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Full title: Patient Preferences for Pain Management in Advanced Cancer: Results from a Discrete Choice Experiment

Short title: Patient Preferences for Cancer Pain Management

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Declaration of Conflicting Interests

David Meads, John O'Dwyer, Phani Chintakayala, Karen Vinall-Collier and Claire Hulme have no interests to declare. Michael Bennett has no financial interests to declare but has conducted research which aims to improvement the self management of symptoms in the community.

Abstract

Background: Pain from advanced cancer remains prevalent, severe and often under-treated.

Aim: Conduct a discrete choice experiment (DCE) with patients to understand their preferences for pain management services and inform service development.

Design: Focus groups were used to develop the DCE attributes and levels. The attributes were: *waiting time*, *type of healthcare professional*, *out-of-pocket costs*, *side-effect control*, *quality of communication*, *quality of information*, and *pain control*. Patients completed the DCE along with clinical and health-related quality of life (HRQoL) questions. Conditional and mixed logit models were used to analyse the data.

Results: Patients with cancer pain (n=221) and within palliative care services completed the survey (45% female; mean age=64.6, range 21-92). The most important aspects of pain management were: good pain control, zero out-of-pocket costs and good side-effect control. Poor or moderate pain control and £30 costs drew the highest negative preferences. Respondents preferred control of side effects and provision of better information and communication, over access to certain health care professionals. Those with lower HRQoL were less willing to wait for treatment and willing to incur higher costs. The presence of a carer influenced preferences.

Conclusions: Outcomes attributes were more important than process attributes but the latter were still valued. Thus, supporting self-management, for example by providing better information on pain may be a worthwhile endeavour. However service provision may need to account for individual characteristics given heterogeneity in preferences.

Key findings and implications

- Patients value control of side effects and provision of better information, areas of care that are often poorly addressed.
- High out-of-pocket costs and long waits may deter treatment seeking at the end of life.
- Patients with poorer health-related QoL and those without family carers have different service preferences and these should be accounted for in service provision.

1. Introduction

Severe pain is experienced by over 50% of cancer patients in the last three months of life with only 8% reporting improvements in pain levels after receiving care.[1] Despite the efficacy of the WHO analgesic ladder approach to interventions, a European survey of 5,000 cancer patients found that 72% still experienced pain, 90% of which was of moderate-to-severe intensity.[1] Elsewhere, a US study found that 33% of cancer patients experiencing pain were receiving inadequate analgesic prescriptions.[2] Evidently, cancer pain is not being managed optimally [3], compromising the quality of life of patients [4, 5] and leading to greater healthcare costs, for example through increases in emergency admissions.[6]

Most patients with advanced cancer prefer to be cared for at home and to die at home.[7] Current NHS policy in England advocates a multidisciplinary approach to management of patients with advanced disease that prioritises pain and symptom management.[8] However, one UK regional study showed that poor pain control is the most frequent reason that cancer patients at home request urgent medical help.[9] This suggests that current service provision is not adequate and that improved support for community based self-management of cancer pain is needed. Improving the Management of Pain from Advanced Cancer in the Community (IMPACCT) is a UK research programme aimed at facilitating this.[10]

Eliciting patient preferences is important in clinical service design.[11, 12] Stated preference survey techniques such as discrete choice experiments (DCE) and best-worst scaling (BWS) surveys are increasingly being used to understand what is important to patients, particularly those with cancer.[13, 14] Preference elicitation techniques are important in economics because they force respondents to weigh-up the costs and benefits of possible alternatives and to make choices and trade-offs. In doing so, a closer approximation of how much ‘value’ respondents really place on the options and their attributes is gained compared to simply asking them what their preferences are.[15]

Several studies have established preferences for cancer treatments (e.g.[16]), pain care services [17] and to determine the trade-offs between pain control and side effects.[18, 19] However, only one (US-based) study has been conducted solely with cancer patients to understand their preferences for pain management.[20] This study found that the most important aspect of analgesic treatment for patients was ‘percent pain relief with analgesics’.[20] The findings have limited value for service planning as the study did not go beyond opioid treatments to consider preferences for wider aspects of pain management which are more related to the process of care such as information, waiting times and the type of healthcare professional providing care.

The aim of this research was to address this knowledge gap by conducting a preference survey exclusively with cancer patients experiencing pain in England. The survey sought to establish which aspects of pain management are most important to patients and their willingness to trade off between these in order to inform future service development policies.

2. Methods

Design: We conducted a discrete choice experiment (DCE) survey where respondents were presented with two unlabelled descriptions of hypothetical pain management services. The descriptions convey different service ‘attributes’ (e.g. ‘contact with GP’) and ‘levels’ (e.g. ‘Weekly phone call’ vs. ‘Monthly visit’) within each attribute.[14] Respondents are asked to consider the pain management service descriptions and choose which they would prefer to receive. In making their choices, respondents are assumed to estimate which would yield the overall greatest utility (or value) for them. Respondents complete several of these ‘choice tasks’ in the survey where some or all of the levels of options are altered. By observing participants’ responses to changes in the options, it is possible to quantify the relative strength of preference for the different attributes and levels presented and willingness to trade-off between them.

