



HOW DO PEOPLE FROM THE SOUTH ASIAN COMMUNITY VIEW, USE AND UNDERSTAND ADVANCE CARE PLANS? HOW READY ARE THEY TO USE THESE ADVANCE CARE PLANS ALONGSIDE OTHER PALLIATIVE CARE SUPPORT?

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## **Executive summary**

### **Introduction**

In Bradford, and nationally, there is evidence that individuals from minority ethnic backgrounds are less likely to have documented Advance Care Plans and are more likely to be admitted to hospital in the end-of-life care period, subsequently increasing the likelihood that they will die in hospital.

### **Aim of the Study**

To use the Community Readiness Model (CRM) to understand the level of readiness amongst the South Asian community to adopt Advance Care Plans as part of their end-of-life care.

### **Method**

Key stakeholders were purposively sampled and were asked to (i) complete a questionnaire to assess the community's readiness for advance care planning and (ii) attend a focus group which explored their views on the community's understandings of, and attitudes about, palliative and end-of-life care.

### **Key findings**

The South Asian community only have a vague awareness of end-of-life care options and of services provided by RIC (Reducing Inequalities in Communities). To improve readiness, there needs to be more fundamental work to understand the community, and how they view the end-of-life period. It is only by improving understanding that initiatives can be planned and delivered in a way that maximises the chances of successful uptake. Within the community, there seems to be a focus on after death concerns, as opposed to concerns within the end-of-life care period. This may reflect a wider societal reluctance to discuss dying, but also may reflect that many discussions that take place currently about end of life focus on what happens around the death (e.g., do not resuscitate; place of death) and not on the care that is available before death.

### **Key recommendations**

- Engage with the community and Voluntary and Community Sector organisations to understand why individuals who live within the South Asian community do not discuss the end-of-life period in advance of this period.
- Increase death awareness as a community issue through public information, facilitated discussion and through existing avenues for public and patient engagement.
- Provide additional training and support of the health team in instigating Advance Care Planning. A whole team approach is needed.
- Give wider end-of-life care staff access to patient notes (e.g., Choices end-of-life facilitators), so that different members of healthcare staff can be better integrated with one another when working with the same patient.
- Create space for active discussions with clerics to identify any tensions/mixed messages about what the end-of-life period requires.
- Develop and share examples of what good end-of-life care looks like.
- Develop understanding of how end-of-life discussions can be normalised within the community.
- Use strategies to implement and encourage end-of-life care discussions amongst family members.
- Begin to encourage the use of the CCG's end-of-life care support services amongst healthcare professionals so that people are able to access palliative care earlier on.

## Introduction

Palliative care aims to help “improve the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual” (WHO, 2020). This type of care aims to “prevent and relieve suffering” by appropriately identifying, diagnosing and treating areas which could later become more detrimental (WHO, 2020). More specifically, end-of-life care focuses on the final days, weeks or months (sometimes years, depending on the condition) of an individual’s life.

Advance care planning is considered to be a process by which individuals can plan their future care and support, including medical treatment and place of care, while they have the capacity to do so (NICE, 2011). It is described as a conversation between individuals, their families and carers about their future wishes and priorities of care. In practice, this includes the completing of an Advance Care Plan document which is shared across services to try to ensure an individual’s wishes are met. Nationally, including Bradford, it is recommended that the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) document is used to create a summary of a person’s wishes and the clinical team’s recommendations regarding clinical care in the event of a future emergency – which is particularly useful if the individual does not have the capacity to make or express choices (Resuscitation Council UK, n.d.).

There has however, been recognition that advance care planning can be reduced to decisions around clinical care and what interventions patients do not want such as resuscitation, rather than a broader, more holistic approach, focussing on what matters to the patient and what they would like to happen at the end-of-life (EOLC Partners Think Tank, 2021). Further challenges of advance care planning were also brought to light by the Care Quality Commission review of ‘do not attempt cardiopulmonary resuscitation’ decision during the COVID-19 pandemic (Care Quality Commission, 2021). The report raised concerns about whether current practice could harm people’s human rights and rights under the Equality Act 2010 with recommendations for a consistent approach to advance care planning with improved oversight and assurance (Care Quality Commission, 2021). These developments highlight the need for an evidence informed, person-centred, approach to advance care planning.

