The views of patients and the general public about expensive anti-cancer drugs in the NHS: a questionnaire-based study

Valerie A Jenkins[1] • Ivonne Solis Trapala[2] • Louise Parlour[1] • Carolyn I Langridge[1] • Lesley J Fallowfield[1]

[1]Cancer Research UK Psychosocial Oncology Group, Brighton & Sussex Medical School, University of Sussex, UK
[2]School of Health & Medicine, Lancaster University, UK
Correspondence to: Valerie A Jenkins. Email: val@sussex.ac.uk

DECLARATIONS

Competing interests
None declared

Funding
Research commissioned by the Department of Health

Ethical approval
The patient study had ethical approval from the Surrey Research Ethics Committee (ref: 10/H1109/20); the public study had ethical consent from the Brighton & Sussex Medical School (10/019/JEN)

Guarantor
LJF

Contributorship
LJF and VAJ were the primary investigators in the conception, design, analysis and interpretation of the findings; VAJ and LFJ wrote the first and

Summary

Objectives To determine the views of patients and members of the public about who should pay for expensive new cancer drugs not recommended by the National Institute for Health and Clinical Excellence (NICE).

Design A study-specific questionnaire was used to elicit the views of patients and the general public between April and June 2010. It examined whether participants thought patients should be told about all possible cancer treatments, if the NHS should always fund non-NICE recommended drugs and attitudes towards self-funding/co-payments. The influence of sociodemographic factors on responses was also examined.

Setting Oncology clinics in Sussex and various locations including old persons' lunch clubs, parks, sports venues and support groups.

Participants Two hundred and 10 patients with common solid tumours, and 416 members of the general public

Main outcome measures Frequencies of responses to items regarding payments for expensive anti-cancer drugs stratified by sociodemographic factors and comparison of responses between patients and members of the public.

Results Most respondents (70% [147/210] of patients and 64% [266/416] of the general public) had heard of NICE. Both groups believed that doctors should tell patients about all available cancer treatments even if the NHS cannot pay (94%, 196/208; 93%, 388/415). However, only 49% (101/207) of patients and 36% (146/409) of the public believed that the NHS should always fund all new cancer drugs that have failed health technology assessments. Strong predictors of willingness to purchase expensive new cancer drugs included younger age (<45 years), sex (female) and higher educational level.

subsequent drafts of the manuscript; IST conducted the analysis and interpretation of the findings; CIL and LP organized the data for analysis; all authors critically reviewed drafts of the manuscript

Acknowledgements
The authors thank all the patients and members of the public who participated in the survey

Reviewer
Fran Boyle

Conclusion The general population appear realistic about the difficulties of providing funding for expensive new drugs. A communication skills training course has been developed to help clinicians with these difficult consultations.

Introduction

Costs of novel cancer drugs are escalating worldwide creating a multitude of economic, social and ethical dilemmas for healthcare providers and commissioners as well as patients and their relatives. It is not always easy to balance the individual desires of patients for costly new treatments that might be clinically appropriate, with wider societal obligations and responsibilities of ensuring some equity when dividing up a finite budget. It is extremely hard, if not unreasonable, to expect a dying patient to consider which elements of healthcare they would see deprived of resources to enable them to have unrestricted access to cancer drugs, especially those that have failed health technology assessments (HTAs).

Many doctors find discussions about individual/exceptional funding requests and self-funding extremely difficult so fail to inform patients about the availability of some of the newer treatments that have not received positive recommendations. Patients need to be given information to make decisions that are right for them and oncologists are often poor judges of the general information needs of their patients.[1] Cancer charities said that patients were being 'left in the dark' about putatively life-extending drugs not routinely available in the NHS[2] and failures to discuss novel treatments is paternalistic.

