DEEP Study: Indirect and Out-of-pocket Costs of Persistent Orofacial Pain

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Appendix Figure 1 Extract from Use of Services and Productivity Questionnaire (USPQ) to give example of questioning style and context to data

SECTION 1: CONSULTATIONS IN LAST 6 MONTHS

Over the **last *six months*** how many times have you visited the practitioners listed below and have you had to pay for the attendance? Please write the number of times in the relevant box below. Please give details of the hospital dental or medical specialties that you have visited for example: restorative dentistry, rheumatology etc. Please indicate if it was a private consultation ie paid for by yourself outside of the NHS. Please give the total private or NHS charges you had to pay for the consultation(s). Please do not include any prescription charges, just those for having the consultation.

...

Question 1.2 Visits to a General Dental Practitioner

Have you seen a general dentist? Yes ☐ No (move to question 1.3) ☐

If yes, did you see them as an NHS patient? Yes ☐ No ☐

How many times did you see the dentist? ☐☐☐

If you had to pay anything for your dental appointments, how much have you paid in total over the last six months? £☐☐☐-☐☐p

Appendix Figure 2 Extract from Time and Travel questionnaire to give example of questioning style and context to data

Section 1 PATIENT TRAVEL COSTS

This first part of the questionnaire asks about the costs of your **travel and attendance** at **any** of the following health care practitioners: General Medical Practitioner, General Dentist, Physiotherapist, Psychologist, Hospital dental specialist, Hospital medical specialist, Alternative therapy for example: chiropractor, osteopath, and acupuncturist.

Question 1.1

Have you ever visited any of the following healthcare practitioners regarding your pain in your mouth and or face? Please tick those that you have seen.

General Medical Practitioner ☐

General Dentist ☐

Physiotherapist ☐

Psychologist ☐

Hospital dental specialist ☐ Please give details of the specialties seen:

Hospital medical specialist ☐ Please give details of the specialties seen:

Question 1.2

Please complete **parts A-H** below for any practitioners you have indicated that you have seen in question 1.1 regarding your pain in your mouth and or face. Please give only **one** mode of transport per practitioner. If you have seen more than one practitioner with respect to your pain eg: 2 hospital specialists, put the additional details in part h "other".

A) ATTENDANCE AT GENERAL MEDICAL PRACTITIONER:

What was your normal mode of transport?

Walk/cycle ☐
Ambulance/hospital car ☐
Public transport (bus, train, metro) ☐ Cost of one way fare £☐☐-☐☐p
Taxi ☐ Cost of one way fare £☐☐-☐☐p
Private car/motorbike ☐ How many miles was a one way trip? ☐☐☐

What was your normal travelling time?

Travelling time ☐☐ hrs:☐☐ mins

What was the normal time spent at the general medical practitioner's surgery?

Time spent at surgery ☐☐ hrs:☐☐ mins

Did someone normally go with you to your appointment?

