IMPRESS guide for commissioners on supportive and end of life care for people with COPD
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Respiratory diseases account for 14% of all deaths in England (20% if lung cancer is included). Chronic lung diseases account for 5% of all deaths of which 85% are caused by chronic obstructive pulmonary disease (COPD). COPD is a disease with a recognised progressive nature that has an uncertain disease trajectory, unlike cancers and several other long term conditions. The Department of Health’s (England) End of Life Care Strategy Quality Markers recommends services for patients with all diagnoses, not only cancer, as has traditionally been the case. In this document we outline the limitations of existing provision for people with COPD and by acknowledging the complexities of the disease, offer suggestions for improvement in both processes and awareness for patients, carers and clinical staff alike.

Epidemiology

It is important to recognise the trends of lung disease within the population of England today. The proportion of deaths from respiratory disease varies significantly from region to region (from 22% in the North East to 18% in the South West), mirroring the pattern of death from smoking-related diseases. The number and proportion of patients dying from chronic lung diseases and lung cancer was greater in the most deprived quintiles, with a clear gradient from most to least deprived. In contrast, there is no clear gradient for ‘pneumonia and acute respiratory infection’ or asthma deaths.

Cause of death (‘underlying’ cause) by deprivation quintile: number of deaths, England, 2007-09.

Note: IMD=Index of Multiple Deprivation
Source: ONS mortality data

This predominance of patients from more deprived quintiles dying from chronic lung diseases and lung cancer should be taken into account in designing communication tools around end of life and advance care planning, assessing needs and planning service provision.

Background
According to the National Audit Office, in 2020 COPD is expected to be the third largest cause of mortality in the western world. Currently in the UK there are almost 900,000 patients suffering from COPD and an estimated two million people with COPD whose condition remains undiagnosed. As it progresses, patients with COPD can face a heavy symptom burden of both physical and psychological suffering, not only from disabling breathlessness but also from pain, anxiety and depression, all of which are poorly addressed. This intensifies as they reach the end of their lives where lack of, or poor advance care planning may exacerbate a patient’s distress. There is currently an inequity in palliative care provision and quality of life between COPD and lung cancer patients. Given the increasing number of COPD sufferers there may need to be proportionately more emphasis on this non-malignant disease to ensure that end of life services encompass all diagnoses and that advance care planning becomes routine in COPD care. Although we can take many of the principles of cancer provision, clearly people with COPD have differing needs and deserve recognition of their unique requirements.

A different illness trajectory and its implications
One of the reasons often given for not addressing end of life issues in COPD is that the disease trajectory is uncertain unlike that of other diseases where stages of the disease can be more clearly defined. In COPD the disease trajectory is unpredictable because despite a slow decline, this decline is punctuated by acute exacerbations of symptoms. It is hard therefore for a clinician to determine a prognosis in a COPD patient.

![Organ System Failure Trajectory](image)

5 http://www.ncbi.nlm.nih.gov/pubmed/21801516
7 http://www.scotland.gov.uk/Publications/2008/10/01091608/3
9 National Audit Office commissioned report from Rand Corporation. Page 20
Fifty percent of people after an admission with acute respiratory failure in COPD (a key marker for inclusion on a palliative care register) will be dead in two years; it follows however, that 50% will be alive in two years. It might be worth considering whether admission for an acute exacerbation is a prompt to start thinking about prognosis.

The 2008 national COPD audit indicates that 17% of people admitted with COPD die within 90 days of admission. It has been suggested that fear of uncontrolled symptoms, for example breathlessness, is a significant factor in the high levels of deaths in hospital. It is notable that the majority of chronic lung disease deaths in 65–84 year olds occur in hospital (70%), with most other deaths in this age group occurring in ‘own residence’ (20%). It is worth considering the provision of ‘just in case’ medications in the patient’s own home to relieve suffering at the terminal stage. This is often quite routine for people with malignant disease, but not always available to people dying with COPD. Patients and their carers should always have a choice when deciding on the place of death. Until community support is able to fully support patients, then hospital should always remain an option, and health care professionals should appreciate that the patient may want to change their choice. In clinical care the DOSE score can help in the identification of people with whom we would want to start looking ahead and thinking about advance care planning. This does not appear routine in current practice and is not recommended in current NICE guidelines, although we would argue this would be considered unacceptable for end-stage cancer. Wherever the patient is, proactive symptom management should be available (see Appendix 1 for patient information).