There are few data showing what the views of the general public or patients in the UK are towards paying for expensive new anti-cancer drugs. Surveys elsewhere show that patients want information about high-cost drugs even if they cannot afford them. Members of the Breast Cancer Network in Australia were interviewed to examine their knowledge, as well as experiences and attitudes towards drugs costing >A$900 per week.[3] One finding was a difference as to what was deemed as high cost; a majority thought >A$100 per week high, with 57% of women considering A$50 per week high, (although the duration of treatment influenced these views). Over one-quarter (28%) had discussed high-cost drugs with their oncologist and none had declined treatment due to financial constraints. In an earlier survey of the Australian public similar responses were found, with 91% of people wanting to be told about expensive drugs that could improve survival by an additional 4–6 months, and 51% prepared to pay for them.[4]

In the UK, the Richards Report[5] clarified the procedures that would permit additional self-payments by patients, and thus ensure that they would not lose entitlement to other National Health Service (NHS) treatment. The report also advised that doctors should receive communication skills training to assist consultations about this difficult topic. We conducted two surveys: one of doctors' experiences discussing additional payments since publication of the Richard's Report[6] and another, reported here, of patients and the general public's views of expensive cancer drugs and their willingness to pay for them.

Participants and methods

Questionnaire

An 18-item study-specific questionnaire devised by the authors with lay input examined issues including: awareness of the National Institute for Health and Clinical Excellence (NICE); desires for information about drugs not funded by the National Health Service (NHS); and willingness to pay for cancer drugs either for themselves or for relatives. Attitudes and willingness to self-fund were examined further through hypothetical scenarios about likely therapeutic gains including extension of life, quality of life, numbers of patients likely to benefit, and the financial costs. We also explored the influence that age, education and the type of newspaper read had on participants' responses; comments to explain their choice of response were encouraged.

Participants

Patients

A convenience sample of 220 patients with common solid tumours, attending for routine follow-up appointments at oncology clinics in Sussex read an information sheet about the survey. Consenting patients completed questionnaires in clinic or at home to return by post. The patient study had ethical approval from the Surrey Research Ethics Committee (Ref: 10/H1109/20).

Public

A convenience sample of 610 members of the general public was approached in various locations including the seafront, parks, trains, university campus, old persons' lunch-clubs, sports venues and a support group for young mothers, enabling a broad sociodemographic mix of people. The public survey had ethical consent from the Brighton & Sussex Medical School (10/019/JEN) and the study was sponsored by the Brighton & Sussex Medical School.

Statistics

We conducted a descriptive analysis of the survey data comparing frequencies of responses between patients and the public. These comparisons were formalized through logistic regressions for binary variables indicating whether participants were aware of NICE, would want to be told about expensive new drugs and whether the NHS should pay for them. Similarly, logistic regression models were fitted for binary variables indicating willingness to pay for drugs offering an extension of life and for improving quality of life for themselves or a close relative, omitting 'unsure' responses. The odds ratio associated with a group indicator, for example public, measures the relative size of the odds of a positive response for members of the public in comparison with the odds for those in the group of patients. In all our models, we adjusted for the demographic characteristics described in Table 1 and the type of newspaper people read. The covariates age and level of education were re-coded using the first three empirical quartiles as cut-off points. Type of newspaper read was coded into three categories: 'I don't read newspapers'; 'broad sheet'; and 'red top'. Goodness of fit was assessed using the deviance of fitted logistic regression models.

Results

The socioeducational demographics of respondents are shown in Table 1. More of the public were younger, with higher educational qualifications and had private health insurance ($P < 0.001$). Responses to survey questions are shown in Table 2.

NICE and the influence of newspapers

Most patients (70%; 147/210) had heard of NICE compared with 64% (266/416) of the public. Members of the public affected by cancer themselves were also more likely to have heard of NICE (OR = 2.87, $P = 0.009$). Forty-one percent (169/414) of the public and 30% (62/210) of patients did not read newspapers. Those who read broadsheet newspapers in both groups were more likely to be aware of NICE than those never reading newspapers; this effect remained when educational level was taken into account (OR = 1.70, $P = 0.024$).

Non-NHS funded drugs

The overall majority did not think that the NHS should pay for all new cancer drugs, however more patients (49% (101/207) than the general public 36% (146/409) felt that the NHS should 'always' pay (OR = 1.61, $P = 0.009$). Those with higher educational qualifications in both groups were less likely to agree that the NHS should do so (OR = 0.54, $P = 0.002$).