In Bradford, and nationally, there is evidence that individuals from minority ethnic backgrounds are less likely to have documented Advance Care Plans and are more likely to be admitted to hospital in the end-of-life care period, subsequently increasing the likelihood that they will die in hospital. How to address such inequalities is not currently clear.

## **Reducing Inequalities in Communities (RIC) initiatives**

Two initiatives have recently been introduced into the community by RIC to support advance care planning:

### **1. Choices**

This has three elements (all of which began in December 2020):

- 1-2-1 support from a trained worker
- Befriender support to the individual or family member (with appropriate training)
- Peer group support for loved ones, /carers and/or family members.

### **2. End-of-life facilitators who provide support, information about the end-of-life care period, and assistance if they think additional services may be needed (Patient caseloads began in September 2020).**

## **The Community Readiness Model**

It is recognised that communities experience different stages of readiness for new initiatives and it is vital to attain alignment between implementation efforts and the level of readiness within a community to achieve a positive level of acceptability and hence take-up of the services provided. The Community Readiness Model (CRM, Stanley, 2014) has been developed to assess levels of readiness. It achieves this by placing a community in one of nine possible stages of readiness ranging from 'no awareness' right through to 'community ownership'. The stage it is in can then guide the work that needs to be done to prepare for the introduction of a new service or intervention.

The CRM has been used in varied settings and to address many different areas of concern. It has been used in Bradford to look at areas including obesity and social and emotional health (Islam et al., 2018; Islam et al., 2019). In consequence, the Born in Bradford team considered this would be the most effective tool to help us ascertain the community's level of readiness to the new palliative and end-of-life care initiatives being brought in by RIC.

### **Aim of this research**

To use the Community Readiness Model (CRM) to assess levels of community knowledge and inform community engagement strategies. This research is part of the wider Born in Bradford Evaluation Framework.

### **Target population**

Focus on identifying how 'ready' the South Asian community within the Bradford Central Locality (PCNs 4, 5 and 6 areas) are to engage with advance care planning.

## What work was undertaken?

This qualitative study involved two components:

1. A questionnaire sent to people identified as key stakeholders within the community. This is a well-established tool within the CRM and was used to generate a numerical score for the level of readiness within the community.
2. Two focus groups that explored these stakeholders' views on community understandings of, and attitudes about, palliative and end-of-life care. Within these groups, stakeholders were asked to comment on RIC initiatives.

Please see Appendix A for a copy of the pre-focus group questionnaire and interview schedule.

Ethics approval for the study was obtained from the HRA and HCRW (date: 26.04.2021, IRAS project reference: 292954).

## Who were our key stakeholders?

To be identified as a key stakeholder, an individual needed to be familiar with what might be provided by palliative and end-of-life care services and also be aware of what were likely to be the views of the community on this subject. The community we were concerned about were the South Asian community living in Bradford Central, but it might also be interpreted by our key stakeholders as including their professional service providers. We worked closely with RIC to identify individuals who were considered to be the most suitable for inclusion in this regard. Once individuals were identified, they were sent an invitation to take part in this study along with a participant information sheet.

Across the two focus group sessions, 10 stakeholders took part and included individuals from a range of different professions such as clinical staff, End-of-life Choices Co-ordinators, members of the Voluntary and Community Sector (VCS) and CCG members.

