Beating Bowel Cancer
Access to newly licensed medicines

1. Introduction
As a charity representing and advocating for bowel cancer patients across the UK, Beating Bowel Cancer has received reports from patients in Scotland who have not been able to access the drug treatments their clinicians feel could benefit them; in spite of the fact that the same treatments are freely available under the NHS elsewhere in the UK.

In response, Beating Bowel Cancer has a clear goal in Scotland – to end restrictions on access to treatments for bowel cancer. We are committed to working with Scotland’s NHS, parliamentarians and the Scottish Government to implement a range of practical improvements that will improve diagnosis, care and outcomes for patients and welcomes this opportunity to offer feedback from the perspective of patients and clinicians on the recently published New Medicines Review (NMR).

2. Drug access: the patients’ perspective
Bowel cancer places a significant burden on the health service in Scotland. It affects 4,000 patients each year, but people are still being diagnosed when the cancer is too advanced and, as a result, their chances of long-term survival are poor. Indeed, Scotland’s rate of bowel cancer is the highest in the UK and outcomes are generally poor compared with countries both UK-wide and around the world.

Patients with bowel cancer may be offered a variety of treatment options as part of their care plan, including surgery, chemotherapy, radiotherapy, and drug treatment. Although the clinical evidence for the use of these treatments is clear, patients have contacted us directly to inform us that they have not been able to access the drugs that their clinicians wish to prescribe.

The picture is clear: for bowel cancer patients across Scotland, securing fair access to drugs can be a lengthy, confusing and frustrating experience. These patients’ experiences are backed up by research from the Rarer Cancers Foundation, which found limited progress in Scotland to reduce regional inequalities in access to cancer drugs.

We know that the first question that comes to bowel cancer patients’ minds after diagnosis is not “will I survive?” Instead they ask “what are my options?” Unfortunately, those options differ depending on which side of the border they live, with patients in Scotland three times less likely to gain access to a cancer drug, which is not routinely funded, than people in England.
For many cancer patients, the result of being denied access to cancer drugs recommended by their clinicians is that they may have to meet extremely high treatment costs from their own resources; a solution that can serve not only to damage outcomes, but also substantially increase stress levels and contribute to financial insecurity. In other cases, patients simply have to forego the drugs prescribed by their doctors or else relocate, in order to access therapies that are only available in England or through other NHS boards in Scotland.

3. The clinicians’ perspective
As with patients, we have been contacted by specialist clinicians who are concerned about the availability of cancer drugs in Scotland.

According to a recent survey of 28 oncologists and haematologists in Scotland, over a third (39%) said they were aware of cancer patients who have relocated to England to receive treatment. Nearly all (96%) of those surveyed consider access to cancer therapies to be better in England than Scotland, with half (50%) highlighting that restricted access has lowered Scotland’s standard of care, compared to the rest of Europe.

The clinicians interviewed in the survey listed a total of 34 drugs rejected by the Scottish Medicines Consortium that they would like to have access to, in a perfect world. This compares with 23 cancer drug treatments available in England yet unavailable in Scotland during the Rarer Cancer Foundation’s 2011 survey.

In the view of clinicians in Scotland who have contacted Beating Bowel Cancer directly, Independent Patient Treatment Requests (ITPRs) were meant to allow doctors to make recommendations for funding for individual patients in certain circumstances. Despite the publication of some national guidelines to support the IPTR process, many clinicians say that it can be complex with requirements which are difficult to satisfy and they also warn of inconsistent decision-making in different health boards.

We know of examples where patients have been discouraged from submitting IPTRs purely because of the nature of the process.

4. The New Medicines Review
Some findings of the Review are welcome. In particular, Beating Bowel Cancer welcomes the steps that the review authors have proposed to improve transparency and access to information informing decisions made by the Scottish Medicines Consortium (SMC), the Area Drug and Therapeutic Committees (ADTC) and by the Individual Patient Treatment Requests (IPTR) process.
Unfortunately, it is far from clear whether the findings of the independent review into medicine access will address the primary barriers to drug access highlighted by patients and clinicians alike for the reasons described below. In addition, we are concerned that the limiting of drug access through the Scottish Government’s new £21m drugs fund is limited only to patients with ultra-orphan diseases, meaning that the great majority of cancer patients will not qualify.

4.1. The Scottish Medicines Consortium

As identified in the research cited above, there are nearly forty cancer drug therapies currently ‘not recommended’ by the SMC, but which specialist clinicians in Scotland would like to have the freedom to prescribe. In order for the review of the practices of the SMC to be deemed a success, it is clear that doctors and their patients must be given reason to have more confidence that the drugs they need will not be blocked.

The measures recommended by Professor Routledge in the NMR have the capacity to lead to systemic improvements for the SMC system by delivering greater transparency and accountability. However, it remains to be seen whether those improvements will translate into fairer drug access for patients. The fact remains that patients will expect changes to the SMC to result in greater parity across Scotland and the UK resulting in improved access to drugs.

Our concern is that the review recommendations will merely serve to provide patients the opportunity to more clearly “see inside” a system that still does not meet their needs and which continues to be a source of frustration because the drugs that they need remain out of reach in Scotland.

4.2. Area Drug and Therapeutic Committees

One of the starkest findings of the NMR is that only 74% of drugs approved by the SMC for use by NHS Scotland find their way onto regional Board formularies because of decisions by ADTCs. The NMR is right to recommend ways by which ADTC decisions can be made more transparent, and we hope that increased accountability and uniformity in the ADTC will deliver more equitable drug access throughout Scotland.

