EAPC Task Force: Mapping Palliative Care Provision for Prisoners in Europe

# Part A Survey Report


***Prepared by members of the Steering Committee:***

**Mary Turner (England)** ***(Co-Chair)***
**Aline Chassagne (France)** ***(Co-Chair)***
**Gail Allan (Scotland)**
**Juliana Bindasova (Czech Republic)**
**Olga Bindasova (Slovakia)**
**Manuel Luis Capelas (Portugal)**
**Jose Miguel Carrasco (Spain)**
**Kenneth Chambaere (Belgium)**
**Elodie Cretin (France)**
**Katherine Pettus (Spain)**
**Stacey Panozzo (Australia)**
**Carla Teves (Portugal)**


**September 2019**

# Table of contents

## List of figures and tables

# Executive Summary

## Introduction

The EAPC Task Force on mapping palliative care for prisoners was launched in May 2017 with two main aims: first, to undertake scoping work in five European countries to map the current provision of palliative care for prisoners; and second, to develop an international network of professionals interested in palliative care for prisoners from as many European countries as possible, and other countries outside of Europe. This report details the methods and findings from the first phase of the mapping work, a survey that was undertaken to collect data about prisons and prison systems in each participating country.

## Background

Prison populations in many countries are rising, in part because of ageing populations, and as a consequence there are increasing numbers of prisoners approaching the end of life in custody. There currently exists very little research in this area, but anecdotal evidence suggests that different countries have different policies and approaches to dying prisoners. To date there has been no scoping or mapping work undertaken across European countries, so there exists no international overview of palliative care provision for prisoners.

The Task Force on Mapping Palliative Care Provision for Prisoners in Europe was established to begin to address this lack of knowledge. The first step was to gain an understanding of prison systems and structures in each country, and develop links with key individuals working within the prison systems in each country.

## Methods

A survey was developed by members of the Steering Committee and completed in eight countries (Belgium, Czech Republic, England & Wales, France, Portugal, Scotland, Slovakia and Australia) between October 2018 and April 2019.

## Findings

The findings from this survey revealed wide variations in prison systems, populations and processes across the eight participating countries. It provided evidence of ageing prisoner populations in some countries, and rising numbers of deaths in custody. Given the projected increases in the numbers of older prisoners with multiple and complex health and social care needs, it is likely that the need for palliative care in prisons will increase over the coming years. However, our findings point to multiple inequalities in relation to health and palliative care experienced by prisoners.

Despite examples of good practice from some countries, the provision of palliative care in prisons is at an early stage of development, and there is currently a lack of national policies or guidance to support its further growth. Although policies about early release on compassionate grounds do exist in most countries, in practice very few prisoners are actually granted release at the end of life. There is therefore a pressing need for clear policy guidance about palliative care for prisoners.

## Recommendations

- **Policy**. There is a clear need for national policies and strategies concerning palliative and end of life care in prison. Options other than custodial sentences (including early release on compassionate grounds) should be considered where appropriate, and where it is not possible to release prisoners at the end of life, policies need to be developed about how best to provide appropriate care in the prison setting, in order to ensure more equitable treatment and care.
- **Practice**. The resources to care for dying prisoners need to be provided, and staff should receive adequate training and support to enable them to deliver palliative and end of life care. There is further scope for sharing ideas and good practice initiatives for different countries, so it is important to use existing networks (e.g. Europris: https://www.europris.org/ and the Worldwide Prison Health Research and Engagement Network (WEPHREN): https://wephren.tghn.org/) and develop new networks to this end.
- **Research**. Further research is needed, both national studies where little or no evidence exists, and international studies to explore comparisons. There is an urgent need to develop appropriate interventions for prisoners with palliative care and end of life care needs, and evaluate the effectiveness and cost effectiveness of these.

## Conclusion

Despite some limitations, this first part of the Task Force project has uncovered valuable information about prisons and prison systems in seven European countries and Australia, and highlighted some important issues and complexities. The next part of the project aims to explore some of these complexities in more detail in selected prisons in the participating countries.