**End of Life Care: Registers and flexibility**

When it comes to working with registers, it is not always clear when people with a range of chronic terminal diseases, including COPD, should be added to an end of life register. People at advanced stages of COPD may survive many years with a range of severe symptoms, and acute exacerbations of symptoms may occur at any time. It is not always clear at what point the patient should move from supportive to palliative care, though often a mixture of the two is indicated. Furthermore, a patient may not want to be on a register, or a clinician may not want to consider it, because of the prospect of discussing a full palliative care package. Equally a patient must not be denied supportive care they need because they are not on a register.

Patients and carers should be more greatly involved in the decision-making process. They should regularly be asked how they think things have gone and are going. They should also be asked when and if they want to be on the register. It is important that clinical staff are equipped to fully explain the pros and cons of different elements of advance care planning, as the decision-making required of patients on the register and their carers may be quite challenging. Clinical staff need to be able to fully explain resuscitation and Do not attempt resuscitation (DNAR) decisions, as well as non-invasive ventilation (NIV), use of liquid morphine for breathlessness and preferred place of care. You will find examples of leaflets to assist clinical staff in Appendix 1.

Ultimately the system put in place needs to be a flexible one that accounts for a longer and more gradual transition from supportive to palliative care, possibly drawing on both. An approach without such distinctions might allow for greater flexibility. It may be better to look back six months and see how things have gone and then look forward six months and work out how things may go. Asking the ‘surprise question’ (would I be surprised if this patient was

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dead in six months?), can also provide guidance concerning advance care planning. It can also be helpful to ask patients and carers how they see the next six months going. It often makes for a useful starting point for further discussions.

An alternative model

An alternative approach might be a register with a two-stage process; firstly, allowing for people with ‘advancing’ COPD and maybe one or more disabling symptoms in need of palliation and then secondly, accounting for those people with COPD where advance care planning is appropriate and full palliative/supportive care required. It is worth noting however that by using multiple registers, patients may appear on separate registers for different symptoms. The success of such a register depends significantly on engagement by all stakeholders. We recommend that care homes also take responsibility for recording necessary data in registers.

Significant event audit
A system for significant event audit would be a useful way to establish why people with advanced COPD were not entered on the register and had inappropriate or poorly informed care in an emergency situation. This process would enable a review to be carried out, if required, to prevent recurrence and drive up standards and ensure issues of responsibility and accountability are tackled. When people die from cancer it is not uncommon to undertake a significant event audit to highlight both areas of good practice and areas that could be improved. COPD would be an ideal area for a similar process which would help local systems to develop appropriate local registers, and improve the communication across boundaries for the benefit of patients and their carers.

Role of registers in improving care
Without an accurate prognosis by a clinician for someone suffering with COPD, we recommend that clinical staff are both fully briefed on the patient’s medical history and ready to discuss with the patient and carer(s) what their advance care wishes are. The register could record this and be updated by patients and clinicians. Many patients and their carers would be pleased to know that clinicians who see them out of hours, in emergency situations or after discharge from hospital have good quality clinical information about them to help clinicians make rational and appropriate decisions with the patient and carers at the time they are seen. A common complaint from patients to clinicians is providing the same information time after time; a good record mitigates this and enables continuity of care, (ideally by the same clinician but if not by clinicians who are aware of what has happened before).