Over one-quarter of patients (27%, 56/207) and one-third of the public (33%, 136/409) thought payment should only occur if NICE recommended the drug. In both groups, those who read broad sheets were less likely to agree that the NHS should always pay compared to those who do not read newspapers (OR = 0.58, $P = 0.01$). Some examples of comments around this include:

> '*The NHS gives a fantastic service to cancer patients; however they have to work to a budget, in order for everyone to have some form of treatment.*' (Patient 101)

> '*Rely on NICE rather than press as to whether the NHS should pay for the drugs.*' (Public 505)

Table 1
Demographics of patients and public

	Patients n = 210	*Public n = 417*
Sex		
Male	89 (42%)	185 (44%)
Female	119 (57%)	232 (56%)
Missing	2 (1)	
Age group (years)		
18–25	2 (1%)	25 (6%)
26–35	5 (2%)	53 (13%)
36–45	11 (5%)	71 (17%)
46–55	33 (16%)	79 (19%)
56–65	41 (20%)	76 (18%)
>65	117 (56%)	113 (27%)
Missing	1	
Partner		
Yes	143 (68%)	270 (65%)
Missing	2 (1%)	1 (0%)
Education qualifications		
None	74 (35%)	71 (17%)
GCSE	49 (23%)	88 (21%)
A levels	16 (8%)	49 (12%)
College/Degree/Diploma	68 (32%)	203 (49%)
Missing	3 (1%)	6 (1%)
Private health insurance		
Yes	17 (8%)	86 (21%)
No	188 (90%)	328 (79%)
Missing	5 (2%)	3 (1%)
Cancer site		*
Breast	75 (36%)	
Colorectal	25 (12%)	
Urological	47 (22%)	
Other	63 (30%)	
Time since diagnosis (years)		
<1	56 (27%)	
1–3	76 (36%)	
4–5	43 (20%)	
>5	35 (17%)	
Type of treatment		
Surgery	103 (49%)	
Radiotherapy	113 (54%)	
Chemotherapy	120 (57%)	
Hormone	58 (28%)	

*45 had cancer; 13 still treated; 65% had a family member with cancer

Should doctors tell patients about all available cancer treatments?

Both groups strongly believed doctors should discuss all treatments even if the NHS does not pay for them (94% of patients [196/208]; 93% of public [388/415]). Some recognized the difficulties that doctors faced when discussing expensive new cancer treatments:

> *'All drugs should be priced to give all people the same chance of getting better. What a horrid situation for doctors to know of a drug that could help a person and that he has to tell you about it, knowing that it is very expensive and you would have to make the choice, think about the family and how this affects them as well.'* (Patient 70)

Other comments revealed that if doctors did not discuss the topic then patients might access more unreliable sources.

> *'A difficult subject, but I would want all information available to make an informed decision. I (and others I'm sure) obtain information from the Internet anyway but getting full information from a reliable health professional is important.'* (Patient 97)

Some, as the following quote shows, did not think that doctors should have to discuss funding.

> *'Doctors should not have to worry about the finance. If a drug is recommended an administrator should discuss with the patient why NICE won't fund it; this would enable the doctor to get on with his/her job and the administration get involved and understand the implications and effect on lack of/or inconsistent funding.'* (Patient 40)

Willingness to pay in extension of life or quality of life (QoL) scenarios

Patients and the public were asked to consider whether or not, if their cancer was getting worse, they would want their doctor to discuss self-funding options for a drug that might lengthen life by an extra 4–5 months. Most patients and the public were strongly in favour of such discussions (84% [175/208] and 82% [339/414], respectively). However when told that the drug might benefit only two out of five patients, that there was no way of knowing who might benefit and it would cost £4000 a month, more of the public (22% [93/414]) were willing to pay compared with patients (15% [30/206]). The numbers willing to consider payment when told that the drug might improve the QoL, by reducing

