**Title:**

**The ENABLE study protocol: Understanding and characterising the value and role of self-management support for people living with cancer that is treatable but not curable**

# Keywords: incurable cancer, self-management, self-management support, qualitative, longitudinal, Delphi, consensus

**Abstract**

*Objective*: Attention is turning to the needs of people living with treatable but incurable cancer, a group with complex needs, living with uncertainty over time. More research is needed to understand how this group self-manage the impact of cancer to strengthen the evidence-base for interventions. This study aims to understand the value and outcomes of self-management support for people living with treatable but incurable cancer.

*Methods*: Qualitative longitudinal methods will examine how support needs change over time in relation to self-management and unpredictable disease trajectories. Thirty patients and 30 carers will be recruited from two hospitals, each participating in three interviews over one year. Patients will be purposively sampled according to age, gender, cancer type and anticipated survival. Carers will be recruited via nomination by patients but interviewed separately. One-off interviews will be conducted with 20 health care professionals, providing data from multiple perspectives. Based on interview findings, a modified-Delphi process will map areas of consensus and disparity regarding conceptualisations and outcomes of self-management support.

*Conclusion*: The key output will be practice recommendations in relation to self-management support, producing evidence to inform service innovation for those living with treatable but incurable cancer.

# Introduction

Attention is turning to the needs of people living with cancer that cannot be cured (Lobb et al., 2015; Maher, Velikova, & Betteley, 2015). Patients are increasingly living for months or years with incurable disease, often undergoing multiple episodes of treatment (Maher et al., 2015). This group of patients has a complex set of needs often managing their own health and wellbeing at home, supported by those close to them, and often wishing to maintain independence, normality and control over their lives (Calman, Beaver, Roberts, 2010; Harley, Pini, Bartlett, & Velikova, 2012; Johnston, Milligan, Foster, & Kearney, 2012; Roberts, 2013), Wang et al, 2018). How this group of patients self-manage the impact of cancer and its treatment is not well understood (McConnell H., 2015; McCorkle et al., 2011; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009; Reed & Corner, 2015) and there is a weak evidence base to inform the development of services and interventions (Fenlon, Foster, & Macmillan Research Unit, 2009; King, 2014). There is also a lack of research both in the UK and internationally examining how this population live with uncertainty over time and how perspectives and needs change in relation to unpredictable illness trajectories.

Although this group of patients are living with cancer that cannot be cured, they are on treatments that can delay progression of cancer, reduce its burden, alleviate symptoms and prolong life (White et al 2018) rather than being managed with palliative care. Patients living with treatable but incurable cancer have only recently been identified and quantified as a specific group, based on analysis of data from the England cancer registry (White, 2018), drawing on a framework identifying three groups of patients living with cancer based on differences in complexity, intensity and longevity of broad clinical need (McConnell, White, & Maher, 2017; White, 2018). The groups are longer-term survival (over 90% live one year or more after diagnosis), intermediate survival (‘cancer as a complex ongoing disease’, over 50% live one-year or more, relapse or recurrence is common and ongoing treatment likely, e.g. metastatic breast, prostate, ovarian); and shorter-term survival (fewer than 50% survive one year, e.g. metastatic colorectal). Patients living with cancer that cannot be cured fall into the intermediate and shorter-term survival groups, which accounts for approximately 29% of all people living with cancer (McConnell et al., 2017).

The evidence for self-management support (SMS) among those living with treatable but incurable cancer is extremely limited (Fenlon et al., 2009; King, 2014). Self-management has been defined as managing consequences of cancer and its treatment, seeking support, recognising and reporting disease progression; and lifestyle changes to promote well-being and survival (Foster, 2015). Some evidence indicates that SMS could address the needs of those who are living with cancer that cannot be cured (Budhwani, Wodchis, Zimmermann, Moineddin, & Howell, 2019; Harley et al., 2012; McConnell H., 2015; McCorkle et al., 2011; Rainbird et al., 2009; Reed & Corner, 2015). A recent scoping review of studies on self-management strategies and SMS needs of patients with advanced cancer found that patients engaged in a variety of self-management behaviours and have an extensive need for SMS (Budhwani et al., 2019). Patient needs for SMS fell broadly within the domains of managing complex, cyclical and chronic symptoms and the impact of those symptoms on the psychosocial aspects of daily life, findings supported by two systematic reviews of the unmet needs of people living with advanced cancer (Wang et al 2018, Moghaddam et al 2016). The importance of the role of carers in addressing the self-management needs of patients with advanced cancer has also been highlighted (Budhwani et al., 2019), with managing patients’ emotions identified as a particularly challenging part of caregiving (Wang, Molassiotis, Chung, & Tan, 2018).