## Data collection

### Questionnaire

There are nine stages of readiness in the CRM. To help numerically identify the community's stage of readiness, a short questionnaire for key stakeholders had been designed. This questionnaire consisted of five questions, each with nine possible answers. The questions focused on how aware local health and social care personnel are of palliative end-of-life care issues and the knowledge/attitudes of the community about planning end-of-life care for themselves and their loved ones. The scale of scores spans from 1 – 9, with 1 showing the community have 'no awareness' of the issue and 9 showing that the community have 'community ownership' of the issue (see Appendix B for a full list of the stages). The scores were assessed prior to the focus groups.

### Focus group

The focus groups explored whether or not the community were aware of the end-of-life care initiatives introduced by the CCG and were facilitated by Rachael Moss and Neil Small. The

groups were conducted online and recorded. The data were transcribed and analysed to identify key themes relevant to policy and practice.

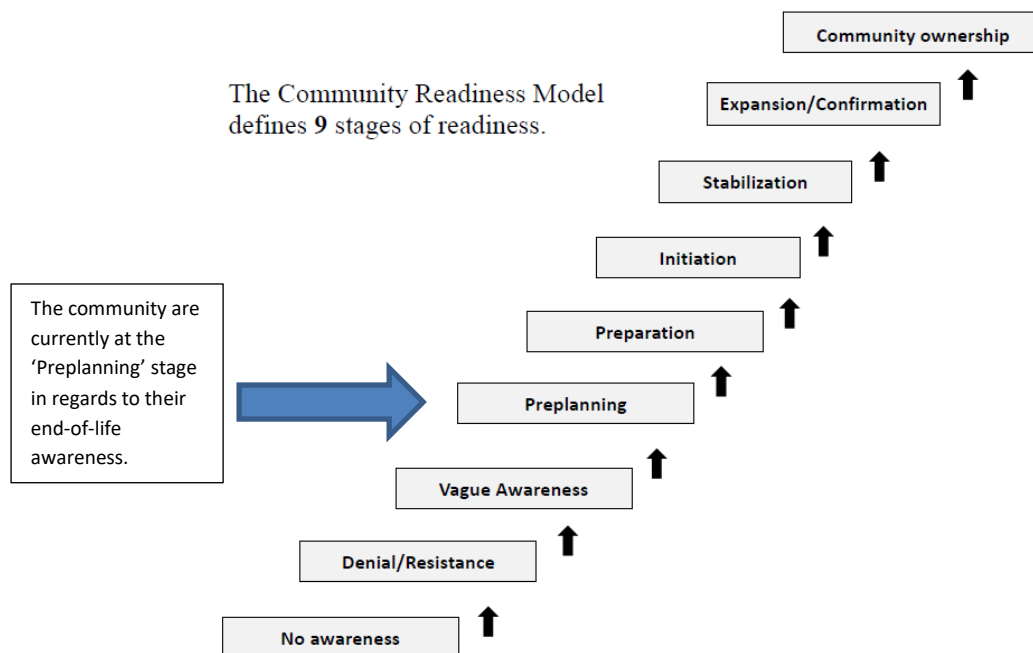
## Our research findings

### Community Readiness questionnaire

There was some difference in scores given; the average scores from participants in the second focus group were lower than those in the first. Participants gave scores ranging from 3.6 – 4.8 (out of 9) across both groups. Participants’ median score was 4.1.

Overall, across all participants, the picture was one of a community with only a **vague awareness** of palliative and end-of-life care as an issue of concern or as an area in which new services were being planned/delivered. Book-ending this sense of vague awareness was a belief that in some areas there was likely to be denial of the need for services or even resistance to initiatives, but there was also recognition that some members of the local community might begin to approach the subject of end-of-life care, this stage is called “**preplanning**”. Please see figure 1 below for the nine stages of readiness with reference to the current ‘preplanning’ stage of the community.

Figure 1. Community Readiness Model stages.





