



## Making an IMPACT: A priority setting consultation exercise to improve outcomes in patients with locally advanced, recurrent and metastatic colorectal cancer

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### ABSTRACT

**Aim:** The IMPACT (Improving the Management of Patients with Advanced Colorectal Tumours) initiative was established by the Association of Coloproctology of Great Britain and Ireland in 2017 as a consortium of surgeons (colorectal, hepatobiliary, thoracic), oncologists, radiologists, pathologists, palliative care physicians, patients, carers and charity stakeholders who will work together to improve outcomes in patients with advanced and metastatic colorectal cancer. To establish this initiative, better information is required to establish how further intervention is focused. This paper details the approaches used, and outcomes generated, from a priority setting exercise to inform the design of the IMPACT initiative.

**Methods:** A mixed method approach was employed to set the priorities of patients, clinicians and other key stakeholders in the delivery of optimal care. This consisted of two patient centered consultation events and a questionnaire.

**Results:** A total of 128 participants took part in the consultation exercise; 15 patients, 5 carers/family members, 5 charity representatives and 113 healthcare professionals. Nine key themes for focus were identified, these were: current service provision, specialist services, communication, education, access to care, definitions and standardisation, research and audit, outcome measures, and funding of specialist care.

**Conclusion:** These future priorities will be developed with collaborative engagement in a systematic manner to produce an overall cohesive programme which will deliver a sustainable and efficient clinical and academic service to improving the management of patients with advanced colorectal tumours.

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### Background

Colorectal cancer (CRC) is the fourth most common cancer in the United Kingdom (UK) [1]. There are over 40,000 new cases of CRC diagnosed per annum and CRC is the second most common cause of cancer-related deaths in the UK. Optimising care of patients with locally advanced, recurrent, peritoneal and metastatic CRC (collectively termed advanced colorectal cancer) was identified as a key priority in the Association of Coloproctology of Great Britain and Ireland's (ACPGBI) research agenda [2]. Although these are a

heterogeneous group of patients there are some important unifying characteristics allowing them to be targeted in a quality improvement programme.

Firstly, there are a significant number of patients who present with advanced CRC. Around 25% of CRC patients will have distant metastases at presentation [3] while 30% of patients without metastases at initial presentation at time of surgical resection will develop distant metastases within 3 years of diagnosis [4,5]. Up to 10% of patients with rectal cancer have involved adjacent organs at presentation and 10% will recur following primary surgery [6]. Secondly, there is a lack of high level evidence in this cohort of patients, with several surgical trials in metastatic CRC disease prematurely closed due to failure to recruit [7–10]. Thirdly, the surgical management of patients with advanced colorectal tumours is often complex, involving the timely referral to either subspecialist CRC surgeons or other site-specific multi-disciplinary teams

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(MDTs) by the local CRC MDTs. In the absence of widely accepted guidelines in the management of patients with advanced colorectal malignancy, there is considerable variation in practice both within and among hospital trusts, resulting in haphazard referral patterns and inequalities in patient access to specialist services [11].

The aim of the IMPACT initiative is to improve the quality of care and clinical outcomes for patients with locally advanced, recurrent and metastatic CRC. This work has been undertaken by ACPGBI in partnership with patients, charitable representatives and other professional organisations and will consist of multiple work packages under the umbrella term of IMPACT: Improving the Management of Patients with Advanced Colorectal Tumours. To establish the IMPACT initiative, much better information is required to establish how further intervention should be focused in such a complex patient cohort. Patient involvement from initiation will be critical in this ambitious programme to ensure successful implementation of both quality improvement measures and clinical research. This paper details the approaches used, and outcomes generated, from a priority setting exercise to inform the design of the IMPACT initiative.

## Methods

A mixed method approach was employed, consisting of qualitative and quantitative data collection. Mixed method evaluations are based on the premise of “triangulation” of evidence, whereby observations of one type are corroborated by other sources, to increase confidence in the findings [12]. This approach has been advocated for service delivery or management interventions which may not yield as conclusive results characteristic of studies based on patient outcome [13]. A staged approach to data collection was used, ensuring patient involvement to inform each stage, as shown in Fig. 1. Ethical approval was not required for this study and verbal consent was obtained from all participants.