The needs of patients living with cancer that is treatable but incurable can resemble needs of patients with other chronic illness conditions (Moghaddam, Coxon, Nabarro, Hardy, & Cox, 2016) and indeed many may be managing other conditions in addition to cancer. The chronic condition literature reports increasing evidence that supporting people to manage their own heath has positive outcomes, such as improved quality of life and reduced use of health services (de Iongh A., 2015). There is growing international recognition that healthcare services need to adapt to better support people living with incurable but treatable cancer and it has been argued that a cultural shift among health care professionals (HCPs) is necessary to promote self-management among patients and carers (Hughes, Closs, Flemming, & Bennett, 2016; Ong et al., 2014). Managing the tensions between instigating supportive care for deteriorating health whilst encouraging participation in self-management as patients and carers transition between services and phases of illness presents a challenge.

Although a small number of longitudinal qualitative studies have been carried out on the experiences of people living with advanced cancer (Grant et al., 2004; S. A. Murray et al., 2002; Roberts, 2013; Walshe et al., 2017), there is a significant gap in longitudinal studies examining the self-management behaviour and SMS needs of those living with advanced cancer, and their unmet needs more generally (Budhwani et al., 2019; Wang et al., 2018). In this paper we describe the protocol for the ENABLE study, a longitudinal qualitative study examining SMS specifically in people living with cancer that is treatable but not curable, to understand how needs and perspectives change over time in relation to unpredictable disease trajectories. To our knowledge this method has not been used previously to specifically understand the value and outcomes of SMS among this group of patients and carers. Interviews will also be carried out with HCPs to provide further data from multiple perspectives. This will be followed by a modified-Delphi process with multiple groups of key stakeholders to identify and map areas of consensus and disparity on conceptualisations and outcomes of SMS.

# Aims and objectives

The overall aim of the ENABLE study is to examine the value, role and outcomes of SMS in people living with cancer that is treatable but not curable cancer. We will focus on patients with intermediate survival (McConnell et al., 2017), as assessed by members of their clinical care team (CCT), ensuring patients have sufficient survival to participate in a longitudinal study.

The objectives of the study are to:

1. Examine the meaning and value of the concept of SMS
2. Characterize roles undertaken by patients, carers and HCPs to support self-management of patients in the context of incurable disease
3. Identify what resources and support are needed and used by people to help them manage the impact of cancer and its treatment
4. Identify and map areas of consensus (and disparity) regarding conceptualisations and outcomes of SMS

**Design and Methods**

This study has two stages (see figure 1). Stage one will consist of qualitative interviews, drawing on a grounded theory inductive approach (Glaser & Strauss, 1967). Three longitudinal face-to-face in-depth qualitative interviews will be conducted with patients and carers over a one-year period and one-off interviews with HCPs. This approach will enable a detailed understanding of individual and social contexts in relation to self-management strategies and how perspectives change over time in the face of the unpredictable nature of the cancer (Calman, Brunton, & Molassiotis, 2013). Interviewing patients, carers and health care professionals will enable triangulation of multiple data sources to develop a comprehensive understanding of SMS (Patton, 1999). Stage two will be a modified-Delphi exercise to explore and map consensus and disparity on the conceptualisations and outcomes of SMS based on the findings from stage one. Understanding different stakeholders’ conceptualisations and priorities for self-management support is important for developing services that address needs.