## A summary of themes identified from the focus group sessions

### Lack of awareness

- Consensus from both sessions emerged – there is a lack of awareness about palliative and end-of-life care and associated services within the community. People only have awareness of services if they have first-hand experience of using the services for one of their relatives. However, even these individuals may not know about new initiatives in palliative and end-of-life care.
- There was some discussion of the value of previous work by the CCG which included undertaking a survey about end-of-life care. This gathered a significant amount of data but any follow-up was curtailed by the restrictions arising from the COVID-19 pandemic. The key point made by those who undertook the survey was that it showed that people did not talk about end-of-life care, but if they were encouraged and supported they would, and when they did they saw this discussion as a positive experience. (This referenced CCG report is entitled 'Talking about End-of-life, Engagement Report, August 2019' and it can be supplied upon request).

### Supporting stakeholder quotes:

*“It’s an almost definite no” [in relation to whether the community are aware of these initiatives]*

*“So they don’t know about it [the palliative and end-of-life care initiatives], but I think people do want to discuss it...”*

*“ I think absolutely our approach has got to be very different and we need to somehow normalise it.” [talking about end-of-life care]*

*“Understanding what’s happening at a community level and what a community needs, takes time...”*

### More work should be focussed on understanding community and family attitudes

- Stakeholders reported that there needs to be a greater understanding of the community and its needs. Trust, communication and timing were elements that were frequently identified as essential components in promoting that understanding. It was noted that these factors were not things that could be rushed or fast-tracked. For example, trust needs to be established between patients, families and healthcare professionals in areas where that trust appears absent. End-of-life care decisions may be one of those areas and effective communication needs to happen throughout the period when palliative and end-of-life care is being considered. Suitable end-of-life care discussions need to occur at the most appropriate time (i.e., not too late in the palliative care period, when an individual may not be able to consider available support).
- The importance of understanding the family unit was also discussed, with several stakeholders stating that it would be important to increase the awareness/understanding of palliative and end-of-life care amongst younger family members. For example, adult children in families are often those who help relay information to their older parents who may not speak English proficiently. In this regard, it remains crucial to remember the whole family when talking about palliative and end-of-life care and what services are appropriate because of the influence such family members may have on those most likely to be in receipt of palliative and end-of-life care services.
- There was considerable consensus in both focus groups that the lack of awareness in Bradford had to be seen in the context of widespread reluctance to discuss death in contemporary society. Only a shift in broad views was likely to result in a sea-change in our communities. While local initiatives – Death Cafés for example - might make some difference a wider shift in awareness seems far off.

#### Supporting stakeholder quotes:

*“...if we just go back a couple of baby steps back into starting off young and making this integral part of us, it'll make a big difference.”*

*“...it being something that's not really community-led and grown...” (about services provided)*

*“...it hasn't got in the community, definitely not got into the South Asian community.... I don't think I've ever come across this [the End-of-life care initiatives].”*

*“...you mentioned the South Asian community for example, our social constructs might be very different to the general take on things”*

*“...it's trying to understand who within the family has that relationship for us as a practitioner to have a conversation with.”*

*“...this is about everybody and it's about trying to be inclusive... communities within communities absolutely we should be working with.”*

### Are there specific needs in sections of the local community?

- There seems to be animosity and distrust between some sections of the community and healthcare professionals across a whole range of areas. One stakeholder linked this with those communities who feel themselves marginalised in contemporary society (characteristically by poverty). In relation to end-of-life care there was a belief this is likely to manifest itself in a feeling that healthcare staff may not be acting in a way that would help prolong life and that their actions may be linked to the wish to save NHS money and resources.
- Our key stakeholders made specific references to the South Asian community throughout the focus group sessions. While the prevailing view was that this community shared many of the attitudes of the wider community regarding a reluctance to discuss death there were some significant points of difference: perhaps the South Asian community may have different “social constructs” compared to other groups within the community. This was linked with a belief that Islam “requires” that one does everything possible to preserve life and that end-of-life care planning may be seen as hastening death. This was also recognised as being a contested view with scholars, including local ones, offering a more “quality of life” alternative view. But the group consensus was that people “don’t listen to scholars”.
- Ideas of good death come from a focus on white Caucasian experiences – from educated people – but we do not know what a good death is for people who live in the South Asian community. If we link performance indicators to existing views we will be encouraging and rewarding the wrong thing. Therefore, we need more specific knowledge of our local community views in order to be able to adjust performance measures to them.

