0

Aetiology	Number of Patients
Degenerative (e.g. simple LBP)	[redacted]
Degenerative + radicular pain	[redacted]
Post-surgical (not laminectomy)	[redacted]
Post laminectomy syndrome	[redacted]
Trauma	0
Fibromyalgia/ME spectrum disorder	[redacted]
PHN	[redacted]
DN	[redacted]
CRPS	0
Central - spinal cord	0
Central - brain	0
Other - please specify	[redacted]
-	Coccyx Pain
Blank	141

Pain Duration	Number of Patients
0-6 months	[redacted]
7-12 months	18
13-18 months	[redacted]
18 months - 2 years	10
2-3 years	36
3-5 years	17
5-10 years	19
10-20 years	22
Over 20 years	[redacted]

Number of Medications (not exclusive to pain medications)	Number of Patients
1	21
2	19
3	20
4	24
5	56
6	40
7	29
8	19
9	[redacted]

Educational Attainment	Number of Patients	Percentage
None	25	20%
Standard Grades	29	23%
SVQ/NVQ	15	12%
Highers	17	13%
Advanced Highers	[redacted]	[redacted]
HNC	[redacted]	[redacted]
HND	11	9%
Degree	18	14%
Post Graduate Qualification	[redacted]	[redacted]

Work Status	Number of Patients	Percentage
Yes, full-time paid work	31	22%
Yes, part-time paid work	17	12%
Yes, voluntary work	[redacted]	[redacted]
No, because of pain	37	26%
No, not because of pain (student, home-maker etc.)	51	36%

Status	Yes	No
Lives Alone	39	114
Receives Benefits	72	79
Legal Proceedings/Compensation Related to Pain	[redacted]	143