Public and patient involvement is integral to the study design; we have incorporated the input of a patient as a named applicant who has contributed to the protocol and who will establish a User Reference Panel (URP) of patients living with cancer that is treatable but not curable and carers. Due to unpredictable trajectories we will identify a group of patients and carers rather than one or two, allowing for different levels of involvement over the course of the study and using a range of accessible methods (e.g. email, phone, face-to-face) to minimise additional burden. The URP will review patient facing documents and topic guides and support piloting of interviews and interpretation of findings and dissemination.

The research team will also be supported by a Study Advisory Group (SAG) of experts (researchers, clinicians, policy makers and patients/carers).

**(*Insert Figure 1: Overview of study design*)**

**Stage 1**

**Patient and carer longitudinal interviews**

**Sample**

Patients and carers will be recruited from outpatient and palliative care clinics at a large district general hospital in the South of England and a tertiary cancer centre in the North. This will enable the recruitment of a demographically broad sample, representing experiences of different healthcare services and other support services that may be available.

Patients with treatable but incurable cancer will be purposively sampled with reference to age, gender and cancer type (McConnell et al., 2017). We will recruit patients with gastrointestinal cancer (any), metastatic prostate cancer, gynaecological cancer (any) and myeloma to represent a range of cancer types that affect men and women and represent a significant proportion of patients who fall into the intermediate survival group. We aim to recruit up to 30 patients (3-5 with each cancer type from each hospital).

Patient inclusion criteria:

* Adults aged over 16 years, no upper age limit.
* Diagnosed with gastrointestinal, metastatic prostate or gynaecological cancer or myeloma
* Assessed by the CCT as treatable but incurable, i.e. their cancer is not curable but they have further lines of treatment available to them. Participants may be newly diagnosed with treatable but incurable cancer or the disease may have progressed after curative treatment.
* Capacity to give informed consent, judged by their CCT.

Patient exclusion criteria:

* Patients likely to die within three months, as assessed by their CCT.

We aim to recruit up to 30 carers. Patients who have been invited to participate will be asked to nominate a ‘person they get most support from’. (Patients who do not have a nominated carer will also be eligible to participate).

Carer inclusion criteria

* Adults over 16 years, no upper age limit.
* Nominated as an informal carer by a patient who has been invited to participate

Carers and patients will be interviewed separately to enable exploration of individual experiences and needs; however patients and carers can be interviewed together if requested (or can have a support person with them). We anticipate that most interviews will be conducted in the home setting, but alternatives will be offered if preferred.

Patients and carers will participate in up to three interviews over one year. The interviews will be approximately four months apart but timings will be flexible based on participant preference, taking into account significant events, as defined by the participant, e.g. clinic visits and illness trajectories. Evidence suggests a flexible approach to timing of data collection is preferred by patients and helps maximize data collection (Walshe et al., 2017).

Based on our previous experience of longitudinal studies (Calman et al. 2013), along with other qualitative longitudinal studies of patients with advanced disease including cancer, and their carers (Johnston et al., 2012; Scott A Murray et al., 2009; Walshe et al., 2017), the sample size has been chosen with the aim of ensuring sufficient participants to achieve data saturation, taking attrition into account, whilst balancing this with the large amount of data likely to be generated. If data saturation (Glaser & Strauss, 1967; Saunders et al., 2018) has not been reached after three interviews have been completed with 30 patients and 30 carers then, with agreement of the study advisory group and with appropriate regulatory permissions and approval from the funder, we will continue to interview additional patients and carers until saturation has been achieved and no new themes are emerging.

Although steps will be taken to minimise attrition through building strong relationships with participants, it is likely some participants may be lost due to deterioration and withdrawal or death. Participants will be asked for consent to retain the data collected up until the point of withdrawal.

**Data Collection**

A researcher will be based in each of the two sites. Eligible patients will be identified by an agreed member of their CCT and introduced to the researcher who will discuss the study with them (and their carer, if applicable) and give them a participant information pack. If no carer is present then patients will be asked to nominate a carer who may wish to take part. If a patient is highly distressed then members of their CCT will make the decision about whether it is appropriate to approach them about the study.