#### *Supporting stakeholder quotes:*

*“...it’s institutional barriers that we haven’t taken down to enable these different communities to participate...”*

*“...people are not used to being asked what matters to you, they’re not used to being given choices...”*

*“...there’s a need probably for more pluralistic approaches, different communities will need different approaches*

## Detail about Advance Care Planning

- As has been identified by the CCG before, the sessions also acknowledged that the community seem to focus on post death experiences/decisions, as opposed to those that could be made during the palliative and end-of-life care period to improve the quality of life of an individual.
- Healthcare staff were seen to focus on the clinical side of Advance Care Plans/end-of-life care arrangements but there were discrepancies in regards to who would be there to help deal with the emotional side of end-of-life care. There was some discussion about the possibility of focusing first on the clinical and then (later) the emotional aspects of care.
- One session highlighted the difficulties in identifying what an Advance Care Plan actually was – was it the conversations surrounding end-of-life care or was it the written documentation of an individual's wishes at that time?
- Stakeholders argued for a rethink in Advance Care Planning so that it would focus on what you want to be done not just what you do not want. It should be about an approach, about underlying principles.
- Stakeholders reported that often families only became aware of palliative and end-of-life care services at the point where their relative is extremely ill. This often makes it more difficult to understand and utilise the palliative care services that are on offer at this difficult time. End-of-life care options should be introduced at an earlier point.

### *Supporting stakeholder quotes:*

*“...our understanding has developed over the last six to eight months, and I think partly that's because of the role of these facilitators are changing...”*

*“...hearing those stories about lack of connection and people not knowing and services not working closely together, I think there's a real issue there about integration of care, from all sides.”*

*“...I think because people don't know about them, obviously that then makes it quite difficult to use them... it being something that's not really community-led, and grown...”*

*“...we've got to start around yeah understanding your rights and I think de-medicalising this as much as possible.”*

### Who should new end-of-life care initiatives target?

- There was a recognition in the groups that as well as the CCG looking to change ideas about end-of-life care planning in members of the South Asian community, it is also important to address and change the approach of health professionals. It was felt that changing professionals' ideas would have a big impact on the community.
- Such a focus on health professionals should involve better training on how to initiate a conversation about palliative and end-of-life care when the person/family was ready. This training should include all health professionals so that anyone could initiate these conversations. One option suggested by the group was that end-of-life care facilitators could focus on health professional change and befrienders on community change.

### Supporting stakeholder quotes:

*"...people from minority ethnic communities are less likely to complete advanced care planning..."*

*"...the availability of service needs to be for all of the communities, and the health literacy.... Needs to be worked upon."*

*"...I'm also not convinced that doctors really do brilliant advanced care plans, they do ones that are medically good some of the time, so I get some helpful ones back about what medical things patients do or don't want, but I don't get a sense of who the patient is and what's important to them..."*

*"...my message to the NHS and CCG would be whatever system you have in place please ensure the medical professionals are aware of it."*

*"...make sure this advanced care planning has all the MDT [multi-disciplinary team] round it."*

### The particular context of the pandemic

- It was not possible to deliver palliative and end-of-life care services/treatments as planned during the pandemic, particularly at the beginning of the pandemic when it became clear to staff that they had to alter the way they delivered care to patients (when patients often had very few hours/days to live). Current service models were not seen as appropriate for end-of-life care in Covid-19.