The Role of Carers
Carers in particular would welcome greater cooperation in advance care planning for COPD sufferers. Carers should only have a say if the patient wishes or is incapable of making a decision. Carers’ views and beliefs may at times be at odds with those of the patient. For instance, the reluctance of some COPD sufferers to discuss end of life care or to seek help can add extra pressure on carers. This often requires careful discussion to maintain appropriate patient confidentiality, but it is highly important to engage both patients and carers.
in discussions that will facilitate advance care planning. If patients knew more about what palliative care meant and who might deliver it at an earlier stage, they might then be more open to discussing end of life planning and be comfortable with the palliative care support from either a district nurse team, or, if complex care and symptom relief was needed, the specialist palliative care team, when the time came.

‘How people die remains in the memory of those who live on’

Greater consideration of the carers’ circumstances would contribute to the quality of the end of life care for the patient. Carers themselves may have their own health problems and would welcome greater planning for a situation in which carers themselves are no longer able to care. Also it may be important for the health care professional to follow up with carers, as often they have become a large part of the carer’s life. One of the neglected areas in holistic care of patients and carers is the follow up we provide to carers both during the illness and during the bereavement phase. Many carers talk as if they have been forgotten after the death of their loved one. It is worthwhile commissioning services that promote some post-death support for the carer and make this an expectation rather than an exception. The bereavement phases for carers are well described in many conditions (though not specifically COPD) and consistently show increased morbidity, mortality and mental health problems.

Greater Communication with Patients and Carers

For patients and carers alike, clear and open lines of communication are important to understand and manage the fluctuating nature of the disease. For patients with chronic decline, it is important to enable them to express and record their wishes with respect to their care at the end of their life. However, because of the fluctuating course of their respiratory disease, it also needs to be made clear that patients have the right to change their mind about previous decisions in the light of changing circumstances. Evidence suggests that patients (and carers) require “early phased support” and ongoing assessment of need throughout the “lifetime journey with COPD”. It has been noted that patients with COPD are generally unaware that COPD is life threatening and have “unmet communication and information needs” in terms of end of life care. Information gaps could be filled through the provision of leaflets and education. There is also evidence to suggest that more patients with COPD wish to discuss end of life care and prognosis with a health professional than currently occurs.

This has implications for health care professionals who may not be used to having these conversations with people with COPD and therefore educational support may also be required. Please refer to the IMPRESS Effective Care – Effective Communication: Living and Dying with COPD educational package, 2nd edition.

Greater Cooperation between Primary and Secondary Care

Development of the existing registers would also facilitate cooperation between services. A more systematic approach to sharing information between primary and secondary care services in particular, would be one way of ensuring staff are fully aware as to the patients’ needs/wishes. What will make the biggest difference is strong clinical leadership and whole systems working with active engagement from commissioners and an integrated approach across primary and secondary care services. In some areas, acute hospital CQUINs have been developed to incentivise communication of an agreed care plan to the GP and the ambulance service within 24 hours. Both ambulance and other out of hours services would benefit from one end of life register covering a large geographic locality as it enables them to find and follow the patient’s wishes more easily. This is likely to be facilitated by the work resulting from the DH End of Life Care register pilots that reported in June 2011. In some areas an end of life care register is available to ambulance, emergency care practitioner, out of hour GP service, GP / local community practice, accident and emergency and hospice services already. This is a starting block for good integrated care.

17 Dame Cicely Saunders, Founder of the Modern Hospice Movement
19 Spathis & Booth, 2008
21 IMPRESS response to DH End of Life Care Strategy: Quality Markers Consultation www.impressresp.com/
22 www.endoflifecareforadults.nhs.uk/publications/localities-registers-report
23 Absolon C (2011) Policy for notification of End of Life Care Register in Somerset (local guidance)
**Summary**

**What do you need to think?**
We need an approach that improves the quality of life of patients facing the problems associated with a life-threatening illness that has a declining trajectory punctuated by acute exacerbations and a gradual shift between supportive and palliative care needs.

This means aiming to
- Reduce exacerbations
- Reduce rate of loss
- Reduce symptoms
- Provide appropriate care at death

We can prevent and relieve suffering by early identification and assessment and treatment of symptoms and other problems along the disease trajectory, with the key being clear communication and documentation.

The predominance of people from more deprived communities dying from chronic lung diseases and lung cancer should be taken into account when planning communication and assessing needs. Resources require allocation to the areas where maximum benefit can be achieved.