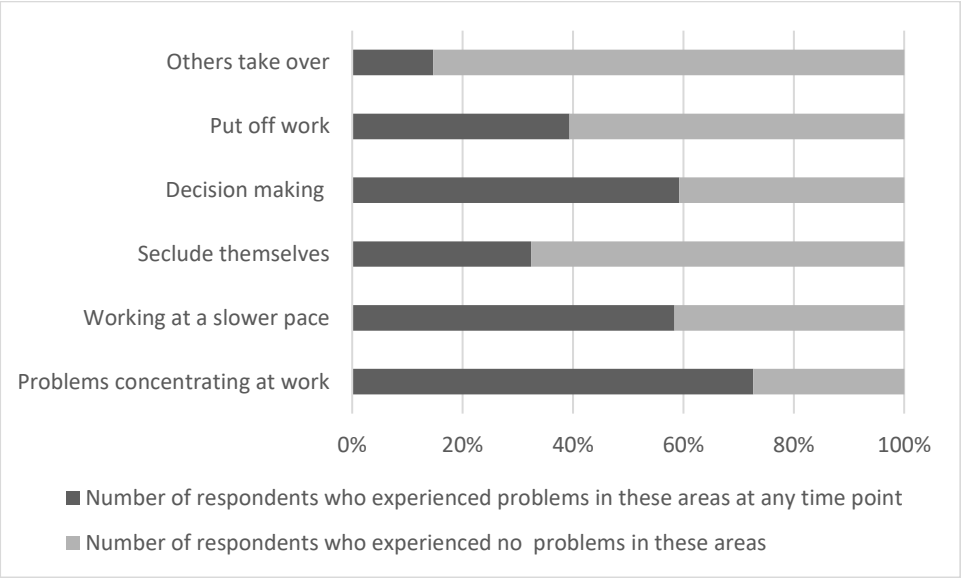
No ☐

Yes ☐

If Yes, please indicate who **normally** went with you to the practitioner below. You may tick more than one box if appropriate:

- Partner/spouse ☐
- Child/children under 16 years ☐
- Other relative ☐
- Paid caregiver ☐
- Other (please **specify)** ☐ Details:……..

Appendix Figure 3 Work attendance with health problems scale (Van Roijen et al. 1996) - 395 observations over 5 time points



Problems experienced at work as a result of POFP were converted from a 4-point ordinal scale response indicating frequency of problems (almost never, sometimes, often, almost always) to a dichotomized format (i.e. never or ever experienced problems) and pooled to provide a cumulative frequency of the employed subsample who had ever experienced the individual problem.

Appendix Figure 4 Adjusting for inflation procedure and worked example

Adjustment for inflation was applied so that all costs were calculated using 2012 prices. While calculation of many costs was based on 2012 reference costs (e.g. mileage rate, average income and valuation of leisure time) and adjustment for inflation was not necessary; other costs reported in questionnaires were comprised of actual expenditure e.g. public transport/taxi costs, out of pocket medication costs, consultation and treatment costs and therefore adjustment for inflation was required to convert these to 2012 prices. The adjustment for inflation method applied used Consumer Price Inflation (CPIH: an index inclusive of housing costs and reported by the Office for National Statistics to be the most comprehensive inflation measure) (Office for National Statistics 2017) with the following rates of inflation:

Year	CPIH % change over 12 months
2013	2.3
2014	1.5
2015	0.4
2016	1.0
2017	2.6

These were applied based on when an individual joined the study, for example if a patient joined the study in 2012 their M0 and M6 were considered to be in 2012 prices, their M12, M14 and M18 were considered to be in 2013 prices and their M24 questionnaire to be in 2014 prices. For example, if this patient reported an out of pocket expenditure on over-the-counter medication of £12 in their M12 use of services questionnaire, this was considered to be in 2013 prices and to convert to 2012 prices the relevant adjustment was applied as follows:

12 x (1/1.023) = £11.73

If the same individual, in their M24 questionnaire, reported expenditure on over-the-counter medication of £18, this was considered to be in 2014 prices and the following calculation was used to convert this to 2012 prices.

18 x (1/1.015) x (1/1.023) = £17.34

Appendix Figure 5 Worked example of a patient appointment unit cost for a patient attending their General Dental Practitioner for their POFP

Information provided by patient in time and travel questionnaire:

Normal mode of transport: Private car

Number of miles for one way trip: 6

Travelling time: 50 minutes

Time spent at surgery: 30 minutes

Accompanied to appointment: No

Was required to arrange childcare or care for dependents: No

Main activity if not attending appointment: Leisure activities

Cost calculation based on information provided above:

Travel cost:

6 miles x 2 journeys (for return journey) x £0.45 (HMRC mileage allowance) = £5.40

Time cost:

50mins (travelling time) + 30mins (appointment time) = 80 mins = 1.33 hours

1.33hrs x £5.16 (U.K. Government's Department of Transport value hourly time value for non-working individuals) = £6.86

Total appointment cost to patient = £5.40 + £6.86 = **£12.26**

Appendix Figure 6 UK Reference Costs

The following values were used when calculating costs for patient time and travel:

- For private vehicles, the UK's Her Majesty's Revenue and Customs (HMRC) 2012 mileage rate of £0.45 per mile was used (HM Revenue & Customs 2013).
- Leisure time was valued at £5.16 using the Department of Transport's hourly time value for non-working individuals (Department for Transport 2015).
- For the calculation of individual's daily and hourly wages; in a six month period, there were considered to be 26 working weeks and therefore in a month there were 4.33 weeks.
- In the case of incomplete employment data, a 2012 average UK hourly wage of £12.77 was used (Office for National Statistics 2016). For the generation of an average daily wage a working day was considered to last 7.5 hrs.