#### Supporting stakeholder quotes:

*“...the reality for people who passed away during lockdown with Covid was there was no choice.”*

*“I think I noticed within the first couple of weeks of this that I had to change my approach to advanced care planning...”*

*“...it was the basics again, building the trust, good communication skills, make sure family and community members were involved...”*

*“...we were also trying to train GPs and everyone else to do this advanced care planning because there was not enough of us to do it all...”*

### Conclusion and recommendations

This research identified that the community currently only have a **vague awareness** of end-of-life care as an issue of concern. This suggests that there needs to be more fundamental work to understand the community, and how they view the end-of-life period. It is only by improving understanding that initiatives can be planned and delivered in a way that maximises the chances of successful uptake. If there are discussions about end of life matters they are focussed on what happens after death and not on the care that is available before death and on the options as to what is included in that care. Specifically, advance care planning tends to be about what should not be done – do not resuscitate or do not admit to hospital for example – rather than on what should be done to increase the quality of a person’s dying.

The CRM method, also underlines the importance of recognising the different communities that exist even within a relatively restricted geographical area like Bradford City. There are specific barriers that need to be addressed including one that links to deprivation and it’s shaping a mistrust of services - including palliative and end-of-life services. There are particular debates in the South Asian community about the nature of religious guidance about end-of-life care that must be engaged with.

The professional community are also not clear about what should constitute end-of-life care services and who should deliver them. The whole team needs to be involved and work together in an integrated way so that discussions can be instigated at the most propitious time for the patient and their family. There needs to be recognition of the medical,

psychosocial and spiritual needs of patients and families with opportunity to discuss what matters in each domain as part of any on-going advance care planning process. There was some discussion in our focus groups that the expertise of End-of-Life Facilitators could be directed at supporting health professionals, especially in general practice and that befrienders could work with patients and families. Such an approach could maximise the reach of services.

Two more underlying issues recurred in the focus groups: first there was a discussion that Advance Care Plans should be a generative rather than a summative discussion – that is they ought to take shape over a long period and with a number of people involved in them and then change as the patients' situation (and perhaps wishes) changed. Second, community views are representative of wider societal reluctance to discuss dying. Unless this is addressed there will be a problem in discussing what would constitute a good death for all.

### **Recommendations:**

- Engage with the community and Voluntary and Community Sector organisations to understand why individuals who live within the South Asian community do not discuss the end-of-life period in advance of this period.
- Increase death awareness as a community issue through public information, facilitated discussion and through existing avenues for public and patient engagement.
- Provide additional training and support of the health team in instigating Advance Care Planning. A whole team approach is needed.
- Give wider end-of-life care staff access to patient notes (e.g., Choices end-of-life facilitators), so that different members of healthcare staff can be better integrated with one another when working with the same patient.
- Create space for active discussions with clerics to identify any tensions/mixed messages about what the end-of-life period requires.
- Develop and share examples of what good end-of-life care looks like.
- Develop understanding of how end-of-life discussions can be normalised within the community.
- Use strategies to implement and encourage end-of-life care discussions amongst family members.
- Begin to encourage the use of the CCG's end-of-life care support services amongst healthcare professionals so that people are able to access palliative care earlier on.

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## Appendices

### Appendix A

#### **Preliminary questions to be completed in advance of the focus group session:**

We want to ask you some questions about how aware local health and social care personnel are of the issues around planning end-of-life care and of local efforts to develop/enhance provision in this area. We are also interested in finding out what your perception is of the knowledge and attitudes of members of the public about planning end-of-life care for themselves and their loved ones.

Our focus is a local one – the area covered by Bradford and Craven CCG.

All the questions are quite difficult because they address complex ideas like “attitudes of leaders” and “community climate”. The categories we include are ones regularly used in assessing community readiness to address a range of health and social care issues. We want you to answer with your own assessment, what do you think, and we don’t want you to ponder too long over the answers you give – this is your assessment and there is not a wrong or right answer. We anticipate each question should only take you a minute or two.

There are five questions each with nine possible answers. Please pick the answer that seems most right to you and put that number in the score box at the end of this form.