Table 2
Responses to questions

	Patients n = 210				*Public n = 417*			
	Yes	*No*	*Unsure*	*Missing*	*Yes*	*No*	*Unsure*	*Missing*
Have you heard of NICE?	147 (70%)	51 (24%)	12 (6%)	0	266 (64%)	128 (31%)	22 (5%)	1
	Always	*Only if NICE recommends*	*Sometimes*	*Missing*	*Always*	*Only if NICE recommends*	*Sometimes*	*Missing*
Do you think the NHS should pay for all new cancer drugs?	101 (49%)	56 (27%)	50 (24%)	3	146 (36%)	136 (33%)	127 (31%)	8
	Yes	*No*	*Don't know*	*Missing*	*Yes*	*No*	*Don't know*	*Missing*
Should doctors tell patients about all possible treatments that are available for cancer even if the NHS does not pay for them?	196 (94%)	4 (2%)	8 (4%)	2	388 (93%)	10 (2%)	17 (4%)	2
	Yes	*No*	*Unsure*	*Missing*	*Yes*	*No*	*Unsure*	*Missing*
If your cancer (if you had cancer) got worse and there was a drug that might lengthen your life by an extra 4–5 months but you would have to pay for it, would you want your doctor to discuss it with you?	175 (84%)	10 (5%)	23 (11%)	2	339 (82%)	43 (10%)	32 (8%)	3
If this treatment cost about £4000 per month would you:	*Yes*	*No*	*Unsure*	*Missing*	*Yes*	*No*	*Unsure*	*Missing*
Pay from personal funds	40 (20%)	94 (46%)	69 (34%)	7	128 (31%)	155 (38%)	130 (31%)	4
Ask family/friends to help pay	18 (9%)	132 (66%)	51 (25%)	9	60 (15%)	262 (64%)	88 (21%)	7
Re-mortgage the house	44 (22%)	101 (50%)	56 (28%0	9	121 (30%)	182 (44%)	107 (26%)	7
	Yes	*No*	*Unsure*	*Missing*	*Yes*	*No*	*Unsure*	*Missing*
If you knew this drug only lengthened the life of 2/5 people and there was no way of knowing if you might be one to benefit would you be prepared to pay about £4000 per month for it?	30 (15%)	93 (45%)	83 (40%)	4	93 (22%)	171 (41%)	150 (36%)	3
	Yes	*No*	*Unsure*	*Missing*	*Yes*	*No*	*Unsure*	*Missing*
If the new drug did not extend your life but might improve the quality of your life – reduce symptoms such as pain or feeling tired, would you be prepared to pay about £4000 per month for it?	32 (16%)	83 (40%)	91 (44%)	4	123 (30%)	154 (37%)	139 (33%)	1

symptoms such as pain or feeling tired, increased for the public to 30% (123/416) and to 16% (32/206) for patients. The varying attitudes are reflected in some of the quotes below:

> *'Having had cancer myself (twice) I do not feel that £4000 per month can be justified when there are people with a much greater need on the NHS.'* (Patient 36)

> *'If we are talking about drugs that will only lengthen life by 4–5 months then £4000 is a lot of money! The NHS does not have unlimited funds and doctors have limited time in a consultation. There is no point telling a patient about a drug the NHS cannot provide.'* (Patient 26)

> *'Quality of life is critically important. If survival can be prolonged with high QOL, I would feel much more positive than if life is prolonged with poor QOL.'* (Public 202)

How would you pay for the drugs?

Patients were asked if they would: pay for the drug from personal funds; ask family or friends; or re-mortgage the house. More indicated that they would re-mortgage the house (22%, 44/201) or use personal funds (20%, 40/203) than ask family or friends (9%, 18/201). Members of the public were more likely to pay for the drug for themselves out of personal funds (31%, 128/413), with 30% (121/410) considering re-mortgaging the house and only (15%, 60/410) prepared to ask family members or friends. Differences between patients and the public were not statistically significant when age and educational level were taken into account, however if members of the public actually, rather than hypothetically, had a close family member with cancer then they were more likely to be willing to re-mortgage the house to pay for treatment (OR = 1.73, $P = 0.042$). In both groups, women (49%, 99/204) were significantly more likely to pay for unfunded treatments that might improve their own quality of life than were men (30%, 56/187), when omitting unsure answers (OR = 2.25; $P = 0.001$).

When 'unsure' answers were excluded, age also influenced responses to several questions: people older than 65 years were significantly less likely to want to pay for treatment, compared to those between 18 and 45 years old ($P < 0.001$).