### Participants

An initial steering group of ten members including clinicians, charity representatives and patients met in May 2016. Key stakeholder partners with wide geographical breadth, and representing multidisciplinary clinical specialties involved in managing advanced colorectal cancer, were identified and informed of the IMPACT initiative and its aims. Invited parties to the initial consensus meeting held on 15 May 2017 at the Royal College of Surgeons in London included patients, CRC charities, clinicians, researchers and allied healthcare professionals with experience in managing patients with advanced CRC. Patients who had undergone treatment for advanced CRC and their carers and family members were also identified and invited to participate via social media platforms Twitter™ and Facebook™, as well as via blogs and forums on charitable websites, in accordance with the INVOLVE guidance on the use of social media in patient and public involvement strategies [14]. Patients were invited to both the IMPACT consensus meeting and also to a dedicated focussed patient prioritisation day to further inform the IMPACT programme on 26 June 2017 at the Royal College of Surgeons.

### Priority setting questionnaire

The next step in the design of IMPACT was to identify the priorities of the patients and the public who had agreed to be part of the initiative. An online survey was developed which, after determining demographic information, engaged with participants to draw on their experiences of advanced CRC to ascertain priorities regarding disease management and treatment decisions. The

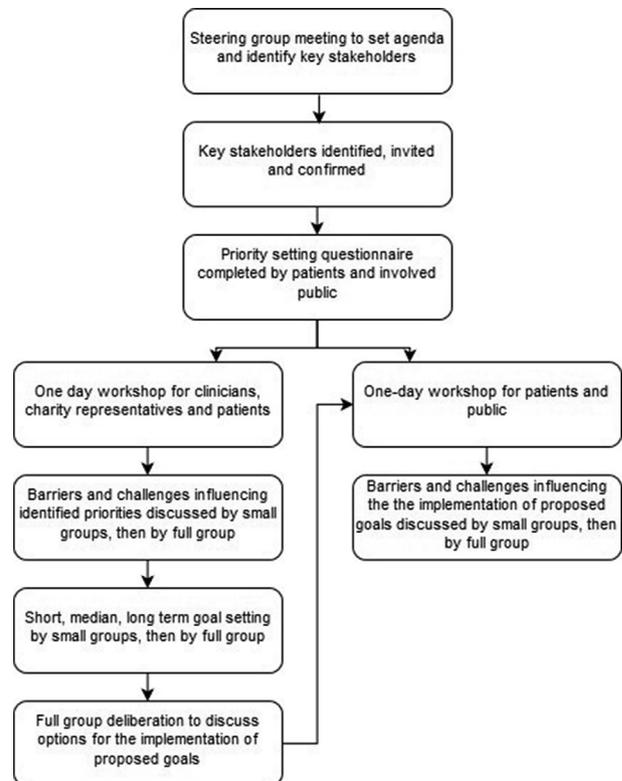


Fig. 1. Flow chart of mixed-methods strategy.

survey was piloted with members of the steering group and revised through re-iteration. This survey was emailed to patients and their carers prior to the second consultation exercise. Participants were asked to rank a number of topical issues in advanced malignancy on a Likert scale of 1 (not important) to 5 (very important). A weighted average out of 5 was calculated for each domain.

### Consultation exercise

Two priority setting face-to-face consultation meetings were held. The first meeting focused on the challenges perceived by healthcare professionals in delivering best possible care to patients with locally advanced, recurrent and metastatic CRC. Current issues were highlighted by several presentations from patients undergoing treatment for locally advanced, recurrent and metastatic CRC. Focus groups were the main method of data collection. Each focus group consisted of patients, carers, charities representatives and healthcare professionals with a total of 15–20 participants per group, including at least one patient. Each group was moderated by a senior healthcare professional and a trainee. Anonymised field notes were collated by trainees to provide records of discussions and provide additional data sources for theme extraction. A total of 10 focus groups were held throughout the day, with focus group sessions lasting approximately 45 min, and priorities then discussed in the wider forum to reach consensus.