If the patient is interested in participating, they will complete a reply slip and the researcher will contact them a few days later to arrange a face-to-face or telephone meeting on a convenient date. At the first meeting the researcher will answer any questions the participant may have and review the information sheet and consent form. Signed consent will be obtained for study participation and for permission to inform the patients’ GP of participation. Verbal consent will be reaffirmed before each follow-up interview.

We anticipate interviews will last approximately one hour depending on the participant’s health. Interviews will be audio recorded and transcribed. All data will be pseudo-anonymised.

Researchers will conduct interviews in a sensitive manner and aim to build rapport with the participant. Should the participant become distressed, the researcher will ask if they would like a break and, when they have recovered, whether they wish to continue. Should the participant raise any questions about their cancer or treatment they will be advised to contact an appropriate HCP. Details of community-based supportive services and resources will be offered by researchers after the interview, as appropriate.

Before the second/third interview, researchers will contact the patients’ CCT or GP to ensure it is appropriate to contact them to arrange a follow-up interview. If they have died they will be withdrawn from the study (with their data retained) and a sympathy card sent to their carer/ family. If it is not appropriate (e.g. a change in the patient’s mental capacity), the patient will not be contacted. The health status of any patient deemed not appropriate to contact will be checked again at a later date and the above procedures followed.

The same procedure will be followed for the carer interviews, with the exception of the health status check prior to follow-up interviews. If it is not appropriate to contact a patient or a patient chooses to withdraw due to ill health or dies, the carer will be contacted at a later date to check whether they would like to continue to participate. If they choose to continue, as with the previous interviews, the interview will be carried out sensitively. Based on our previous experiences of conducting interviews with bereaved carers (Orlowska et al., 2018), they are an under researched group with valuable insights and experiences to contribute.

A broad topic guide will be used to guide the interviews while allowing flexibility for the discussion of additional topics relevant to participants’ experiences of self-management. The topic guide will be piloted with support from the URP (see box 1).

After each interview a preliminary summary will be written, giving an overview of emerging themes and concepts and as a basis to recap with the participant at the start of each follow-up interview. Each follow-up interview will begin by asking participants to reflect on the content of their previous interview(s) and discuss what may have changed.

**Box 1: Broad topic guide for patients and carers: Topics and example questions**

* Support and roles undertaken relating to self-management eg. What kind of support has been available to you (eg carers, health care professionals)?
* Performance of daily activities eg. Tell me about how you go about day-to-day activities?
* Facilitators and barriers to self-management eg Tell me about when you coped well or not so well?
* Management strategies, eg Please focus on one challenge or problem you have experienced and tell me about how you coped/ managed?
* Changes in self-management over time eg. Since the previous interview have you developed new strategies to help you to manage/ cope? Can you tell me about changes since the previous interview?
* Managing multiple morbidities eg. Please tell me about any other health conditions that you have to manage/ cope with? Tell me about any strategies/ ways of managing that you have developed in relation to previous health problems?
* Relevant self-management outcomes eg. What makes you feel you’ve had a good day?

**Health care professional interviews**

**Sample**

A range of HCPs working with patients living with treatable but incurable cancer, including nurses, oncologists, supportive care specialists, allied health professionals, third sector professionals will be purposively sampled across both NHS Trust sites as well as community-based clinicians such as GPs. We aim to recruit up to 20 HCPs using a snowball sampling technique, asking participants to identify other appropriate HCPs to gain a wider range of HCPs.

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**Data collection**

The researchers will email HCPs an information sheet, inviting them to participate and if they are willing, an interview will be arranged at a convenient date, ideally at their workplace. HCPs will be interviewed once using a topic guide exploring their roles, support needed for effective self-management, facilitators and barriers to the implementation of SMS and relevant self-management outcomes.