We should ensure all our patients receive ‘best practice’ care for their condition and have some role models about what that means for COPD care.

Data on place of death is becoming more accessible and can be used to understand the current position
http://www.endoflifecareintelligence.org.uk/profiles/2/Place_of_Death/atlas.html

**What do you need to do in the practice?**
The End of Life Locality Registers evaluation found that the commonly agreed minimum dataset used by all pilot sites incorporates a number of items. These now form a national standard (see Appendix 2).

In addition, IMPRESS suggests you might consider:
- Who is aware of the diagnosis and prognosis (patient, family, not just main informal carer)
- Current problems such as admissions in the last year
- Who the patient lives with (alone, family, friend, other)
- Discussions around NIV and ceilings of treatment
- Wishes of patient, carers or relatives

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Jane Scullion  
Stephen Holmes  
Sandy Walmsley  
Siân Williams  
Lucy Denham

April 2012

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Appendix 1 Examples of patient information about non-invasive ventilation, resuscitation and use of liquid morphine for breathlessness

Source: Department of Respiratory Medicine, Whittington Health
To start with, you need to wear the mask as much as possible for the first 24 hours. It can be removed for short periods to enable you to eat and drink as normal and for your medicines and nebulisers.

To monitor your progress, a peg-like probe will be placed on your finger.

Also a blood test will need to be taken after the first hour to check that your oxygen and carbon dioxide levels are getting better.

Your normal treatments for your breathing condition, such as nebulisers, antibiotics and steroids will continue alongside using the NIV.

Generally people need to stay on NIV for a few days, but everybody is different.

After the first 24 hours you will usually be asked wear it for 2 hours in the morning and afternoon as well as overnight and then we will cut it down to overnight only.

Your doctor will discuss your treatment with you. The length of time you need it will depend on how quickly the oxygen and carbon dioxide levels in your blood improve.

If you have any further questions please do not hesitate to ask any of the people involved in your care and they will be happy to help.
Non Invasive Ventilation (NIV) is a machine that is designed to help your breathing and might be used when you are having a flare-up of your breathing problem.

At this time your breathing gets hard work and your muscles can become tired.

This sometimes leads to a build-up of waste gas (carbon dioxide) and not enough oxygen getting into your blood.

NIV supports your breathing to give your muscles a rest and allow them time to recover.

It doesn’t breathe for you, but gently assists each breath that you take.

This can help to get your oxygen and carbon dioxide levels back to normal.

You will need to wear a facemask, which fits firmly but not tightly. This is so the air from the machine doesn’t leak out but can support your breathing.

As you take a breath in you will feel a flow of air from the machine, then as you breathe out there will be a little resistance to help keep your lungs open.

It can feel a bit strange or even uncomfortable to start with however most people find that they get used to it fairly easily.

The physiotherapist will set the machine up and make sure that it is as comfortable for you as possible.

The nursing staff will check on you frequently so if you do find it uncomfortable they can help.

You will have your buzzer near by to call for help at any time.
If you decide you do not want CPR you will continue to receive all other treatment felt to be appropriate by your medical team. Details of your decision will be recorded in your medical notes.

**Lasting Power Of Attorney**

If you have appointed someone to be your Lasting Power of Attorney* (LPA) they can make decisions about your care – only if you are unable to do so for yourself.

If you were too sick to have a discussion about resuscitation and we did not know your wishes, we would try to determine what is in your best interest although timing may not allow us to do this in detail. Most people do not have a legal LPA and in this case we would talk to your next of kin. In asking them if you would want to be resuscitated, we would be asking them to help us to understand your wishes, not for them to make the decision about resuscitation for you.

Please note they would not have any legal right to decide unless they have lasting power of attorney.

* for guidance on how to make a LPA go to:

http://www.publicguardian.gov.uk

Even so relatives often find these discussions distressing at a time that is already very difficult for them.

You can help reduce this stress and anguish by setting aside 30 minutes or less, find a quiet place, sit down with someone you love, your GP or Consultant and discuss what you would want at the end of your life.