The second consultation day was specifically focused on aligning the challenges and goals identified in the initial consultation exercise with those of patients and involved public. The majority of attendees had direct experience of locally advanced, recurrent or metastatic CRC, either through being a patient relative or carer. Focus groups were held to discuss the themes identified by the priority setting survey and the initial consultation exercise. A total of four focus groups were held throughout the day with 10 participants per group.

## Data analysis

Quantitative data obtained from the questionnaire were collated. The weighted average of each response was calculated and ranked accordingly. Qualitative data were collected using anonymised field notes created by the trainee moderators of each focus group. Field notes were analysed using the principles of thematic content analysis [15]. The findings from the quantitative and qualitative components of this study were synthesised. Analysis was conducted by two researchers (DH and AV) and was an iterative process, with constant discussion and refinement of emerging themes.

## Results

### Participants

A total of 128 participants took part in the consultation exercise; 15 patients, 5 carers/family members, 5 charity representatives and 113 healthcare professionals. Participants represented wide geographical coverage throughout the UK. The patients and carers/family members had direct experience in metastatic CRC (n = 8), recurrent rectal cancer (n = 4), locally advanced rectal cancer (n = 4) and locally advanced colonic cancer (n = 4). The specialities of the healthcare professionals involved were colorectal surgery (n = 72), hepatobiliary surgery (n = 5), clinical oncology (n = 5), specialist nursing (n = 5), radiology (n = 4), medical oncology (n = 2), thoracic surgery (n = 1), pathology (n = 1), palliative care (n = 1) and speciality trainees (n = 17).

The majority of the healthcare professionals attending the priority setting event had a specialist interest in at least one aspect of management of patients with advanced CRC, as shown in Table 1. They also tended to work in specialist centres, with the majority of centres in which participants worked offering on-site MDT discussion for patients with locally advanced and recurrent colonic and rectal cancer, as well as resectable and unresectable metastatic disease.

### Survey results

There were 25 patient and public surveys completed. The majority of domains were deemed to be 'very important' to patients with locally advanced, recurrent or metastatic CRC, with 7 out of 11

**Table 1**

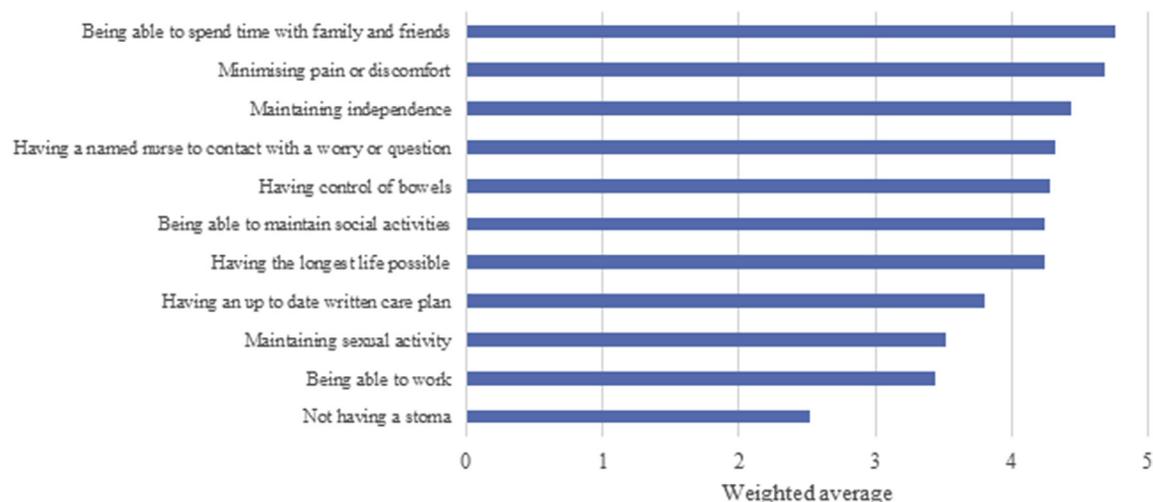
The on-site services offered by the units of the healthcare professional participants and their areas of specialist interests.