**Analysis**

**Box 2: Stages of data analysis based on Satink et al. (2016) and Charmaz (2006)**

* Initial reading of interview data
* Preliminary coding by two researchers
* Research team meeting to discuss and refine coding
* Coding of each separate case (all interview data of one participant)
* Grouping of codes into categories for each separate case
* Memos of each case and general memos to capture any reflections
* Longitudinal comparisons within cases and categories to focus on changes over time
* Focused coding to examine the categories in relation to the emerging concepts and phases
* Research team meeting to discuss final themes
* Development of final themes
* Themes from patients, carer and HCP interviews compared and cross-checked

Analysis of patient and carer interviews will take a longitudinal approach, drawing on the constant comparative method used in grounded theory (Charmaz, 2006; Corbin & Strauss, 1990). The two researchers will code the data in close collaboration with other members of the research team, using the framework matrix facility within NVivo to examine themes longitudinally, enabling comparisons within each case and across cases, focusing on changes over time (Calman et al., 2013). The stages of data analysis are outlined in box 2, drawing on the longitudinal aspects of analysis used by Satink and colleagues (2016) in their longitudinal qualitative study of self-management among stroke survivors. HCP interviews will be analysed using the same stages, with the exception of the longitudinal comparison. The interview data will be triangulated through comparing and cross-checking findings from the interviews with patients, carers and HCPs (Patton, 1999). Based on an iterative process, emerging themes will be used to develop explanatory accounts. Analysis will draw on sociological perspectives of self-management, (eg. Ellis et al. (2017); (Ong et al., 2014; Taylor & Bury, 2007) to address the social as well as individual context of self-management, in addition to more traditional psychological theories of individual behaviour change (eg. Bandura (1994).

**Stage 2**

**Modified-Delphi exercise**

Based on findings from stage one, a modified-Delphi process with three phases (survey tool generation followed by two surveys) will be conducted to explore and map consensus and disparity regarding concepts and outcomes of SMS, based on our previous experience of modified-Delphi exercises (Gonçalves, Marques, Demain, & Samuel, 2018). Identifying outcomes relevant to a range of stakeholders (patients, carers, professionals who deliver services and commissioners) will inform design and evaluation of self-management interventions, and potentially improve the uptake and enactment of self-management. Stakeholders from each of the following groups will be recruited to participate as panel members in the modified-Delphi exercise:

**Survey tool generation**

Item generation will be undertaken by creating a full list of items to reflect the entirety of items generated during stage one, based on analysis of the qualitative interview data across all stakeholder groups (Patients, carers and HCPs). The statements will be compiled by going through each node and identifying the key, re-emerging themes. In order to maintain authenticity excerpts from the transcripts will be used verbatim in the creation of the statements. These will be reviewed for completeness and clarity by the research team and the User Reference Panel.

The full list of items will then be refined through a process of cognitive interviewing with stakeholder representatives who have taken part in the qualitative interviews (stage one) (three-six per stakeholder group). Cognitive interviews using think aloud and probing techniques (Willis, 2004) will be conducted to refine the list to ensure clarity and reduce variation in the way that respondents interpret questions and social desirability biases. Think aloud is a participant led approach, where the participants will be asked to explain what they are thinking as they complete each item. Probing is a researcher led approach, where the researcher will ask questions about how participants are interpreting key words or phrases and their understanding of and preferences for different response formats.

We aim to recruit up to 25 from each of the following groups, giving a total of approximately 100 participants, a sufficient number to gain a range of views from different stakeholders, based on our previous experience of modified-Delphi exercises (Demain et al. 2014) and reflecting sample sizes in other Delphi studies (Diamond et al., 2014; Trevelyan & Robinson, 2015).

*Patients*: Patients with cancer that is treatable but not curable.

Carers: Informal carers of patients with cancer that is treatable but not curable

Professionals who deliver services: People from a range of relevant professions including nurses, oncologists, supportive care specialists, allied health professionals and the third sector.

Commissioners/policy representatives: people commissioning services for people living with cancer that cannot be cured.

Patients and carers will be identified and recruited through hospital clinical care teams, using the same eligibility criteria and method as recruitment for the interviews in stage one (see above). To recruit professionals who deliver services and commissioners/ policy representatives with appropriate expertise the research team will use their professional contacts and publicly available contact data and professional organisations to send invitations. We will also use snowball sampling, asking professionals to identify other appropriate colleagues to be invited. Interested individuals will be invited to respond to an advert or invitation by contacting the researchers. In addition all participants from stage one (including patients and carers) will be invited to participate, in line with other Delphi studies (Gonçalves et al., 2018). On response, sociodemographic information will be collected. Participants will be purposively sampled to maximise sample diversity in terms of gender, age and ethnicity for patients and carer stakeholder groups, and professional expertise for HCP and commissioner stakeholder groups. All results will be anonymous and panel members will not be identifiable to each other.