# Part A Survey Report

## 1. Introduction

### 1.1 Purpose and aims of the Task Force

The EAPC Task Force on Mapping Palliative Care Provision for Prisoners in Europe was launched in May 2017. The Task Force was established with two main aims:

1. To undertake scoping work in five European countries to map the current provision of palliative care for prisoners.
2. To develop an international network of professionals interested in palliative care for prisoners from as many European countries as possible, and other countries outside of Europe.

The scoping work was planned in two parts: first, a survey to collect information about prisons and prison systems in each country; and second, a short, specific questionnaire about palliative care to be sent to each prison in the participating countries. This report details the methods and key findings from the first part of the scoping work, Part A Survey: Prisons and Prison Systems.

### 1.2 Steering Committee

A Steering Committee was established at the start of the project, led by co-chairs Mary Turner (England) and Piotr Krakoviak (Poland). The Steering Committee initially consisted of six members, the two co-chairs plus Aline Chassagne (France), Elodie Cretin (France), Juliana Bindasova (Czech Republic) and Katherine Pettus (Spain).

Over time, the work of the Task Force became known through open meetings and 'Meet the experts' sessions at EAPC congresses, as well as other conference presentations from Steering Committee members and the newsletter circulated to all members of the network. As a result, other countries approached members of the Steering Committee and expressed an interest in participating in the mapping work. In this way, Scotland, Australia, Portugal and Belgium joined the Task Force, and those leading the work in each country were invited to join the Steering Committee. By May 2019, Steering Committee members were:

Mary Turner (England) *(Co-Chair)*
Aline Chassagne (France) *(Co-Chair)*
Gail Allan (Scotland)
Juliana Bindasova (Czech Republic)
Manuel Luis Capelas (Portugal)
Jose Miguel Carrasco (Spain)
Kenneth Chambaere (Belgium)
Elodie Cretin (France)
Katherine Pettus (Spain)
Stacey Panozzo (Australia)
Carla Teves (Portugal)

### 1.3 Participating countries

Although the original aim was to conduct the mapping project in five countries, because of interest shown in the Task Force, eight countries completed the Part A Survey between September 2018 and April 2019. These countries were (in alphabetical order): Australia, Belgium, Czech Republic, England & Wales, France, Portugal, Scotland and Slovakia (NB. although Scotland and England & Wales are all part of the United Kingdom, they have different prison systems and governance so have completed separate surveys). The Steering Committee would like to express its thanks to all who helped with completing the survey.

## 2. Background

Prison populations in many countries are rising, in part because of ageing populations, and consequently there are increasing numbers of prisoners approaching the end of life in custody. Whilst research in this area is developing in some countries, in others there is little or no research and, even where there is a growing body of research, it is still in its infancy and there remain large gaps in knowledge. To our knowledge, the only country that has so far conducted a national study into palliative care in prison is France (Pazart et al, 2017). In addition, different countries have different policies and approaches to dying prisoners; in some places such prisoners would always be released at the end of life, whilst in other countries compassionate release is rare. To date there has been no scoping or mapping work undertaken across European countries, so there exists no international overview of palliative care provision for prisoners.

The Task Force was established to begin to address this lack of knowledge by mapping palliative care provision in five European countries. Key areas to be scoped include how existing palliative care services work with prison services; whether and how volunteers are engaged in providing palliative care to prisoners; and how controlled drugs for palliative care are managed within prisons. However, in order to do this, it was necessary first to gain an understanding of prison systems and structures in each country, and also to develop links with key individuals working within the prison systems in each country.

## 3. Aims of the Part A survey

The Part A Survey aimed to provide a description of palliative care in prisons in each participating country, including information on:

- Prison populations, types and nature of prisons
- Population trends and projections for the next 5-10 years
- Existing palliative care services and provision for prisoners approaching the end of life
- Examples of good and/or innovative practice.

# 4. Methods

## 4.1 The survey tool

Members of the Steering Committee developed a tool for collecting the survey data. A draft survey was created and circulated to members for comments; further work on the survey took place at EAPC congress in Bern, Switzerland in May 2018 to incorporate feedback and suggestions. The Steering Committee agreed the final tool in July 2018.