Appendix Figure 7 Calculating presenteeism costs using the QQ method

The QQ method, as described by Brouwer (Brouwer et al. 1999) was used to estimate the productivity loss using the quality and quantity data from the use of services and productivity questionnaire. Quality and Quantity were reported by respondents on a 0-10 scale where 10 was usual quality and 0 indicated very poor quality.

If a respondent who worked for 8 hrs a day reported 7 out of 10 on the quantity scale and 6 out of 10 on the quality scale the calculation was as follows.

Quantity loss (hrs) = (1-7/10) x 8 = 2.4hrs

Quality loss is calculated in the same manner, however before calculating the quality loss, the quantity loss is subtracted from the time worked i.e. we assume that the respondent worked the equivalent of 8-2.4 = 5.6hrs.

Quality loss (hrs) = (1-6/10) x 5.6 = 2.24hrs

The final QQ score is the sum of the quantity and quality loss calculated = 4.64hrs per day.

This value is multiplied by the number of days that the respondent reported working while experiencing pain and multiplied by their hourly rate of pay to estimate the total cost of presenteeism.

Appendix Figure 8 Imputation procedures and worked examples

Management of missing data was as follows:

Missing salary data were substituted by UK average values.

Missing time and travel data were not imputed at an item level as these were used to inform mean unit costs applied to patients with missing time and travel data (see example 1 below), However if a patient's partially complete data was greater than the mean unit cost value then this was used in preference to the mean unit cost.

Missing use of services and productivity data were assumed to be non-applicable where questions were left completely blank and hence a zero value was used. Where questions were partially completed (e.g. a respondent had indicated they incurred a cost but did not provide the amount) mean imputation was performed, at an item level. Median imputation was performed for categorical variables (those describing problems experienced at work).

Example 1. Imputation using average unit cost

A patient's total time and travel costs are the sum of the cost of their attendance at each of the healthcare professionals that they were asked about in the USPQ. If a patient had not provided information about a specific practitioner in the time and travel questionnaire then the average value of visits to that practitioner was used. For example, in their 18M USPQ, if a patient reported attending 3 GP appointments, 2 GDP appointments and 1 Physiotherapist appointment in the past in the previous 6 months, but had only provided time and travel information about their GDP (£3.60 per appointment) and Physiotherapist (£10.80 per appointment) in the Time and Travel questionnaire, then the mean value for a GP appointment (£11.62) was used. This patient's time and travel cost would be as follows:

Time and travel costs per 6 months at 18M:

= GP appointment cost x 3 + GDP appointment cost x2 + Physiotherapist appointment x1

= £11.62 x 3 + £3.60 x2 + £10.80 x1

= £52.86 per 6 month period.

Example 2. Imputation using average number of appointments

Similarly to the above example a patient may have indicated in their 14M month questionnaire that their time and travel costs for a GP visit was £5.60 and in their 12M questionnaire indicated that they had visited their GP in the previous 6 months but did not indicate how many times, this value was imputed using the mean number of GP appointments at that time point (4.4). Cost was then calculated using the imputed number of visits multiplied by the cost of their appointment.