		Number (%) n = 113
On-site MDT services	Locally advanced colon cancer	95 (84)
	Locally advanced rectal cancer	92 (81)
	Recurrent colon cancer	83 (73)
	Recurrent rectal cancer	79 (70)
	Colorectal cancer with peritoneal disease	40 (35)
	Resectable metastatic colorectal cancer	82 (73)
	Unresectable metastatic colorectal cancer	65 (58)
Area of specialist interest	Primary colorectal cancer	91 (81)
	Locally advanced rectal cancer	77 (68)
	Locally advanced colon cancer	75 (66)
	Locally recurrent rectal cancer	61 (54)
	Locally recurrent colon cancer	58 (51)
	Potentially resectable metastatic colorectal cancer	57 (50)
	Liver metastases	22 (19)
	Lung metastases	13 (12)
	Unresectable metastatic disease	26 (23)
	Hyperthermic intraperitoneal chemotherapy and cytoreductive surgery	6 (5)

having a weighted average of more than 4 (Fig. 2). Having the ability to spend time with friends and family, minimising pain and discomfort, and maintaining independence ranked as the most important. Maintaining sexual activity, being able to work and not having a stoma were deemed to be somewhat less important priorities by comparison. Having the longest life possible was ranked 8th out of 11 possible domains. In regard to treatment decisions, this cohort prioritised access to specialist treatment and research, even if this meant more hospital appointments and increased travel (Fig. 3).

### Qualitative themes

A total of 9 qualitative themes were identified from combined analysis of field notes from the clinical consensus and patient involvement meetings: 1) current services, 2) specialist services, 3) communication, 4) education, 5) access to care, 6) definitions and standardisation, 7) research and audit, 8) outcome measures, and 9)



**Fig. 2.** Overall priorities in those with advanced CRC ranked according to weighted average.

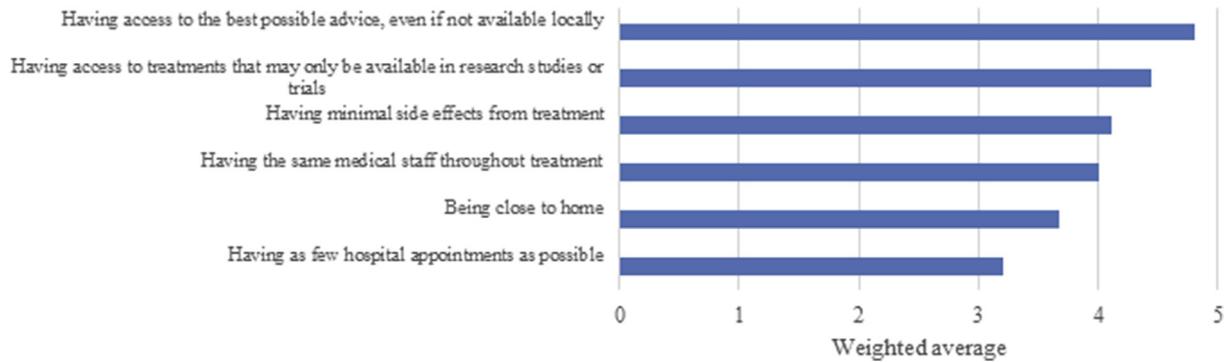


Fig. 3. Priorities guiding treatment decisions in those with advanced CRC ranked according to weighted average.

funding of specialist care. Quotes from clinicians, patients, charities and other key stakeholders outlining and underpinning the identified themes are presented in Table 2.