Attribute development: We followed guidance for the DCE design and development by incorporating qualitative research.[21, 22] We generated the content of the DCE survey through a literature review and focus group (n=2) work with patients (n=10; 40% male, median age=70; age range =48-86) with pain from advanced cancer who attended one of two hospices in Leeds. A topic guide (included in supplementary material) was developed following a scoping review and discussion with clinicians and used to facilitate the focus groups. Patients were asked to talk about their cancer pain, how well it was controlled, important aspects of pain management, the care they received and any service improvements they would like to see. Focus groups were audio recorded, transcribed verbatim and analysed by two researchers using thematic analysis following the recommendations set by Braun and Clarke aiming to identify key themes.[23] The transcripts were managed in NVivo (©QSR International, 2012). Key themes identified by the qualitative analysis of the focus groups included the supply of pain medications, the role of day centres/hospices, access to medications and education on morphine use (see supplementary material for full results summary). A long list of 16 attributes (supplementary Table A) was arrived at via consensus meetings between researchers, clinicians and nurses after discussion of the focus group results. A ranking exercise was conducted with a group of healthcare professionals (N=24) to reduce the list to a practicable number and to suggest attribute levels. A meeting was held with the healthcare professionals and they were presented with, and allowed to discuss, the draft attributes. They were then asked individually to rank order the eight attributes they felt were most important to patients. The ranking scores, focus group material and additional clinical expertise were used to refine the attributes including the collapsing and removal of some. The levels for out-of-pocket costs were informed by a previous feasibility survey covering healthcare resource use and patient costs completed in this patient group and part of the same research programme. Of the final seven attributes, four were comprised of three levels and three were comprised of two levels. The language of the final attributes and levels (shown in Table 1) were tested with patients prior to the main survey.

DCE survey: Ngene software (version 1.1.1 ©ChoiceMetrics Pty Ltd, Sydney, Australia) was used to create an efficient design of the DCE survey by maximizing D-efficiency. The design resulted in 36 binary choice sets that were divided into 6 blocks of 6 choice sets each. Each of the choice sets had all of the attributes present and all of the levels were represented but in different combinations across the 6 sets. Priors were not included in the design and, since there was no strong expectation of heterogeneity, interactions were also omitted. Each respondent was randomly allocated one block consisting of six choice tasks. In addition to the choice tasks, respondents completed socio-demographic questions, cancer and pain-related questions and the EQ-5D questionnaire.[24]

Sampling: Community-based patients with pain from advanced cancer who were aged 18 and over were eligible for the study. Advanced cancer was defined as metastatic cancer or that receiving palliative therapy. Patients with pain were defined as those receiving analgesic treatment for cancer symptom-related or therapy-related pain. Patients had to be able to complete the questionnaires and provide informed consent to participate. Patients completed the DCE in a pen and paper format with the research nurse present to help provide clarification if necessary. Thirteen palliative care services across England recruited patients to the study. Pre-specifying the required sample size for a DCE is complex, relying as it does on *a priori* knowledge of the parameters to be estimated in the models.[21] However, based on previous experience, we were confident that a sample of n=200 (assuming 7 attributes each with $\leq$3 levels and 6 choice task completions by each respondent) would provide sufficient data to estimate robust models. Ethical approval was granted by NRES Committee South East Coast - Brighton and Sussex (Reference: 13/LO/0662).

Analysis: The data was analysed using conditional and mixed logit models. The size and direction of the coefficient indicated the importance of that level in determining the choice of the individual and can be considered to represent preference weights.[14] The model coefficients were used to provide marginal rates of substitution between different pain management attributes, denoting respondents' willingness to 'trade-off'. To facilitate this, the levels of two attributes (out-of-pocket costs and waiting time) were entered into the model as continuous variables. The central value of the range was taken as the value for waiting time. The 'out-of-pocket costs' attribute was used as the subjective valuation mechanism; however, we acknowledge the values produced may not reflect willingness to *pay* for services. All other explanatory variables were treated as categorical and dummy coded in the analysis. Interactions were tested between attribute levels and sub-groups to test for heterogeneity of preferences. Sub-groups tested were: age group (above/below median of 66 years); gender; whether patients had an informal carer (defined as completion of a carer questionnaire) or not; cancer duration groups (above/below median of 1.5 years); pain severity groups (mild vs. moderate/severe); pain relief groups (<70% vs. ≥70%); EQ-5D groups (above/below median of 0.52); and healthcare cost groups (above/ below median monthly cost of £430). We also ran a model using effects coding [25] for categorical variables; as this provides a coefficient for all levels we can illustrate the preference change with each level. The mixed logit model informed on the level of unobserved heterogeneity in the preferences; we assumed this was present in all parameters and tested this by allowing all to be random in the analysis. Relative model quality was judged using Akaike and Bayesian Information Criterion values (AIC and BIC). All analyses were conducted in STATA (©StataCorp, Texas, USA).