Do it now when you are able to. None of us know what will happen in the near future!

**Your decision is important.**

You can change your mind at any time about any aspect of your expressed wishes or plans. However, if you change your mind it is important to make all the relevant people aware.

We encourage you to view this information as a routine part of advanced care planning to cover all contingencies. This information should reassure you of your part in decision-making and inform you that your decision is important.

It is not meant to cause you increased concern.

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**Resuscitation**

*What it Means and Your Role in Making a Choice*

A document planned for our patients as a result of patient consultation, support and action.
Before reading this leaflet please be assured that it is for information purposes only. These issues are sensitive and some people may worry when the subject of resuscitation and end-of-life decision-making is mentioned. Just because this subject has been raised, does not mean that we expect you to die imminently. We want our patients to have a clearer understanding of these topics, to encourage you to consider what you would want under certain circumstances, and to inform someone of your wishes.

Why now?
Feedback from our patients to date has indicated that 1/3 want more information on advanced planning and recording of wishes. We also found that there are common misunderstandings about the term ‘resuscitation’.

What is “Resuscitation”
By ‘resuscitation’, we mean “Cardiopulmonary Resuscitation” (CPR). If a patient’s heart or breathing stops they will die in a matter of minutes. This is called a cardio-respiratory arrest. When CPR is attempted, the aim is to restore a heartbeat and breathing.

Usually, this will involve:
1. calling the emergency team;
2. chest compressions;
3. possibly using electricity to restart the heart;
4. possibly putting a tube down the throat to assist breathing;
5. giving drugs through the veins.

The patient is unconscious during these procedures and unaware of what is happening.

While this action would be appropriate for some patients, it would not be in the best interest for others.

If asked whether you want CPR, you are being given the opportunity to say whether or not you want medical staff to attempt to restart your heartbeat and breathing in the event of a “cardio-respiratory arrest”

Only 20% of patients survive long enough to leave hospital after attempted CPR. This chance may be reduced even further if you have a chronic heart or lung disease.

The ‘Resuscitation Room’
The word “resuscitation” is often confused with “treatment” and people often think that if they say ‘no’ to resuscitation then they will be saying ‘no’ to treatment. That is not the case.

In some hospital A+E departments, there is a room called the ‘Resuscitation Room’. This room is not only for CPR. Sometimes patients may need more intensive treatment which is best given in the resuscitation room eg oxygen, nebulisers, intravenous antibiotics, non-invasive ventilation (NIV), etc.

Who Makes the Decision about CPR
The consultant in charge of your care will always make the final decision on medical grounds, but a patient’s wishes will be taken into consideration. Therefore it is very important that these wishes are known.

A consultant can decide that it would not be in a patient’s best interest to be resuscitated, either because a positive outcome is unlikely, or because the patient’s health would very likely be worse if they survive the attempt.

Medical Consultants will not give treatment that goes against their clinical judgement but if you disagree with their decision you can ask for a second opinion.
You or your family / carer may wish to discuss the issues raised in this leaflet. Please do not hesitate to ask any questions to your health care professional.

Oxygen and breathlessness
Is oxygen a treatment for breathlessness? No, but this is a common misunderstanding. Oxygen is used to correct low oxygen levels and reduce strain on your heart and lungs. You can also have a normal oxygen level and be very breathless which is why we use other treatments for breathlessness like Oramorph.

Oramorph (liquid morphine) for use in breathlessness

A patient’s guide
What is Oramorph?
Breathlessness caused by a long term or chronic respiratory condition can be frightening and disabling. There are both medical and non medical treatments that may be recommended, one of which is Oramorph.

Oramorph is a liquid form of morphine, which is used in very small doses for the relief of long term or chronic breathlessness.

Why is it used?
You may feel concerned at the thought of using morphine for a number of reasons:

You may recognise this as a medicine used for pain including when someone has cancer or is dying. This is absolutely not why Oramorph is used for breathlessness.

You may think that using morphine will make you addicted. The small amount of morphine used to treat breathlessness does not cause addiction.