#### Current services

Lack of clarity about current services available within the UK for patients with advanced CRC was a major theme. This is further compounded by the fact that patients with advanced disease, particularly with peritoneal disease and recurrent CRC, are not adequately captured by either administrative data sets or current clinical registries including the National Bowel Cancer Audit [3] and Scottish Cancer Registry [16]. There was some concern amongst clinicians regarding low volume centres managing complex cases on an occasional basis without appropriate support or only offering specialist services to selected patients without onward referral of patients who might benefit from more specialised approaches than locally available. Consequently, there was felt to be a need to map out current clinical services for patients with advanced and recurrent CRC on a national basis. This will help identify and quantify regional services to develop an acknowledged and transparent national network, thus helping to build and deliver high quality services. For patients with metastatic disease, there was considerable concern regarding the utilisation of current services, with significant local and regional variation throughout the UK in the number of patients referred to, and offered surgery at, specialist hepatobiliary and thoracic services.

#### Specialist services

The development of dedicated, regional advanced CRC MDTs was considered to be a key, longer-term objective in improving outcomes for patients with advanced CRC. This would entail a movement away from the current 'organ-specific' model used by most centres. The advanced CRC MDT would ideally consist of all key clinical stakeholders (colorectal surgeons, hepatobiliary surgeons, thoracic surgeons, clinical and radiation oncologists, palliative care physicians, specialist nurses, radiologists, histopathologists, dedicated MDT co-ordinators) and enshrine the need for a patient advocate who had personal knowledge of each patient discussed. A hub and spoke model for each region would require development, with local MDTs linking into and referring all advanced CRC patients to their dedicated regional, advanced centre. This would enable coordinated discussion and integrated patient-centric decision-making in an effective and efficient manner. These regional advanced MDTs could then be linked to help build and deliver a national network, as well as providing feedback to local centres on patient outcomes.

Given the results of the patient questionnaire indicating that patients would be prepared to travel to receive the best possible

care, the development of dedicated advanced cancer clinics was deemed to be a valid long term goal in the delivery of services in this cohort of patients. It was acknowledged that this group of patients require ample time within the clinic setting to discuss diagnosis, treatment options and prognosis. Such clinics would need to be delivered in a pan-speciality manner, with colorectal surgeons, hepatobiliary and thoracic surgeons, oncologists, palliative care physicians, nurse specialists, radiologists and clinical psychologists. In the shorter term, it was proposed that patients requiring input from a multitude of specialities should be appropriately recognised prior to clinic appointments. Adequate provisions should be made to ensure all the right specialists are available for unified clinic attendances allowing for a more fluid patient pathway.

#### Communication

Healthcare professionals, patients and charity stakeholders all acknowledged the considerable amount of work required to improve communication both between healthcare professionals and patients, and between local and specialist MDTs. The development of dedicated communication training programmes embedded within the framework of managing advanced CRC was felt to be desirable.

Patients and charity representatives expressed a desire for high quality and easily accessible communication regarding treatment options in the advanced CRC setting. They also expressed a desire for standardisation of language amongst the clinical community when discussing outcomes in patients with advanced CRC. The importance that patients place on communication is clearly reflected in the survey results, with the availability of a named nurse to direct questions and concerns, ranked as one of the more important priorities. It was suggested that the presence of a dedicated patient advocate as a member of the advanced CRC MDT could act as a named contact as well as facilitating communication across specialities.

#### Education

All stakeholders acknowledged that appropriate education to highlight awareness regarding potential management options in this cohort of patients was key to improving longer-term outcomes. It was felt by patients that a lack of awareness regarding the full range of potential treatments and their availability by the local MDTs led to conflicting advice regarding treatment and prognosis, as well as delays in receiving overall treatment. From a clinical perspective, education of the members of local colorectal MDTs, particularly those based at centres without on-site specialist services, with regards to available regional services and current treatment options was deemed an important target for quality

**Table 2**

Patient, clinician and stakeholder quotes reflecting the nine themes.