*The first two questions relate to health and social care professionals’ knowledge about efforts made in progressing end-of-life care.*

Question A. What is your assessment of how knowledgeable members of the local health and social care community are about the local initiatives/practices to provide end-of-life care in a way that means services can prioritise what matters most to patients and to their loved ones:

1. No knowledge about possibilities of planning for end-of-life care.
2. Only a few have knowledge of possibilities of planning for end-of-life care.
3. Some people are aware of local efforts to make planning end-of-life care possible.
4. Some people are aware of local efforts to make planning end-of-life care possible and are familiar with what these efforts are.
5. Some people are aware of local efforts to make planning end-of-life care possible and are familiar with debates about how to do this.
6. Many people are aware of local efforts to make planning end-of-life care possible.
7. Many people are aware of local efforts to make planning end-of-life care possible and at least some people are aware of the effectiveness of planning end-of-life care.
8. Most people are aware of local efforts to make planning end-of-life care possible.
9. There is extensive knowledge in the health and social care community about local efforts to make planning end-of-life care possible, about who these efforts are for and about their effectiveness.

Question B. This question is about local leadership – how those people who make key decisions about health and social care consider planning for end-of-life care:

1. Local health and social care leaders think planning for end-of-life care is not a concern.
2. Local health and social care leaders think planning for end-of-life care may be a concern but it is not one that can be addressed.
3. Local health and social care leaders think planning for end-of-life care may be a concern but is not a priority.
4. A small number of local health and social care leaders are trying to address planning for end-of-life care.
5. At least some local leaders are participating in developing, improving, or implementing efforts to undertake end-of-life care planning.
6. Local leadership plays a key role in leading steps to address planning for end-of-life care.
7. Local leadership is acting in such a way as to ensure the long-term viability of planning for end-of-life care.
8. Local leadership plays a key role in expanding and improving efforts, through evaluating and modifying efforts, seeking new resources, and/or helping develop and implement new efforts.
9. Local leadership is continually reviewing evaluation results of efforts to improve end-of-life care and is seeking to ensure appropriate personnel and financial support is in place.

*The next two questions refer to community beliefs, that is the general public and also those people who may need end-of-life care for themselves or for their loved ones.*

Question C. This question is about “Community climate”. This is a difficult dimension to be specific about – it’s around how much you think this is an issue that would resonate with local communities:

1. Planning end-of-life care is not considered an issue of concern.
2. The need to plan end-of-life care may be a concern but it is not one that can or should be addressed.
3. The need to plan end-of-life care may be a concern but it is not a priority.
4. Some community members believe that this issue is a concern in the community and that some type of effort is needed to address it.
5. At least some community members are participating in developing, improving, or implementing efforts.
6. At least some community members play a key role in developing, improving, and/or implementing efforts, possibly being members of groups or speaking out publicly in favour of efforts.
7. At least some community members play a key role in ensuring or improving the long-term viability of efforts to improve end-of-life care.
8. The majority of the community strongly supports efforts or the need for efforts. Participation levels are high.
9. The majority of the community are highly supportive of efforts to address end-of-life care needs.

Question D. This question refers to members of the community, local people including those who may need to plan end-of-life care.

1. Community members have no knowledge about the issue of planning end-of-life care.
2. Only a few community members have any knowledge about the issue.  
Among many community members, there are misconceptions about the issue.
3. Some community members have heard of the issue, but little else. Among some community members, there may be misconceptions about the issue.
4. Some community members know a little about the issue of planning end-of-life care.
5. Some community members know about the ways end-of-life care is being supported locally.
6. Some community members know a lot about end-of-life care provision locally.
7. Most community members know a lot about end-of-life care provision locally.
8. Most community members have detailed knowledge about the issue, and about the challenges in providing end-of-life care locally.
9. Most community members have detailed knowledge about end-of-life care locally, its effect on the community, and how to address it locally.