Also, the doses offered for breathlessness are very small which keeps side effects to a minimum. The benefits generally outweigh the side effects.

Oramorph has been used as a treatment for breathlessness for many years and is proven to be effective and safe.

As we have been using Oramorph to treat breathlessness at the Whittington Hospital for at least seven years we now have a lot of experience.

Will it help?
Patients have told us they find it very helpful in relieving their breathlessness. Many say it has allowed them to sleep better and to cope better with daily activities. Things we have been told by patients are:

- I have had the best night’s sleep in years
- It has helped with my daily routine, my day was a lot easier

How does it work?
Oramorph works quickly to relieve the feeling of breathlessness and does not linger in your system.

Before starting Oramorph you will be carefully assessed. This is to ensure that this is the correct treatment and we have not missed something else causing increased breathlessness. For example, a chest infection, which would be treated with steroids and antibiotics. Patients who find Oramorph useful can then continue on it long term.

What are the possible side effects?
As with all medicine there may be side effects which can include:

- Constipation, which we will treat with a gentle laxative
- Skin itching (mild)
- Drowsiness (rarely)
- Itchiness and drowsiness usually goes away over time and with continued use of Oramorph.

You might notice that the packet information leaflet includes a warning that states that it is dangerous to take when you have a breathing condition. This is only if you are needing to take large doses to treat pain. Oramorph is not dangerous in the low doses we prescribe for treating breathlessness.
### Appendix 2: End of Life Care Coordination: core content National information standard ISB 1580

#### Summary of Data Items

<table>
<thead>
<tr>
<th>Data Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Record creation date AND record amendment dates</td>
</tr>
<tr>
<td>2</td>
<td>Planned review date</td>
</tr>
<tr>
<td>3</td>
<td>Person’s Details: Name including preferred name Date of birth Usual address NHS number Telephone contact details Gender Need for interpreter Preferred spoken language Disabilities</td>
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<tr>
<td>4</td>
<td>Main informal carer: Name Contact details Is the nominated person aware of the person’s prognosis?</td>
</tr>
<tr>
<td>5</td>
<td>GP Details Name of usual GP Practice name, address, telephone numbers</td>
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<td>6</td>
<td>Key worker Name Contact details</td>
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<tr>
<td>7</td>
<td>Formal Carers (Health and social care staff and professionals involved in care) Name Professional group Contact details</td>
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<tr>
<td>8</td>
<td>Medical details</td>
</tr>
<tr>
<td>9</td>
<td>Primary end of life care diagnosis Other relevant end of life care diagnoses and clinical problems Allergies or adverse drug reactions</td>
</tr>
<tr>
<td>10</td>
<td>Just in Case Box/Anticipatory medicines Whether they have been prescribed Where these medicines are kept</td>
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<tr>
<td>11</td>
<td>End of Life Care Tools in use Name of tools e.g. Gold Standards Framework, Liverpool Care Pathway (or other integrated care pathway), Preferred Priorities of Care</td>
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<tr>
<td>12</td>
<td>Advance statement Requests or preferences that have been stated</td>
</tr>
<tr>
<td>13</td>
<td>Preferred place of death 1st and 2nd choices</td>
</tr>
<tr>
<td>14</td>
<td>Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) Whether a decision has been made, the decision, date of decision, date for review and location of documentation</td>
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<tr>
<td>15</td>
<td>Person has made an Advance Decision to Refuse Treatment (ADRT) Whether a decision has been made and the location of the documentation</td>
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<tr>
<td>16</td>
<td>Lasting Power of Attorney Has someone been appointed Lasting Power of Attorney (LPA) for personal welfare?</td>
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<td></td>
<td>• without authority to make life-sustaining decisions</td>
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<td></td>
<td>• with authority to make life-sustaining decisions Name and contact details of LPA</td>
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<tr>
<td>17</td>
<td>Names and contact details of others (1 and 2) that the person wants to be involved in decisions about their care</td>
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<tr>
<td>18</td>
<td>Other relevant issues or preferences about provision of care?</td>
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