3. Results

3.1. Patient sample*:* Two hundred and forty-eight patients were recruited and completed the survey. There were some missing data with 27 (10.9%) completing the resource use and quality of life sections of the survey but not attempting the DCE section. There was 3% missing or spoilt responses from those who did complete the DCE section. Pearson Chi^2 tests indicated that non-completion of the DCE was not related to gender or pain severity but there was a trend that those in the older age group (over 66 years) were less likely to complete the survey (p=0.032). Those whose highest level of education was secondary school also appeared more likely to not complete the DCE than those who received a college or university education (p=0.002). The sample characteristics are included in Table 2. Almost all participants were white Caucasian but there was a good distribution across pain severity and EQ-5D scores. See supplementary material for block completion samples.

3.2. DCE analysis: Results of the conditional logit model and mixed logit model are included in Table 3. Conditional Logit: Squared terms for the waiting time and cost attributes were not significant and excluded from the final model. The model and coefficients were significant with all the estimated preference coefficients being negative. Thus, less desirable levels were associated with reduced utility which indicated that the survey had theoretical validity. The ordering of the level coefficients for the pain control attribute was also as anticipated: moderate pain control was worse than good control, and poor pain control was worse still. Limited non-satiation tests were possible due to the survey design but indicated that only 2.7% of people provided an irrational response (in 36 choices). Preference weights for the levels with effects coding are shown in Figure 1. The greatest preference was for good pain control with lower levels of positive preferences for immediate service (0 waiting time), seeing a specialist pain doctor, incurring no out-of-pocket costs, having good side-effect control and good communication and information. By some margin the level leading to the greatest utility decrement was poor pain control, followed by an out-of-pocket expense of £30 and then moderate pain control. We conducted an exploration of dominance in responses and did find evidence for this. For example, 33.5% of respondents always chose the option where pain control was better, compared to 4% always choosing an option based on waiting time.

A number of the interactions between attribute level and respondent characteristic were significant (see supplementary Table B). Males were more averse to poor side-effect control than females (p=0.042). Those with lower EQ-5D scores were less willing to accept poorly controlled side-effects (p=0.026), less willing to wait for treatment (p=0.002) and willing to incur higher out-of-pocket costs (p=0.021) in receiving pain management. Those who had cancer for longer were more averse to severe pain (p=0.036), perhaps reflecting real experiences of sub-optimal management. There also appeared to be some heterogeneity according to the level of support an individual had as those who had a carer were more likely to accept pain management by a GP (p=0.017) and willing to incur higher out-of-pocket costs (p=0.007) than those who didn’t have a carer. Interactions with pain level (mild vs. moderate or severe) were largely insignificant although, counter-intuitively, those who had mild pain were more averse to waiting for treatment. A finding more in line with expectations was that those with poor pain relief (<70%) were less willing to wait for treatment.

Mixed Logit: The mixed logit model appeared to improve fit statistics however preference weights were very similar to those for the conditional logit model (Table 3). Notable differences were an increased disutility associated with specialist pain nurse care, poor side-effect control and poor information in the mixed logit model. This model also had the effect of decreasing the disutility associated with moderate pain control and increasing it slightly for poor pain control. The results indicated that there may be significant heterogeneity in four parameters: waiting time, out-of-pocket costs, communication and good pain control. Although on average patients preferred lower wait times, lower cost, good communication and good pain control the results suggest there may have been some heterogeneity present. From the magnitudes of the mean estimates and the corresponding standard deviations, z scores (standard normal distribution) were calculated and indicate that 8% preferred longer waiting times, 14% preferred higher costs, 8% preferred poor communication and 3% did not prefer good pain control.

We calculated willingness to wait and pay based on mixed logit models by keeping the cost or wait time as fixed (and all others random). Table 4 includes the trade-offs in the form of willingness to wait and pay for the different pain management attributes based on the mixed logit results. On average, patients valued a reduction of one day in waiting time as equivalent to £7.72. This may also be interpreted as meaning that patients were willing to incur costs of £7.72 to avoid waiting a day for treatment. Similarly, patients valued seeing a specialist pain doctor rather than a GP as equivalent to £23.80 and good side-effect control, good information and communication (vs. poor) were valued between £27 and £35. Avoiding poor pain control was highly valued at around £83 per month. When the trade-off was between the waiting time and the rest of the treatment aspects, patients would be willing to wait 3.26 days longer to see a specialist pain Dr rather than a GP and approximately an additional 3.5-4-5 days to achieve good side-effect control and to receive good information and communication. Willingness to wait for good pain control (vs. poor) was much higher, an average of just over 11 days.