Theme	Patient Quote	Clinician Quote	Other Stakeholder Quote
1) Current Services	'Scottish services in my experience work very well and communicate well between institutions'	'Regional centres need to know what resources are available and what the referral patterns are'	'A central directory of specialists and what services individual trusts offer for patients with advanced disease is needed. This should be accessible to patients, clinicians and support groups. Perhaps it already exists on the ACPGBI website?'
2) Specialist Services	'Establishing a specialist network where all patients are referred to their nearest centre should not come at the expense of patient choice'	'We should be looking to move away from an organ specific approach e.g. colorectal MDT for primary, hepatobiliary MDT for liver metastases, to working together and thinking as 'cancer surgeons'	
3) Communication	'I am the modern patient, used to making choices and being a consumer, I need more information to understand and process my options'	'Currently there are huge deficiencies in communicating between specialties. If I write a letter, it won't be opened, read or actioned for days or maybe weeks We need a more efficient process of communicating' 'Maybe we need a local 'champion' who is responsible for coordinating referrals to MDTs. Someone who is passionate about this and willing to settle the logistics. Maybe this will improve communication'	'Charities and patient organisations should be involved in the process of agreeing a new language of terminology around advanced cancer that patients are happier with'
4) Education	'There is a patient and professional education gap'	'An education programme is required for all professionals involved in the MDT, so that people know all the latest evidence and potential treatment options available. This will ensure that no patient is turned down for something they could/should be considered for' 'Maybe the way forward is through education; for instance a hub and spoke model with education aimed at the spokes being common place'	
5) Access	'Just because there is nothing that can be done for me at one place, does not mean that something cannot be done elsewhere'	'Patients have variable access to MDTs and MDTs have variable access to specialist services'	'Patients often contact Beating Bowel Cancer asking how they can get a second opinion and if someone can be recommended'
6) Definitions and Standardisation		'Individual networks have individual guidelines – it's all different! These need to be amalgamated or standardised for simplicity'	'We need a joined up approach to delivering care for these patients, not just a consensus on how to delivery care for individual components'
7) Research and Audit	'It's important for the patient to really understand what the trial is about and how it is going to work. I feel that a video some online content would work well because you can watch it in your own time' 'I wish there was an obligation to tell us about trials'	'The challenge in this patient cohort is to identify a research question where there is truly equipoise'	'Patients and family members frequency come to our internet forum to ask about clinical trials, these people are desperate and often don't know who else to approach'
8) Outcome Measures	'For me, quality of life is the most important outcome. Everyone has their own expectation of what this means. When I start a new treatment I would realistically expect it to go down a bit, but the goal is not too much' 'Avastatin wasn't available in Scotland. I wrote to ask for funding but it was denied. It would have only given my daughter 2 months but she was getting married and the time would have meant the world to her'	'We should consider using standardised quality of life questionnaires in all future studies assessing benefit of intervention in this cohort'	
9) Funding		'Are there sufficient timely resources for (for instance) 1000 resectable peritoneal metastases? This keeps me awake at night' 'It is all very altruistic of all here to suggest everyone is referred for a specialist opinion but there is not the infrastructure in place to deal with it'	

improvement.

Education and training should also be considered for developing specialist skills among CRC surgeons. Ensuring these clinicians are adequately trained to operatively manage advanced CRC and its potential complications is central to delivering high quality services. Appropriate mentorship and/or preceptorship was felt to be important, with the development of appropriate fellowship programmes to help support this endeavour.

#### *Access to care*

Equitable access to resources and services was identified as a key step in ensuring all patients with advanced CRC receive appropriate and high quality treatment in a timely fashion. Several factors were felt to potentially influence patients' and clinicians' ability to access specialist services. These included no formal access to specialist services through developed networks and referral pathways and the lack of an embedded system for a 'second opinion' in the majority of MDT working. Clinicians often gained access to specialist services through non-structured and informal referrals, thus highlighting the lack of standardised referral patterns and clinical networks.

The lack of access to specialist services and treatments was a source of great concern to patients, family members and charity stakeholders. This is highlighted within the patient and public survey, which demonstrates access to treatment, irrespective of geographical location, is the most important factor when considering treatment options. Patients often attributed the lack of access to services with the lack of funding available for certain treatments within certain regions. Improving access to all potentially available effective treatments, regardless of locality, is another secondary key priority in this cohort of patients.