*The final question returns to a consideration of issues for professionals including those who plan health and social care.*

Question E. This question relates to resources available to implement local end-of-life care provision. It is concerned with the capacity to develop/improve services beyond those currently in place.

1. There are no resources available for (further) efforts.
2. There are very limited resources that could be used for further efforts. There is no action to allocate these resources to this issue. Funding for any current efforts is not stable or continuing.
3. There are some resources that could be used for further efforts. There is little or no action to allocate these resources to this issue.
4. There are some resources identified that could be used for further efforts. Some people are looking at how to use these.
5. There are some resources identified that could be used for further efforts to address the issue. Some people are actively working to secure these resources.
6. New resources have been obtained and/or allocated to support further efforts to address this issue.
7. A considerable part of allocated resources for efforts are from sources that are expected to provide stable or continuing support.
8. There is some support for further innovations in end-of-life care.
9. Diversified resources and funds are secured, and efforts are expected to be ongoing. There is additional support for new efforts.

## Interview schedule

Bradford and Craven CCG would like to develop the use of advance care planning and to ensure it is appropriate and available to all sections of the CCG population. These questions are designed to assess the current level of awareness about advance care plans (ACP) in the CCG and about barriers to their use. Some questions refer more to the awareness of health professionals and some are asking you to consider awareness in the general population, including in patients and their families.

We have invited you to participate because you are in a position to authoritatively comment on this issue in this CCG and to further the use of advance care plans.

To be successful, Advance Care Plans need to be supported by health professionals and need to be acceptable to patients and their families. This requires trained and supported staff with sufficient access to relevant health professionals and sufficient resources to act on the advance care plans decided upon. It also needs the ideas underpinning advance care plans to be shared with patients and families at appropriate times in their treatment and in such a way that it encourages participation and does not excite fears for the future.

We want to ask some questions about advanced care planning in Bradford and Craven CCG – we want to get a sense of how ready the community are to use and create their own advance care plans, so we want your opinion of the overall picture rather than your own, individual, position.

There are two relevant initiatives underway in the CCG at present:

- **End-of-life Facilitators:** are nurses by background, they work full-time to support individuals who are in the End-of-life stage, and work with the individual/ family/carers to support them and signpost to other appropriate services. Facilitators work as part of the Proactive Care Team and there is funding for 3 facilitators. (1 is on maternity leave, and other 2 are soon leaving their roles).
- **Choices End-of-life Care:** a social prescribing and befriending service.
  1. Offer 1-2-1 support: for a minimum of 12 weeks
  2. Befriending support: to the individual or family member(s)
  3. Peer support group: for carers/family members

1. Do you think the community is aware of these initiatives?

If yes:

a) what is likely to support their further utilisation?

b) what might be barriers?

*Prompt –*

- *Are you aware of any issues surrounding ACP?*
- *What leadership could be used to promote ACP use?*
- *What resources are there to support ACP use?*
- *Is there any opposition to the idea of ACP?*

If no:

a) how can awareness be increased?

b) what might be barriers to achieving increased awareness (see prompts above)?

2. Do you think there are other ways (in addition to the 2 above) of developing the use of ACP?  
and: Do you think the two initiatives set up are the best way of developing ACP?

3. Are there any patient groups who need to be targeted to increase their knowledge of ACP and their involvement in using advance care plans when it may be appropriate?

4. In your experience, do you think there are patient groups within the Bradford and Craven CCG area where increasing take-up of ACP will be particularly difficult?

*Prompt –*

- *Specific ethnic groups*
- *People with particular diagnoses (COPD/dementia/etc.)*
- *Younger people*
- *People living alone i.e., without family support*

5. Suggesting to a person that they make an ACP may prompt anxiety but in some it may also make them think of potential conflicts with their faith. Is this something you have encountered? How might service providers and community leaders respond to this concern?

6. Do you think current approaches and planned initiatives re: ACP will be appropriate for patients with life-threatening Covid-19?

## Appendix B

The Community Readiness Model defines 9 stages of readiness.