4. Discussion

We found that the most important aspects of pain management were: good pain control, incurring zero out-of-pocket costs and good control of side-effects. Poor and moderate pain control and £30 out-of-pocket costs drew the highest negative preference weights. There was little evidence that patients were willing to trade pain outcomes for aspects of process, (or health for process utility) as the pain attribute was much more important than the others presented. However, the other outcome attribute (control of side-effects) was much less powerful and good side-effect control yielded preference weights similar to receiving good information about pain management and seeing a specialist pain doctor. Previous studies have suggested the negative impact of analgesic side-effects was significant and that patients would often trade-off pain control against the side-effects of pain medications. For example, Chancellor et al [18] found pain impact was second in importance to nausea side-effects in their DCE and Gregororian et al [19] found that both chronic and acute pain patients rated avoiding vomiting as more important than pain relief; nausea was almost as important. These findings are echoed elsewhere although Meghani and colleagues found it was the type of side-effects (with nausea and vomiting being the worst) that was more important than their severity.[20]

In general, patients preferred to be seen by a healthcare professional other than a GP; this may be a real preference reflecting experiences but may have been influenced by the level descriptors of 'specialist' pain doctor or nurse for the other two attribute levels. The preference weights suggest that, while respondents preferred immediate treatment with zero out-of-pocket costs, they were willing to wait a few days for treatment and incur some costs (£10). Respondents were willing to incur costs ranging £23.80 to £34.42 to reduce waiting time by 4 days, receive good information and communication (vs. poor) and to see a specialist pain doctor (rather than a GP). However, they were willing to incur costs over £83 to receive good pain control. For the superior attribute levels, patients were willing to wait around 4 days but would wait over 11 days for good pain control (vs. poor).

A number of the interaction effects were significant suggesting pain management preferences depend on patient characteristics and circumstances, especially patients' level of health-related quality of life (HRQoL) and whether they have an informal carer or not. Several of these effects appear to provide evidence of the internal validity of the DCE. For example, those with lower HRQoL were less willing to wait for treatment and willing to incur higher out-of-pocket costs. The mixed logit results also indicate significant heterogeneity in preferences for several of the service aspects. For a small minority, there was a suggestion of counter-intuitive preferences (e.g. prefer longer wait times for treatment); this may be due to a lack of participant understanding or engagement or be an artefact of the survey design.

Strengths and limitations

This is the most in-depth study to date employing stated preference techniques to elicit the preference of cancer patients in palliative care for pain management. The use of DCE methodology enabled the capture of 'process' utility; the value placed on services and interventions that is not readily measurable by the standard quality-adjusted life year (QALY) approach.[26, 27] For example, feeling confident about how much morphine to take may have little value in the QALY framework but here was shown to be important to patients in terms of the value placed on good information. While overwhelmingly patients preferred positive pain outcomes, it was clear that people also valued process aspects of service including good information and communication.

While the design of the survey was based on patient input, the sample size for the qualitative aspect of the study was probably below the optimal. In addition, we relied in part on healthcare professionals to inform attribute selection and this may have led to a different DCE design than had we relied solely on patients. However, the substantial breadth and depth of experience of the healthcare professionals brought was valuable and the survey was checked with patients prior to being finalised. As the survey sample were almost all white Caucasian and since those who completed the survey had higher levels of education than those who didn't, the generalizability of the findings to other groups requires some caution. We did not test patient's understanding of the DCE method although the DCE was carefully explained to individuals. Caution is required in interpreting the 'willingness to pay' values for two reasons; these values were based on a costs incurred attribute and they are influenced by the expectations of the respondents. Thus as healthcare is free at the point of use in England, these values may not represent the willingness to pay *should* patients be required to pay but, rather, where healthcare is 'free', they represent the willingness to incur costs in accessing that care. Thus, the values may not be generalizable to other types of healthcare system. However, they still highlight the importance of out-of-pocket costs for patients. Finally, as in all stated preference studies, the caveat must be applied that the responses may neither accurately reflect true preferences nor reflect well the actual choice behaviour by patients in reality.[28] However, in the absence of demand information for new services, it is likely that the preferences provided by such surveys can still improve decision making overall.

Future research could explore the use of stated preference techniques alongside economic evaluations to determine the cost-per QALY of each attribute and level and enable the identification of services that meet demand but are also cost-effective. This may face several challenges, not least the issue of who should value services and interventions, the patient or the general population.[29]Additional research is also required to establish the external validity of the survey predictions if they are to be the basis for decision making.

Implications for clinical practice

Not surprisingly, good pain control was the most important factor in pain management preferences. However, patients also valued good information and communication, and control of side effects. Providing information such that the patient has increased confidence in taking analgesics, or providing continuity of care, for example, may be relatively low cost routes to improving services. GPs were the least preferred healthcare professional; however, the preference for information and communication outweighed that for certain healthcare professionals. These findings suggest that supporting self-management of cancer pain (for example better information on pain, medicines management, dealing with side effects, etc.), would be valued by patients. High out-of-pocket costs might deter treatment seeking for patients at the end of life and hence should be minimised where possible. The heterogeneity in results also suggests particular attention should be focused on those with the lowest HRQoL and for those who do not have an informal carer. These groups of patients may feel less supported and had different preferences for care, particularly for more prompt response by a health care professional. Thus, service development must allow for heterogeneity in preferences and be sensitive to personal factors and health status, especially when choices are offered.