Our chief concern with the Review’s findings is that such improvements may take considerable time to come into effect; if they happen at all. For bowel cancer patients trying to access treatments in their area without moving to another Board area provider, time is in short supply. It remains to be seen whether the Review’s call for the use of National Meetings to inform consensus between ADTCs on novel medicines will deliver the speedy outcomes that cancer patients require.
4.3. Review of Individual Patient Treatment Requests
The review of the effectiveness of the IPTR process reflects many of the problems highlighted to Beating Bowel Cancer by patients and clinicians. The process has been poorly understood due to a shortage of public information, while patients and doctors have been left confused and frustrated by a system that is perceived to offer a bias against cancer drugs and a ‘postcode lottery’ for access to drugs that are ‘not recommended’ by the SMC.

While we acknowledge the review’s finding that evidence of a bias in the IPTR process against cancer drugs may be anecdotal, we would point out that the very real experience of individual bowel cancer patients, matched by frustrations experienced and reported by clinicians must be addressed. It is particularly concerning that the review found that many doctors were inexperienced in making IPTR requests, or simply regarded the process as a chore, and that this had a negative effect on the success of patients accessing drugs in some areas.

Insofar as they represent a tightening of guidance around IPTR applications that should improve the experience for patients, Beating Bowel Cancer welcomes Recommendations 6-12 in the review.

However, the most important factor for patients remains the same: whether or not the IPTR process allows them to access the drugs recommended by their clinicians. Beating Bowel Cancer’s feedback from patients who have used the IPTR system is that the recommendations in the NMR will not do enough to improve a system that, in their view, was stacked against them from the outset.

Those patients expect to see a fundamental overhaul of drug access that accepts the view offered by their own specialist clinicians; that they should be given free access to treatments that are available elsewhere in the UK and which have a real chance of helping in their own cases.

For that reason, Beating Bowel Cancer, and the patients we support, are not convinced that the review will lead to improved drug access for these patients in the short to medium term.

4.4. Rare Conditions Medicines Fund (RCMF)
We note that the Scottish Government has acknowledged the problem of access to drugs for ultra-orphan conditions by introducing the Rare Conditions Medicines Fund (RCMF). The RCMF, while a welcome respite for those suffering from ultra-orphan conditions, will do nothing to offer reassurance to the growing number of patients in Scotland suffering from bowel cancer and
conditions like it, who are unable to access drugs through NHS Scotland for financial reasons.

We would urge the committee to note the success of the Cancer Drugs Fund (CDF) set up by the UK government to provide access to drug therapies in advance of the introduction of value-based pricing in January 2014. While we are not advocating the duplication of the CDF in Scotland, its effectiveness in helping patients in England and Wales should be noted. Beating Bowel Cancer has been campaigning hard at Westminster to ensure that bowel cancer patients – the single largest group benefitting from the UK Government’s Cancer Drugs Fund\textsuperscript{viii} – have greater certainty for the future when the CDF is replaced in 2014.

The NMR has been consistent in rejecting the creation of a drugs fund specifically for cancer treatments, because this would unfairly single out cancer patients for special treatment. We share the view that patients should be treated equally, regardless of their condition. The fact remains however, that the system retains enormous inequality, because bowel cancer patients in Scotland are in many cases simply unable to access treatment because of where they live.

Bowel cancer patients who rely on the CDF deserve the chance to access drugs freely through the NHS. Aside from those patients who succeed through IPTR applications, there is no similar avenue for cancer drug access (other than for ultra-orphan conditions) in Scotland, and patients have been offered no assurance through the New Medicines Review that this situation will improve.

**Conclusions**

Bowel Cancer patients in Scotland expect and deserve a system of drug access that delivers the best possible care for their individual condition, as recommended by their clinicians.

While the recommendations outlined in the NMR would deliver improvements to existing structures, we remain to be convinced that they will offer bowel cancer patients the equitable access to the conditions that they need.

Whatever actions come out of the New Medicines Review, the Scottish Government must ensure that it delivers practical change that addresses the postcode lottery that patients in Scotland are currently experiencing.

Moreover, it must learn the lessons from current confusion over the future of the Cancer Drugs Fund in England. The Scottish Government must urgently address the problem of unequal drug access once and for all.
We therefore urge ministers to listen to patients and clinicians who expect the NMR to lead on to the creation of and implementation of a better, fairer system of access to a wide range of drugs and treatments for the growing number of Scots diagnosed with bowel cancer every year.

**Beating Bowel Cancer**

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4 Access to Cancer Drugs in Scotland survey, Adelphi research, February 2013
5 A 2010 Clinical Oncology UK Workforce report stated that there are a total of 67 clinical oncologists in Scotland. Cf. The Royal College of Oncologists Clinical Oncology UK Workforce Report 2010, 2013.
7 The Scottish Government, *New Medicines Reviews 2013*, May 2013
8 Beating Bowel Cancer extrapolated an estimate for the number of bowel cancer patients who have benefitted from the Fund and the future demand based on a response to a Parliamentary Question and research from the Rarer Cancers Foundation on applications to the Cancer Drugs Fund. For further details on these calculations, please follow this link: www.beatingbowelcancer.org/cdfnational