= £5.60 x 4.4

= £24.64

Example 3. Imputation using average wage

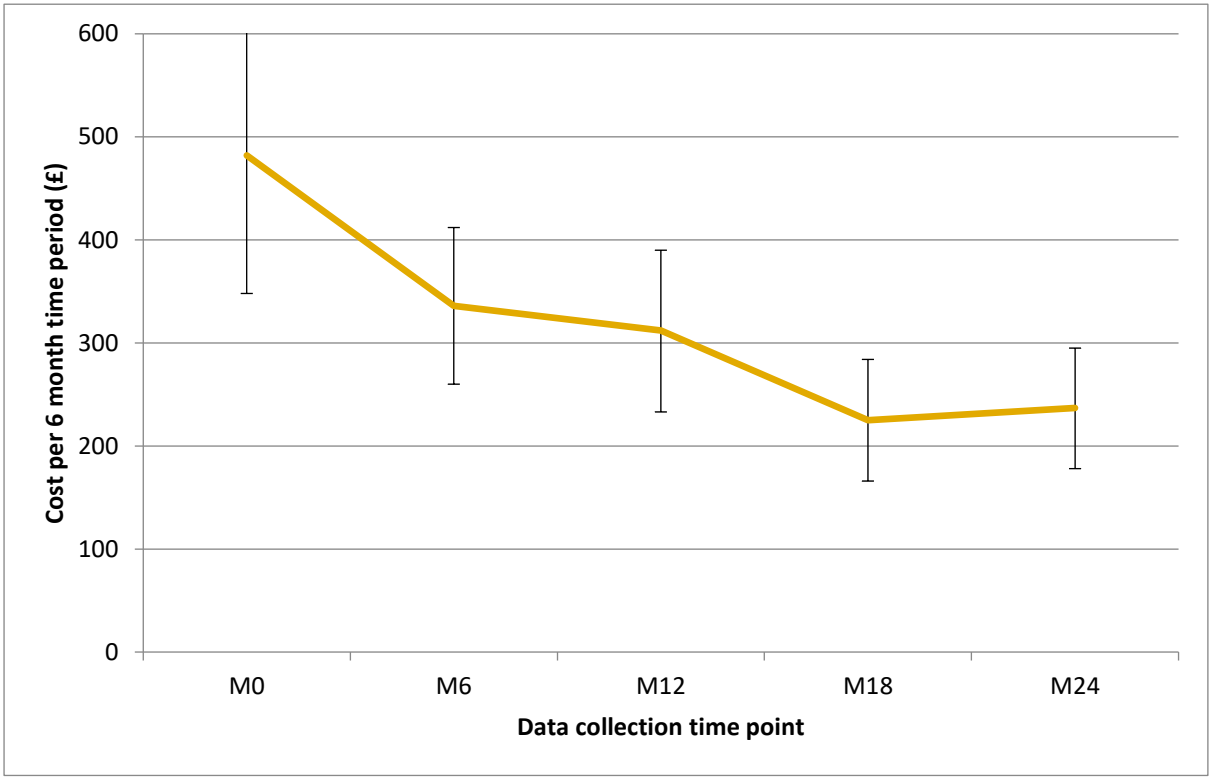
A patient's indirect costs (through absenteeism or presenteeism) are the sum of the time lost from work. If a patient had a QQ score (see calculation in Appendix Figure 5) of 4.64hrs per day, reported experiencing pain at work for 18 days in the previous 6 months, but had declined to provide income details in their CRF then the average UK average wage was used (£12.77):

Presenteeism cost per 6 month period = QQ score x hourly wage x days worked while in pain.