5. Conclusions

The preferences for pain management in advanced cancer were strongest for outcomes but aspects of the process of care were also valued. Thus, while pain control should remain the focus, supporting self-management, for example by providing better information on pain may be a worthwhile endeavour. However service provision may need to account for individual characteristics given heterogeneity in preferences.

Keywords: discrete choice experiment, cancer pain, patient preferences

Author contributions:

David Meads designed the study, analysed the data and wrote the manuscript; John O'Dwyer helped design the study, write the protocol, was involved in the generation, testing and refinement of the survey and managed data collection; Claire Hulme was involved in the study design and interpretation of results; Phani Chintakayala provided guidance on the survey design, analysis and interpretation; Karen Vinall-Collier helped with the ethics application, conducted the qualitative analysis and helped with site co-ordination; Michael Bennett assisted with the survey design and set-up, provided clinical input, helped interpret the results and write the paper.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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Table 1: Final attributes and levels

Attributes	Levels		
Waiting time for reliable medical advice and pain treatment	No wait (Immediate)	1 to 2 days	3 to 7 days
The healthcare professional who is responsible for your pain management	Specialist Pain Doctor	Specialist Nurse	Your GP
Out-of-pocket cost to you per month (e.g. costs such as prescriptions, travel, parking & telephone call that you would have to pay)	£0	£10	£30
Level of control over the side-effects of pain treatments	Good control	Poor control	
Level of communication between your GP, pharmacist and you	Good	Poor	
You are given information which makes you confident about taking the right amount of morphine	Yes	No	
Level of pain control during the day and night	Good Control	Moderate Control	Poor Control

Table 2: Sample characteristics

N = 221	**Mean (SD)**	**Range**
Gender		
N Female	100 (45.25%)	--
Age	64.66 (12.27)	21.6-92.2
Ethnicity		
White	218 (98.64%)	--
Other	3 (1.36%)	--
Highest level of education		
University or college or equivalent	63 (28.90%)	--
Intermediate between secondary level and university	51 (23.39%)	--
Secondary school	102 (46.79%)	--
Primary school (or less)	2 (0.92%)	--
Time since diagnosis (years)	3.35 (3.91)	0.4-18
EQ-5D Utility Index*	0.42 (0.33)	-0.43-1
EQ-5D VAS	55.22 (21.36)	10-100
Pain severity in last 24 hours (0-10)**		
No or Mild (0-4)	100 (45.66%)	--
Moderate (5-6)	67 (30.59%)	--
Severe (7-10)	52 (23.74%)	--
Pain relief in last 24 hours (0-100%)	64.81 (24.13)	0-100
How satisfied have you been with the pain management service you received over the last month?		
Very satisfied	96 (44.86%)	--
Quite satisfied	79 (36.92%)	--
Neither satisfied nor dissatisfied	24 (11.21%)	--
Quite dissatisfied	9 (4.21%)	--
Very dissatisfied	6 (2.8%)	--