The survey tool consisted of 40 questions in six sections:

A: Types and categories of prisons
B: Prison populations
C: Healthcare in prison
D: Policies and practices
E: Examples of good or innovative practice
F: Regulatory approvals required for the Part B scoping work.

(See Appendix A: Part A Survey)

## 4.2 Data collection and analysis

The country leads in each participating country took responsibility for collecting the data and completing the Part A Survey. Data were collected through online searches of publicly accessible sources; these included government departments of health and justice, prison administrations and prison advocacy organisations. The sources used for each question were recorded (e.g. website addresses), together with the date on which the information was accessed.

The responses from each country were then collated for each question in order to facilitate analysis; each question was analysed in turn. Numerical data were subjected to simple descriptive statistical analysis (the small number of participating countries limited the scope and depth of statistical analysis). For free text data, thematic comparisons were made between different countries as far as possible (see Findings section below).

## 4.3 Ethical considerations

The survey only sought information that was already in the public domain, and the tool was designed to be completed through internet searches. No personal data were sought or collected, so ethical approval was not required.

## 4.4 The quality of the data

We acknowledge that in some countries the quality of some of the available data was poor; the amount of data in the public domain varied widely between countries. We are therefore only able to report what could be found (although the lack of data in some areas is a

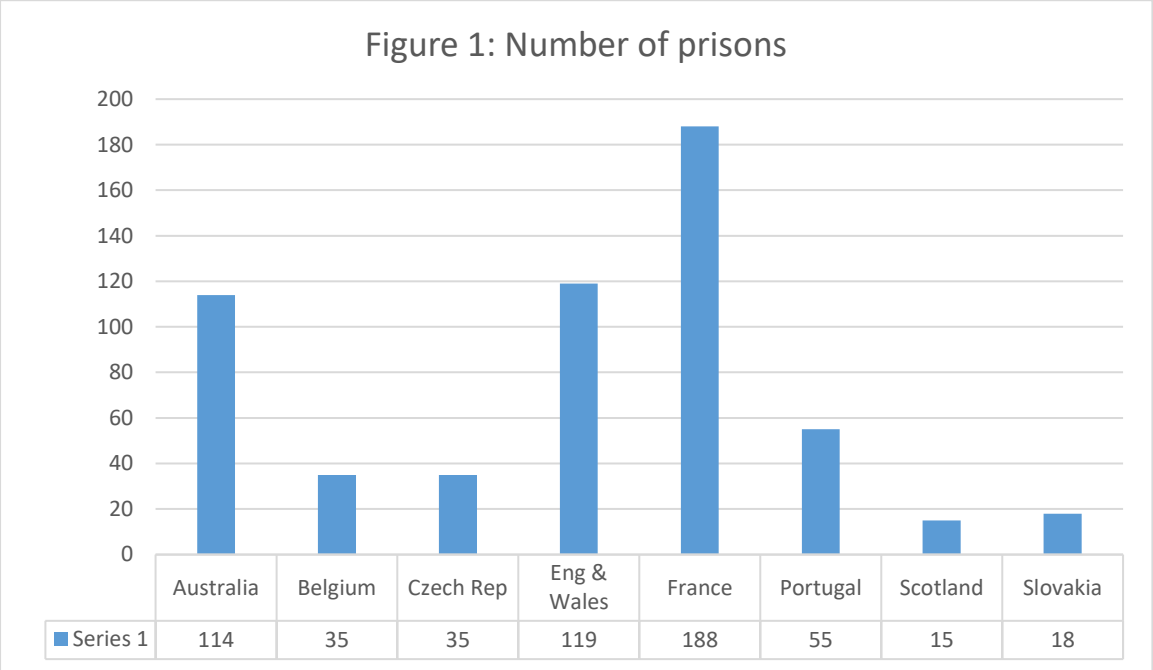
valuable finding in itself). In some countries, freely available data was supplemented by informal conversations with colleagues in the different prison services.

# 5. Findings

## 5.1 Section A: Types and categories of prisons

### 5.1.1 Number of prisons in each country

Figure 1 shows the number of prisons in each country. The numbers range from 15 in Scotland to 188 in France, but no data were collected on the size of each prison (number of inmates), the size of each country (population) or any geographical factors that might affect the number of prisons required.