**Survey procedure and analysis**

Two surveys will be undertaken.

The first will involve stakeholders completing a survey either in paper format, returned with a prepaid envelope, or online survey using survey software. The survey will consist of a full list of identical items for all stakeholders, asking them to rate their perception of the importance of each item using a five-point Likert rating scale ranging from one (not important) to five (very important). They will also be asked to suggest any additional outcomes.

Consent will be provided with the return of the surveys. Survey one participants will be asked for permission to contact them again to take part in the second survey. The first survey will be open for approximately two months, during which time a reminder to complete the survey will be sent to those who have yet to respond.

The findings of the first survey will be analysed using descriptive statistics to identify the outcomes given the greatest importance by each stakeholder group. The 20 outcomes given the highest mean importance score by each stakeholder group will become the items for the second survey. The mean scores may differ by stakeholder groups therefore each stakeholder group may receive a different list of items for the second survey. One reminder will be sent to those who have not completed the survey after two months.

In the second survey each participant will be asked to i) select the 10 items (from 20) which they considered most important to them and then ii) to rank these 10 items in order importance.

The second survey will be open for approximately two months during which time a reminder to complete the survey will be sent to those who have yet to respond.

Data from Survey 2 will be analysed to determine the outcomes given highest priority by each stakeholder group. We will identify the frequency with which participants in each stakeholder group ranked outcomes to be one of their ‘top 10 priorities’. We will consider there to be adequate within stakeholder group consensus if the majority (>50%) of participants in that stakeholder group rank it a ‘top 10’. We will then plot the data to identify items which met this criteria for all four stakeholders. We will also identify any disparity between stakeholder groups.

The reporting of this modified Delphi study will meet the agreed reporting guidelines for Delphi studies (Diamond et al., 2014; Sinha, Smyth, & Williamson, 2011).

### Dissemination

Findings will be widely disseminated through journal papers, conference presentations, a policy brief for commissioners and posts on social media and the study website. We will hold stakeholder events, including an engagement workshop for patients, carers, HCPs and commissioners, to launch study findings and recommendations. The research team will also be engaging with all UK health policy making bodies to enable their results to feed into future policy for cancer care. The key output will be practice recommendations to address patient and carer need in relation to SMS. This will create a foundation on which to build a patient and carer-led intervention to facilitate self-management and promote well-being amongst those affected by incurable cancer.

**Discussion**

People living with cancer that is treatable but not curable have a complex set of needs and can live with uncertainty over long periods. This poses a unique challenge, and needs to be balanced with the fact people often wish to maintain independence, normality and control over their lives (Calman, Beaver, Roberts, 2010; Harley et al., 2012; Johnston et al., 2012; Roberts, 2013). More research, in particular longitudinal research, is needed to understand how people living with treatable but incurable cancer manage the impact of cancer and its treatment (McConnell et al., 2017; McCorkle et al., 2011; Rainbird et al., 2009; Reed & Corner, 2015) Budhwani et al 2018, Wang et al 2018) to strengthen the evidence base for interventions (Fenlon et al., 2009; King, 2014). To address this gap a longitudinal design will be employed, an approach not previously adopted to examine SMS amongst this particular patient group, enabling the generation of insights into how perspectives, strategies and needs of patients and carers change over time in relation to self-management and the unpredictable nature of the disease. The ENABLE study will bring together data from patients, carers and HCPs enabling a detailed understanding from multiple perspectives. A modified-Delphi process will follow, identifying and mapping areas of consensus regarding conceptualisations and outcomes of SMS**.** This study will produce much needed evidence to inform service development and assessment to better meet the needs of this growing group of patients and carers.

**Statement of ethical approval**

This protocol has received ethical approval from the Health Research Authority in the UK (Research Ethics Committee reference 19/SC/0132).

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