*EuroQoL 5 Dimension questionnaire; high scores represent better quality of life

**Average severity

Table 3: Logit model results

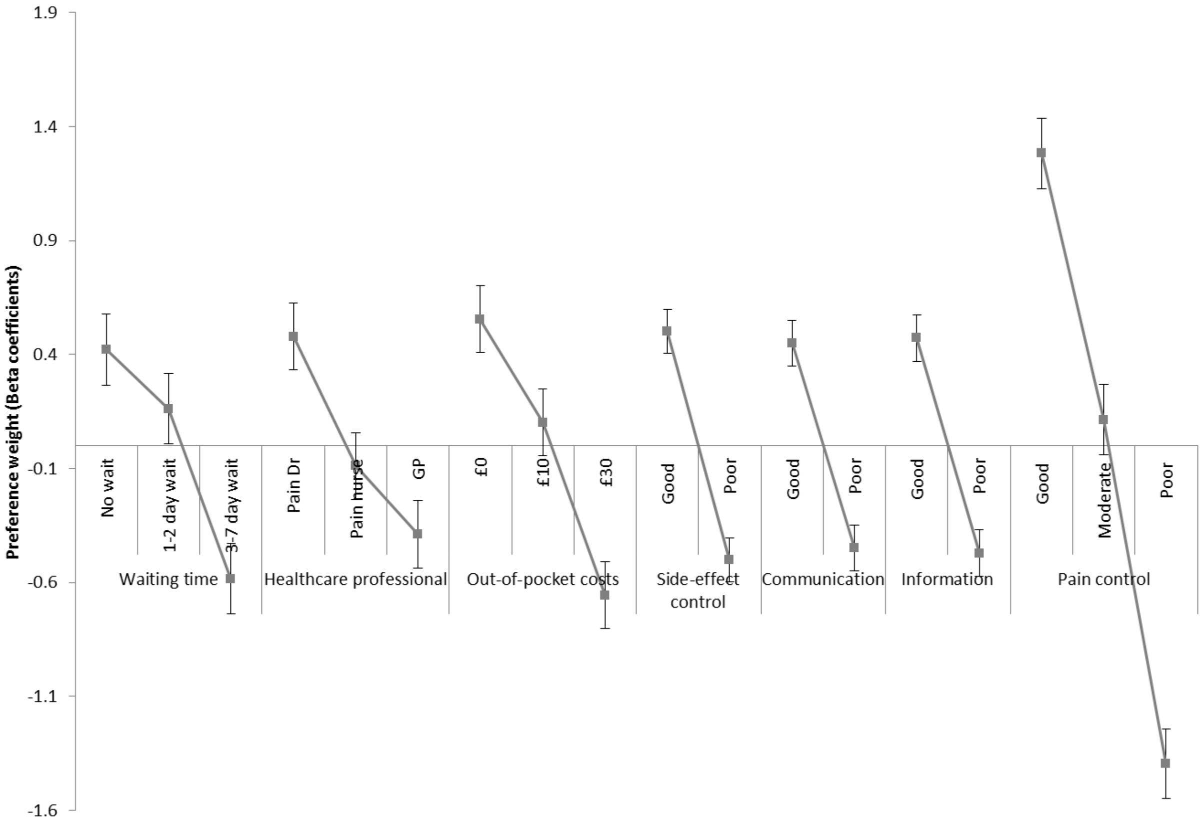
	Conditional Logit		Mixed Logit	
Choice Level	β	SE	β	SE
Waiting time	-0.205**	0.025	-0.255**	0.042
Professional (Specialist pain Dr vs.)				
Specialist pain nurse	-0.566**	0.131	-0.675**	0.232
GP	-0.869**	0.124	-0.812**	0.157
Cost	-0.040**	0.004	-0.034**	0.006
Side-effect control (Good vs.)				
Poor	-1.001**	0.098	-1.118**	0.149
Communication (Good vs.)				
Poor	-0.899**	0.101	-0.890**	0.146
Information (Good vs.)				
Poor	-0.942**	0.103	-1.128**	0.164
Pain control (Good vs.)				
Moderate	-1.154**	0.122	-0.617**	0.206
Poor	-2.683**	0.138	-2.727**	0.297
Standard Deviation				
Waiting time			0.184**	0.042
Professional (Specialist pain Dr vs.)				
Specialist pain nurse			0.653	0.232
GP			0.179	0.157
Cost			0.031**	0.006
Side-effect control (Good vs.)				
Poor			0.103	0.149
Communication (Good vs.)				
Poor			0.644**	0.146
Information (Good vs.)				
Poor			0.172	0.164
Pain control (Good vs.)				
Moderate			0.049	0.206
Poor			1.463**	0.297
Log-likelihood	-965.91		-537.90	
AIC	1948.82		1111.79	
BIC	2002.50		1217.14	
No. observations	2572		2572	
No. of respondents	221		221	

*Assumed positive; **P<0.001; AIC = Akaike Information Criterion; BIC = Bayesian Information Criterion

Table 4: Willingness to pay and wait for service attributes [mixed logit model]

	Willingness to pay (£)			**Willingness to wait (Days)**		
Level	Mean	Lower CI	Upper CI		Lower CI	Upper CI
Waiting time (Days)	£7.72	£4.60	£10.83	N/A		
Specialist pain nurse	£20.70	£6.51	£34.89	3.06	1.13	0.18
GP	£23.80	£14.16	£33.44	3.26	1.84	5.00
Cost	N/A			0.13	0.08	0.18
Poor side-effect control	£33.87	£22.17	£45.58	4.53	3.13	5.93
Poor communication	£27.37	£17.67	£37.07	3.57	2.47	4.68
Poor information	£34.42	£22.70	£46.15	4.42	3.17	5.68
Moderate pain control	£19.72	£6.61	£32.83	2.74	0.79	4.68
Poor pain control	£83.30	£57.06	£109.54	11.18	8.34	14.02

Figure 1: Preference weights for service attributes [effects coded, conditional logit results]



Supplementary Table A: Long list of potential attributes

Category	**Attribute**
Pain control	Level of pain control
	Sleep quality following pain control
	Chance of admission to hospital due to uncontrolled pain
	Pain control during chemotherapy
Access issues	Access to advice on pain
	Length of wait to see your GP/Consultant
	Chance of running out of your pain medication at home
	Pain medication was delivered or needed to be picked up
Side-effects	Control over the pain medication side-effects
Education and knowledge	Confidence in taking the right amount of morphine
	The type of healthcare professional who treats you
	GP knowledge of your treatment options
	Having the same contact person
	Amount of information provided about pain treatments
	Level of communication between you, the pharmacist and your GP
Costs	Out-of-pocket costs

Supplementary Table B: Interactions [conditional logit]

Interactions of attribute x sub-group variable were tested individually. Only significant interactions (where p<0.05) from these are reported below.