#### *Definitions and standardisation*

It was felt important while taking the IMPACT initiative forward, that the term 'advanced CRC' is universally defined, with agreement by all key stakeholders. Alongside this, it was deemed important to consider standardisation of national and local clinical guidelines regarding the management of advanced CRC, and possibly present these in a more accessible manner. Patients and clinicians felt that there is a requirement for nationally defined criteria as to which patients should be referred to specialist MDTs, including dedicated advanced CRC MDTs, hepatobiliary and thoracic MDTs. This would act to standardise referral patterns, empower local MDTs and ensure equitable access.

#### *Research and audit*

Robust evidence to inform the management of advanced CRC is lacking. The development of national clinical networks was felt to be important in identifying a critical mass of specialists dedicated to improving outcomes in this cohort. This national network, with access to a potentially larger pool of patients for recruitment to research, and better understanding of equipoise, would be ideally placed to recognise key research questions and deliver well-designed, high quality studies.

Patients in both the focus groups and the survey expressed an active interest in participating in clinical research, and in particular clinical trials. They expressed frustrations over lack of accessibility to information outlining current active clinical trials, and suggested the possibility of developing a repository of clinical studies to overcome this. The lack of clinical trials overall and the closure of previous clinical trials in advanced CRC due to lack of engagement and slow recruitment was deemed to be disappointing. Patients highlighted that innovative methodology would be required to successfully recruit and retain participants with advanced CRC, with due consideration given to the complexities surrounding recruitment, randomisation and follow up.

#### *Outcome measures*

Clinicians expressed concerns that the current outcome measures used in advanced CRC were too heavily focused on oncological and survival outcomes, with little emphasis on formal measurements of quality of life and symptom control. In this setting, where large survival benefits are unlikely to be realised, these outcome measures were deemed to be more important. It was evident from the patient survey that patient-reported outcomes such as being pain free and maintaining independence were prioritised over longevity (Fig. 2). Patients outlined the importance of being able to understand and balance clinical and oncological outcomes in combination with quality of life outcomes when comparing treatments.

#### *Funding*

There was considerable discrepancy between clinician and patient perspectives when considering the issue of funding. For patients and charity stakeholders the main concern regarding funding related to the perceived regional and national inequalities in funding for treatment, thus leading to variation in access to treatments. Further issues around funding were highlighted when comparing treatment options available within the public and private sectors of the healthcare system. Charity stakeholders supported this perspective and acknowledged the difficulties some patients faced in securing funding for particular treatments.

For clinicians, the issue of funding was focused on the significant changes to existing infrastructure that will be required if current services are to be developed. There was concern that present services are functioning at capacity and consequently would not be able to cope with any increases in demand through increased patient referral to specialist services.

#### **Discussion**

This consultation exercise brought clinicians, patients and charity stakeholders together to prioritise outcomes in advanced colorectal cancer. The overarching aim of this IMPACT exercise was to highlight the agenda of patients, clinicians and other key stakeholders in the delivery of optimal care. This study employed a patient centered, mixed-methods approach to identify nine themes to be addressed as part of an initiative to improve services and outcomes for patients with advanced CRC in the UK. Patient-oriented research is of high priority within colorectal surgery [17]. Priority setting initiatives have previously been used to identify consensus with regards to research priorities in a range of complex clinical scenarios [18], our exercise provides a broader perspective in advanced CRC, focusing on quality improvement, service provision, education and research.

The themes identified by the IMPACT initiative have important clinical implications. To illustrate this, travel time has been shown in this study and other recent to work to be less important to patients than complication risk, mortality risk and access to a specialist MDT [19]. Although there was consensus amongst all key stakeholders regarding the potential benefits of further centralisation of advanced CRC services, there is evidence to suggest that referral rates to specialist services amongst patients who are not treated at the site of the specialist centre may be lower [11,20,21]. Therefore, it will be essential to establish and disseminate widely accepted referral criteria to ensure equity of access, which will act to reduce any potential negative implications of service centralisation.