> *'I'm an 80-year-old pensioner, paid taxes all my life. Don't expect to pay for my treatment.'* (Patient 199)

> *'I am an OAP living off no income. I couldn't afford to pay any money so if they stop the treatment I'm afraid that would be it. Sorry.'* (Patient 100)

> *'Certainly in my situation at age of 40 with two young children, I would find the money from somewhere if it meant that my life was prolonged or made easier. We should be given the opportunity if there are better drugs out there.'* (Patient 89)

> *'I am 28 years old: too young to give up and I would fight for anything that may give me a chance to survive longer.'* (Patient 65)

Preparedness to pay for relatives

When the public were asked to consider the scenario of paying for a close relative responses showed a more positive inclination than if it was for themselves, with 35% (145/416) saying they would pay if it lengthened life and 43% (178/416), if it improved their relative's quality of life. When the 'unsure' responses are excluded, 11% (21/183) members of the public would pay to lengthen their relative's life but not their own, compared with only 2% (4/183) who would pay for themselves but not their relative ($P < 0.001$). Similarly 13% (27/209) would pay to improve their relative's QoL compared with their own (2%, 4/209; $P < 0.001$). This is reflected in the following quotes:

> *'£4000 is a lot of money to find, but if it was for a very close family member (e.g. husband, child, grandchild), it might be a possibility to raise the money. Re-mortgage the house for instance.'* (Public 597)

> *'My father died eight years ago from cancer and I would have wanted to give anything a try.'* (Public 10)

Women (77%, 110/143) were more likely to pay if it improved their relative's quality of life compared

to men (58%, 68/119), omitting unsure answers (OR = 2.54, $P = 0.002$). Similarly 68% (86/127) women compared with 50% of men (59/118) would also be more likely to pay if it lengthened life, excluding unsure answers (OR = 2.08, $P = 0.012$).

Age was an important factor for all the questions concerning paying for a close relative. Older people (>65 years) were less likely to pay compared with younger age groups (18–45 years) ($P \leq 0.002$). The odds ratios comparing the responses of oldest and youngest age groups, ignoring 'unsure' answers were: from personal funds (OR = 0.25, $P = 0.001$); re-mortgaging house (OR = 0.24, $P < 0.001$); ask the family or friends (OR = 0.121; $P < 0.001$); lengthen life for only two out of five people (OR = 0.27, $P = 0.002$) and improve QoL (OR = 0.26, $P = 0.001$).

Discussion

The results from the survey show that the majority of patients and the general public are more sanguine about the stark reality that not all cancer drugs can and should be funded by the NHS with its finite resources. One-third of the public and more than one-quarter of patients felt that only those drugs that NICE recommend as worth the costs should be funded. Importantly the majority of both groups did wish to be informed about all possible cancer treatment options, even those not paid for by the NHS.

This survey was conducted in a relatively affluent part of the UK (South East England) as reflected in the 21% who had private health insurance, compared to the national figure in 1998–1999 of 18% for a household headed by a professional group or 8% of households with a retired household head.[7] We did not collect individuals' household income data, nor explore the price ranges that might encourage people to consider self-funding drugs, but the results mirror findings from two Australian surveys.[3,4]

In our study, groups strongly favoured disclosure about unsubsidized expensive anti-cancer drugs and wanted to be active participants in treatment decision-making, as did 91% of the public in the Australian survey.[4] Age was a strong predictor of the public's desire to be treated with the expensive cancer drug, with 86% of those under 70 years wanting to receive treatment compared with 73% of those aged 70 years or older. Also, older patients were less likely to want to pay or ask relatives to pay for the drug, whether it gave extra length of life or improved quality of life. The results show a range of responses to the vexed topic as to who should pay for expensive new cancer drugs that fail to achieve reasonable thresholds following health technology assessment. So how do clinicians in the UK deal with this situation?