Sub-group	**Interaction (Sub-group#attribute level)**	**β**	**SE**	**Z value**	**P value**	**N**	**AIC**	**Interpretation**
Gender	Male#Side-effects	-0.387	0.190	-2.03	**0.042**	2572	1947.7	Males are much more averse to poor side-effect control than females
Pain severity group	Severe Pain#Wait	0.113	0.045	2.51	**0.012**	2554	1929.6	Those who are mild are more averse to waiting for advice and treatment
Pain relief group	Good relief#Wait	0.156	0.046	3.41	**0.001**	2500	1894.1	Those with poor pain relief are less willing to wait for treatment
HRQoL group	High HRQoL#Side effects	0.432	0.194	2.23	**0.026**	2560	1941.4	Those with low HRQoL are much more averse to poor side-effect control than those with higher HRQoL
	High HRQoL#Wait	0.142	0.046	3.11	**0.002**	2560	1936.6	Those with low HRQoL are less willing to wait for treatment than those with higher HRQoL
	High HRQoL#Cost	-0.018	0.008	-2.31	**0.021**	2560	1941.0	Those with low HRQoL are willing to incur higher out-of-pocket costs in receiving treatment than those with higher HRQoL
Duration group	Long duration#Moderate pain	-0.137	0.235	-0.58	0.56			
	Long duration#Severe pain	-0.520	0.248	-2.1	**0.036**	2528	1931.5	Those who have had cancer for longer are more averse to severe pain than those who have had it for less time
NHS Cost group	High cost#Wait	-0.109	0.045	-2.44	**0.015**	2572	1945.9	Those with higher costs/health care use are much more averse to waiting for services than lower cost individuals
Informal carer group	Has carer#Specialist Nurse	0.090	0.237	0.38	0.704			
	Has carer#GP	0.570	0.238	2.39	**0.017**	2572	1947.4	Those who have a carer are much more likely to accept healthcare provision by a GP than those without a carer
	Has carer#Cost	0.022	0.008	2.71	**0.007**	2572	1944.4	Those with a carer are willing to incur higher out-of-pocket costs in receiving treatment than those without a carer

AIC = Akaike Information Criterion

1. Please consider the two options below. They describe different services that may be available for cancer-related pain management. We would like you to think about the aspects of each service and to choose which one you would prefer to receive.

Please tick one box to indicate which service you would prefer

	Service 1:	**Service 2:**
Waiting time for reliable medical advice and pain treatment	1 to 2 days	No Wait (Immediate)
The healthcare professional who is responsible for your pain management	Specialist Pain Doctor	Specialist Nurse
Out-of-pocket cost to you per month (e.g. costs such as prescriptions, travel, parking & telephone calls that you would have to pay)	£30	£0
Level of control over the side-effects of pain treatments	Poor control	Good control
Level of communication between your GP, pharmacist and you	Poor	Poor
You are given information which makes you confident about taking the right amount of morphine	No	Yes
Level of pain control during the day and night	Moderate Control	Poor Control
Please tick only one option:	☐	☐

IMPACCT Health Economic Patient Preference Focus Groups

Discussion Guide

Welcome and Introductions	**Time: 3 mins**
• Introduce facilitator and rapporteur • Introduce Academic Unit of Health Economics • Introduce IMPACCT project - aims	
Aims of session	**Time: 3 mins**
• To talk to people with experience of cancer-related pain • Get an understanding of what is important to them in terms of the care they receive • To generate an open discussion (not a question and answer session)	
Ground rules and participant introductions	**Time: 3 mins**
• Explain the role of the facilitator and rapporteur • Cover confidentiality and anonymity • Consent forms • We would like to audio record the session just to make sure we don't miss any important points – any names mentioned will be wiped from the audio transcripts • Ask participants to introduce themselves and brief details of their illness history • Any questions before starting?	
Question 1:	**Time: 15 mins**
What has been your experience of receiving treatment for your cancer pain? What were the good and bad points in the care you received? Probes Location of care Access to healthcare staff (e.g. for assessment/advice) Access to treatment (ease/convenience and speed)	

Efficacy of treatment

Assessment and management of side effects

- constipation,
- mental cloudiness/sleepiness,
- mood changes/alterations,
- nausea,
- respiratory depression,
- sleep disorders/ hallucinations,
- sweating
- vomiting

Expertise of staff (which types)

Time spent with healthcare staff

Level of personal control over treatment and decisions

Communication with healthcare/voluntary sector staff

Sufficient follow-up?

In line with expectations?