From an academic perspective, it is important to note the limitations within the current evidence base. Conducting research in patients with advanced CRC has been acknowledged to be challenging, with concerns regarding clinician and patient equipoise, timely recruitment and high rates of attrition [7–10]. Consequently,

engagement with all key stakeholders from the onset is a crucial step in identifying any potential challenges and in identifying strategies to overcome these challenges, thus ensuring the success of any future endeavour. Alongside issues with recruitment and retention, research in this cohort of patients is often conducted in small sample sizes with highly selected patients due to the application of stringent eligibility criteria. This limits the generalisability of such studies due to the lack of adequate representation of the overall disease cohort. It is therefore essential that future studies are designed to have high external validity, reflecting the heterogeneous nature of advanced CRC with results that are generalisable and applicable to all patients. Furthermore, research in advanced CRC has largely focussed on survival without adequate weight being given to quality of life or patient-reported outcomes.

It is important to acknowledge several key steps, which have already been taken by a number of groups in a bid to improve outcomes in this cohort of patients. Aintree NHS Hospital Trust established a CRC MDT specifically for patients with advanced disease in 2013, with early reports that this has been smooth in its integration. This highlights the feasibility of making changes to service delivery to what many may feel is an ingrained system [22]. Furthermore, the National Bowel Cancer Audit has published the results of an organisational audit carried out across England and Wales, which details the regional availability of hepatobiliary and thoracic MDT services [3]. There has been recent work on aligning outcome measures in CRC surgery with the development of a core outcome set for use in clinical trials [23]. Although this focuses only on CRC patients who have undergone surgery, the scope was broad and included quality of life outcomes. Adherence to this framework in future CRC clinical trials may facilitate outcome comparison. In addition, the ACPGBI and the Pelican Cancer group are together working on a nationwide IMPACT initiative involving an educational programme for members of the CRC MDT [24]. During 2018 and 2019, 13 regional one-day workshops will be delivered across the UK, to which key members (surgeon, palliative care, radiologist, oncologist, pathologist and clinical nurse specialist) from each local CRC MDT will be invited. At these workshops a range of clinical presentations of advanced CRC will be discussed, with the aim of improving communication between MDTs and raising awareness of treatment options. As well as an educational component to these events, the views of attendees as to the main barriers they may experience to achieving the best outcomes for their patients will be gathered and used to plan further intervention. These individual initiatives align themselves with the overall IMPACT goals and future strategies.

The themes identified as part of this consultation exercise are likely to be broadly generalisable to cancers of different tumour sites, particularly those in which diagnostic and therapeutic services are offered in different locations. This research is also likely to be applicable to other countries with a health care system that is free at the point of access. It is the authors opinion that the barriers to performing patient centered research in this cohort have, in the past, contributed to a paucity of research in this area. This study has demonstrated the success of a mixed methods approach to triangulate the views of patients, care givers, charity representatives and clinicians in this complex and heterogeneous cohort.

There are several limitations of this work to acknowledge. Patients who participated in this priority setting exercise were identified from social media and via blogging websites. Evidence suggests that patients who engage with the wider community using such platforms tend to be better informed regarding their disease process, and treatment options, which in turn alters their communications with health professionals involved in their care [25]. This may have influenced how representative the patients involved in this initiative were of the general population of those

with advanced CRC. The majority of healthcare professionals participating were consultant surgeons working in specialist centres with a specialist interest in the management of patients with advanced CRC. Across the UK many patients with advanced CRC cancer are managed by a team with no subspecialist interest in advanced CRC, who may be based at a centre with no on-site specialist services. The generalisability of these findings across all centres and healthcare professions should therefore be considered.

## Conclusion

This study summarises the results of a priority setting exercise which has identified nine key areas to target to ultimately improve outcomes for patients with advanced CRC. This exercise will act as a catalyst to develop these themes into a tangible quality improvement programme. These future priorities will be developed with collaborative engagement in a systematic manner to produce an overall cohesive programme which will deliver a sustainable and efficient clinical and academic service to improving the management of patients with advanced CRC.

## Conflict of interest

No conflict of interests.

## Declarations of interest

None.

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