There are few data collected about patients and the general public's views about non-NHS-funded anti-cancer drugs. Oncologists find discussions about the subject challenging; they worry about distressing patients and their families by offering a treatment that the NHS cannot fund and which patients may not be able to afford.[8] In a recent UK study, many clinicians felt very uncomfortable about even raising the issue of unfunded drugs especially if they worked solely within the NHS.[6] Additionally, the overwhelming majority of clinicians (98%) had received no help or guidance in having such discussions. The difficulty talking about additional payments for expensive new treatments is not limited to Australia and the UK. A recent article comparing the attitudes of Canadian and US members of ASCO, stated that 26% of the 167 respondents rarely or never discussed costs with patients and 31% acknowledged a high degree of discomfort when doing so.[9]

Since the survey reported here was conducted, the UK Coalition Government announced that they would end the power of NICE to make recommendations about which drugs the NHS should fund. In response to the complaints by some cancer charities, doctors and newspaper campaigns, they have also established a £200 million 'Cancer Drugs Fund' which is administered by independent panels in different Strategic Health Authorities.[10] The interim £50 million fund covering six months from October 2010–March 2011 proved difficult to deliver with fewer applications than expected.[11] Even when the system is operational, discussions about access to expensive new drugs through individual/exceptional funding requests, the cancer fund and/or additional self-payments by patients will have to continue. Helping clinicians deliver these uncomfortable discussions with patients in an appropriate and

balanced manner is vital to enable wise decision-making. One recommendation in the Richards Report[5] was for the Department of Health to commission a training programme to help all parties. An educational DVD package entitled 'Getting the Right Balance' has recently been completed with seven different scenarios depicting some of the issues and difficulties that arose from our surveys of both clinicians, patients and the public.

Conclusion

Despite desires to avoid a 'post-code lottery', policy changes have created some continued confusions about the process for accessing funds This together with stark economic realities means that additional payments are likely to stay for some time to come. Doctors, patients and their families will therefore need to engage in difficult discussions about the true cost-benefits of further treatments at a time when they are just coming to terms with the seriousness of their illness. However, the patients and the general public who participated in this survey appear understanding, sanguine and realistic about the problem of funding expensive new drugs than perhaps even the policymakers may realize.

References

1 Elkin EB, Kim SH, Casper ES, Kissane DW, Schrag D. Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol* 2007;**25**:5275–80

2 Adams S. Cancer patients "left in dark" over unfunded drugs. *The Telegraph* 2010 November 6. See http://www.telegraph.co.uk/health/8113057/Cancer-patients-left-in-dark-over-unfunded-drugs.html

3 Kaser E, Shaw J, Marven M, Swinburne L, Boyle F. Communication about high-cost drugs in oncology – the patient view. *Ann Oncol* 2010;**21**:1910–14

4 Mileshkin L, Schofield PE, Jefford M, *et al.* To tell or not to tell: the community wants to know about expensive anticancer drugs as a potential treatment option. *J Clin Oncol* 2009;**27**:5830–7

5 Richards M. *Improving access to medicines for NHS patients: a report for the Secretary of State for Health*. London: Department of Health, 2008. See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089927

6 Fallowfield LJ, Solis-Trapala I, Jones A, Barret J, Langridge C, Jenkins V. Discussing expensive anti-cancer drugs. *Br J Healthc Manag* 2011;**17**:206–12

7 Office for National Statistics. Households covered by private medical insurance: by socio-economic group of head of household, 1998–99: Social Trends 30. Newport: ONS, 2002

8 Thomson J, Schofield P, Mileshkin L, *et al.* Do oncologists discuss expensive anti-cancer drugs with their patients? *Ann Oncol* 2006;**17**:702–8

9 Schrag D, Hanger M. Medical oncologists' views on communicating with patients about chemotherapy costs: a pilot survey. *J Clin Oncol* 2007;**25**:233–7

10 Department of Health. Cancer Drugs Fund will provide £200 million a year [press release]. London: Department of Health, 2010. See http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_120941 (last checked 21 June 2011)

11 Adams R. Cancer Drugs fund "is a Mess". *The Telegraph* 2011 February 5. See http://www.telegraph.co.uk/health/healthnews/8303632/Cancer-Drugs-Fund-is-a-mess.html (last checked 21 June 2011)

© 2011 Royal Society of Medicine Press
This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by-nc/2.0/), which permits non-commercial use, distribution and reproduction in any medium, provided the original work is properly cited.