Question 2:	**Time: 15 mins**

What are the most important aspects of cancer pain management for you?

Probes

Location of care

Access to healthcare staff (e.g. for assessment)

Access to treatment (ease/convenience and speed)

Efficacy of treatment

Assessment and management of side effects

Expertise of staff (which types)

Time spent with healthcare staff Level of personal control over treatment and decisions Communication with healthcare/voluntary sector staff Sufficient follow-up? In line with expectations?	
Question 3:	**Time: 15 mins**
If you were designing a service to provide cancer pain care what would it look like? Probes Ask why participants choose factors they do Is there a consensus in the group about factors? If not, why? Subgroup factors?	
Question 4:	**Time: 10 mins**
How does management of cancer pain affect your carers/friends and family? Probes Additional time or travel required? Practical implications for care they provide? Emotional impact?	
Additional questions from discussion	**Time: 5 mins**

Summary	**Time: 5 mins**
• Run through and check key factors and discussions • Anything missed from discussions?	
Session end	**Time: 2 mins**
• Complete socio-demographic questionnaire • Re-iteration of confidentiality and anonymity • Thanks for participation	
	Total time: 1 hr 16 mins

Analysis plan IMPACCT focus groups analysis

The data collected in the focus groups was subjected to a thematic analysis in order to gain a sense of the predominant or important themes. The themes identified, categorized, coded and analysed therefore serve as a reflection of the entire data set offering a rich overall description.

Thematic analysis was undertaken following the recommendations set by Braun and Clarke (2006) as a means of 'identifying, analysing and reporting patterns (themes) within data. Firstly, the transcripts of the audio recording were read to identify meaningful units of text relevant to the research topic. Second, units of text dealing with the same issue were grouped together in analytic categories and given provisional definitions. The same unit of text could be included in more than one category. The interpretation of these themes was conducted by a process of reading and re-reading. Third, the data were systematically reviewed to ensure that a name, definition, and exhaustive set of data to support each category were identified. Once coding was complete the data was examined for differences and commonalities both within and across code categories. Finally themes were grouped into a thematic diagram in order to interpret the interrelationships.

Themes for discussion and development:

Supply Management

- Planning/ordering ahead to ensure they have enough pain medication
- Worry/panic caused from low stock, especially at weekends
- Pharmacist role; communication with GP helpful
- Problems with delivery service; orders not always correct.
- Inflexible delivery times: Tied to home waiting for delivery –"*They can't give you a time/You've got to be in all day*"
- New packaging can cause issues. New types of tablet can lead to problems swallowing
- Day-centre plays an important role in re-assessing medications & solving problems
- Having organised pill boxes; problems remembering reduced –"*then I know I've taken them and I've not taken too many*"

- GP computer places limitations on prescription renewals

Day-Centre/Hospice

- Helps to avoid A&E and hospitals
- Some were not aware of benefits of attending as a day patient. One patient thought there would be no exit on entry.
- Re-assessing pain relief & sorting problems with GP & pharmacy
- Friendly & empathising
- Role of nurses at day-centre valued

Sleep

- Pain meds cause drowsiness
- Sleeping at day time
- Disturbed sleep at night due to pain & discomfort
- Lack of comfort; trouble breathing; joint pain at night
- Aids (E.g. pillows and grab-rails) for comfortable sleep & getting out of bed

Morphine/Morphine Education

- Side-effects; constipation, drowsiness, appetite etc.
- Building up a tolerance over time might make it tough to keep track
- Finding the right balance between pain control and being "knocked out"
- Some patients avoid taking morphine due to side-effects & fear of overdose; using other therapies instead; E.g. hot-water bottle, hot bath (Morphine education)

24hour access/Specialist Access for Cancer

- Longer appointments would be helpful as patients wouldn't feel rushed
- GPs should have a good knowledge of pain medication and new pain relief treatments
- GP familiarity with case and patient history; continuity of care
- Avoiding A&E: emergency out of hours access to pain relief
- Understanding of patients physical and emotional difficulties
- Pharmacy links to GP helpful
- More accessible, both GPs and consultants

Psycho-social side

- Distress caused by cancer pain - "*A constant reminder that you have cancer*".

- Impatience and envy of healthy people; Intolerant of their minor health problems
- Involving family in pain management allows them to feel useful
- Social life; Pain unpredictable so can’t plan ahead
- Sexual relations suffer
- Self-care deteriorates due to pain

Mobility Aids and House-Modifications

- Sleeping aids to promote restful sleep
- Grab rails for getting in/out of bed and bath

Chemo & Co-morbities

- Side-effects & impact on pain management

Samples completing survey blocks*

Block No.	n	Percent	Cumulative
1	38	17.19	17.19
2	33	14.93	32.13
3	36	16.29	48.42
4	34	15.38	63.80
5	42	19.00	82.81
6	38	17.19	100.00
Total	221		

*Pair specific samples not presented as they were unique to each block and missing data were minimal