= 4.64 x £12.77 x 18

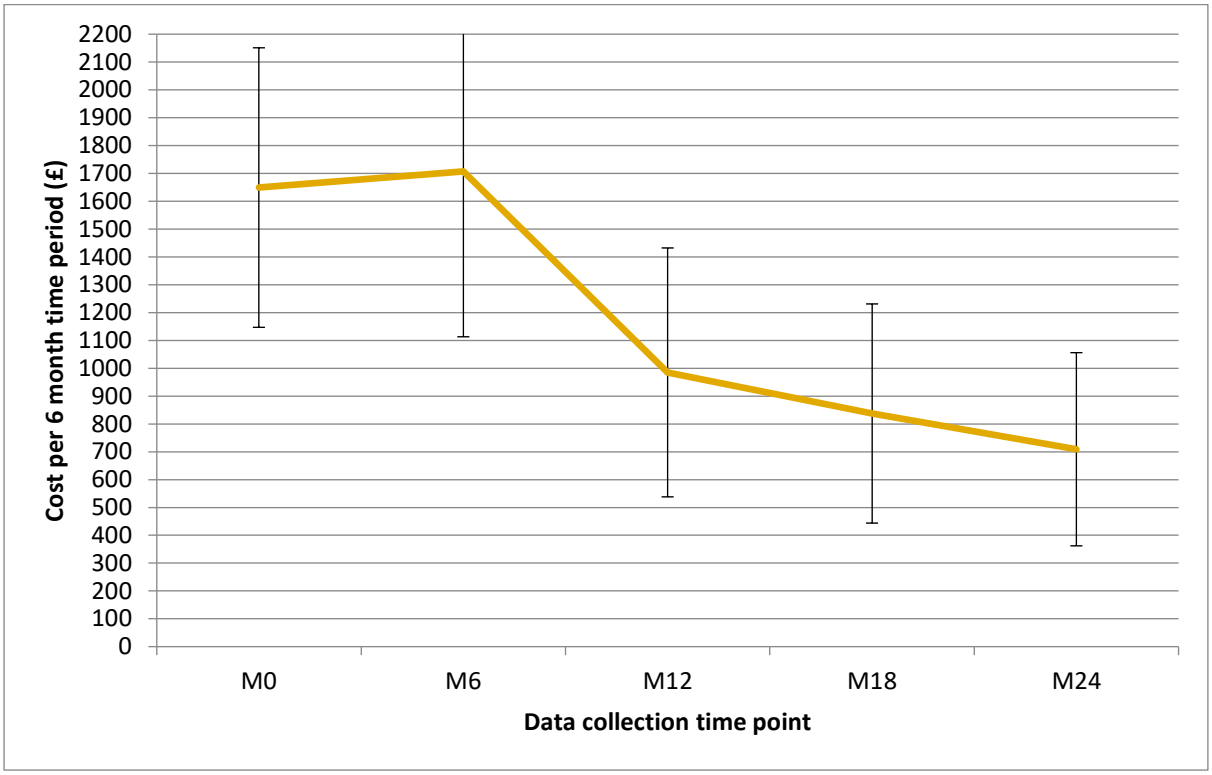
= £1066.55 presenteeism cost per 6 month period

Appendix Figure 9 Patient out of pocket costs over the 5 study time points



*A one way ANOVA and Bonferroni post-hoc test suggested significant differences between M0 and M12, M18 and M24 costs: ($F(4, 785) = 4.90$; $p<0.01$). Error bars represent 95% confidence interval of the mean cost at each time point.

Appendix Figure 10 Employer indirect costs over the 5 study time points



*A one way ANOVA and Bonferroni post-hoc test suggested significant differences between M6 and M24 costs: ($F(4,390) = 3.42$ $p<0.01$). Error bars represent 95% confidence interval of the mean cost at each time point.

Appendix Table 1 Recruitment location of those recruited at baseline[1]

Recruitment location	Recruited from clinic		Recruited by advertisement[2]		Total	Total
	N	%	N	%	N	%
General Medical Practice	49	24.3	21	58.3	70	29.4
General Dental Practice	32	15.8	15	41.7	47	19.7
Total primary (community, non-specialist) care	81	40.1	36	100	117	
Oral and Maxillofacial Surgery	40	19.8	-	-	40	16.8
Oral Medicine	13	6.4	-	-	13	5.5
Neurology/surgery	23	11.4	-	-	23	9.7
Restorative dentistry (Prosthodontics, periodontics, endodontics)	45	22.3	-	-	45	18.9
Total secondary/tertiary (specialist) care	121	59.9	0	0	121	
Total of all patients	202	100	36	100	238	100

[1] The one individual who withdrew their data at M18 is not included in this table therefore total is 238 instead of 239

[2] The advertisement was placed in primary care locations, local student halls of residence, university leisure centers, a local museum and several local pharmacies. Patients were classified based on their reported most recent use of health services.

Appendix Table 2 Generalized Gamma Linear Regression Model (Log Link Function) of factors associated with out of pocket costs (705 observations over 5 time points)

Variable	Coefficient	95% Confidence Interval		p value
Dichotomized GCPS* state (low, 0 to IIa; high, IIb to IV) (reference category: Low GCPS)				
High GCPS	0.78	0.57	0.99	<0.01
Time point (reference category: 0M)				
6M	-0.28	-0.56	-0.01	0.05
12M	-0.36	-0.64	-0.08	0.01
18M	-0.66	-0.95	-0.36	<0.01
24M	-0.53	-0.83	-0.22	<0.01
Age Group, years (reference category: 20-29)				
30-39	0.11	-0.35;	0.58	0.63
40-49	-0.11	-0.56;	0.34	0.64
50-59	0.03	-0.42;	0.49	0.88
60-69	0.55	0.10;	1.00	0.02
70-79	0.27	-0.23;	0.77	0.29
80-89	0.93	0.20;	1.65	0.01
Male (reference category: female)				
Male	-0.16	-0.43;	0.11	0.25
Education (reference category: no public examinations)				
Secondary examinations	0.38	0.05;	0.72	0.02
Degree or higher	0.41	0.08;	0.75	0.02
Collapsed IMD Score**(reference category: bottom 50%)				
Top 50%	-0.08	-0.29;	0.13	0.44
Diagnosis (reference category: musculoskeletal origin)				
Neuropathic/vascular	-0.36	-0.59;	-0.13	<0.01
Combined	0.23	-0.03;	0.49	0.08
Duration of pain, years (reference category: <1 year)				
1 - 4	0.57	0.24;	0.90	<0.01
≥ 5	0.52	0.20;	0.84	<0.01
Constant	4.79	4.16;	5.42	<0.01

*Graded Chronic Pain Scale

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Appendix Table 3 Patients reporting employment in the Use of Services and Productivity Questionnaire over the 5 time points

Time point	M0 (n=198)	M6 (n=172)	M12 (n=155)	M18 (n=136)	M24 (n=129)
Number reporting being in employment (%)	97 (48.99)	89 (51.74)	80 (51.61)	66 (48.53)	63 (48.84)

Appendix Table 4 Generalized Gamma Linear Regression Model (Log Link Function) of factors associated with indirect costs (352 observations over 5 time points)

Variable	Coefficient	95% Confidence Interval		P value
Dichotomized GCPS* state (low, 0 to IIa; high, IIb to IV) (reference category: Low GCPS)				
High GCPS	1.21	0.73	1.69	<0.01
Time point (reference category: 0M)				
6M	-0.14	-0.71	0.44	0.64
12M	-0.61	-1.23	0.00	0.05
18M	-0.28	-0.94	0.38	0.41
24M	-0.89	-1.54	-0.24	0.01
Age Group, years (reference category: 20-29)				
30-39	-0.27	-1.08	0.54	0.51
40-49	-0.15	-0.98	0.68	0.72
50-59	-0.20	-0.99	0.59	0.62
60-69	-1.65	-2.62	-0.68	<0.01
Male (reference category: female)				
Male	0.52	-0.10	1.13	0.10
Education (reference category: no public examinations)				
Secondary examinations	-0.81	-1.97	0.35	0.17
Degree or higher	-0.86	-2.05	0.33	0.16
Collapsed IMD Score** (reference category: bottom 50%)				
Top 50%	0.07	-0.39	0.53	0.77
Diagnosis (reference category: musculoskeletal origin)				
Neuropathic/vascular	0.05	-0.44	0.54	0.85
Combined	0.83	0.16	1.51	0.02
Duration of pain, years (reference category: <1 year)				
1 - 4	0.83	0.02	1.65	0.04
≥ 5	0.54	-0.30	1.38	0.21
Constant	6.93	5.58	8.28	<0.01

*Graded Chronic Pain Scale

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