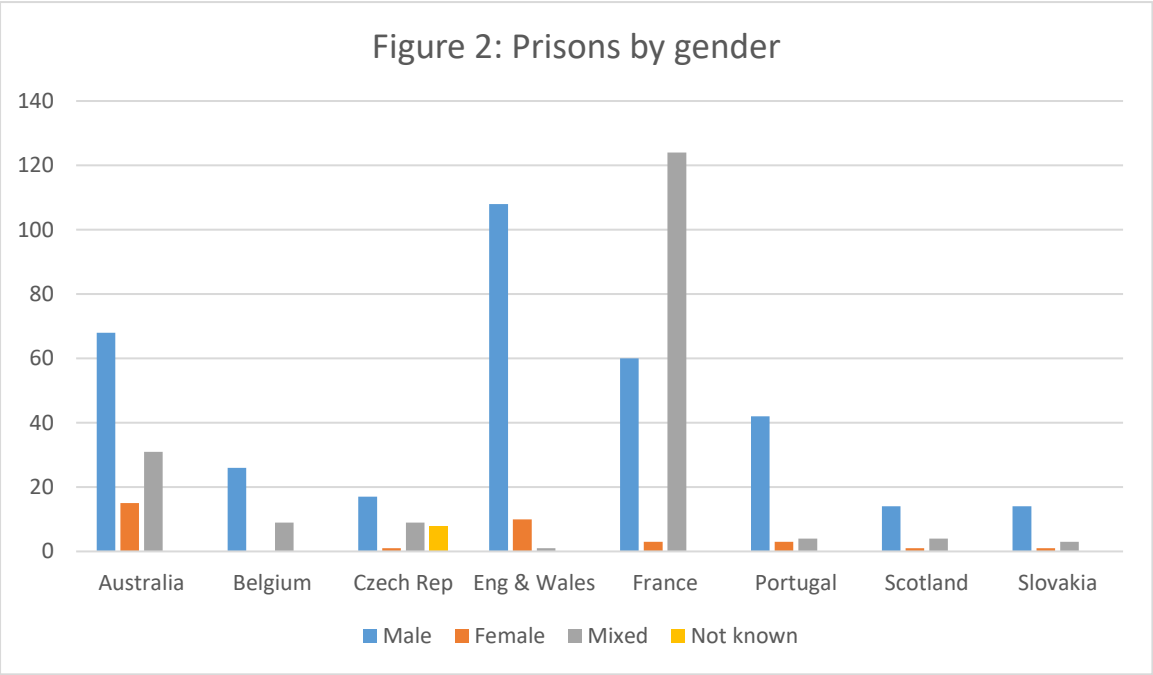



### 5.1.2 Prison funding

The survey revealed that in all participating countries all prisons are funded by the state, although in some countries a small number of prisons are contracted out to and operated by private organisations.

### 5.1.3 Male and female prisons

Most countries segregate prisons by gender, apart from in France where most prisons are mixed, having units for both men and women in the same establishment. Figure 2 shows the number of male, female and mixed prisons in each country. The numbers of female prisons are small, in keeping with the relatively small number of female prisoners.




### 5.1.4 Immigration detention and removal centres

All countries apart from Portugal reported having some form of immigration centres; however, these were excluded from the numbers of prisons reported above because of the different approaches to immigration and the difficulty of comparing like with like.

### 5.1.5 Other types of prisons

In some countries there is evidence of other types of prison; some examples of these are:

- All countries reported having prisons only for people on remand (not yet sentenced); the number of these varied from one in England & Wales to 86 in France.
- Some countries have prisons just for those serving long sentences. In Australia and France such prisons are commonplace (93 and 94 respectively), whereas in the Czech Republic and Slovakia the numbers are much smaller (although the total number of prisons is also smaller in these countries).
- Some countries have specialist prisons that cater for people with severe psychiatric disorders. In Belgium, there are two forensic psychiatric centres, and one 'Institute for the Protection of Society'. Similarly, the Czech Republic has two institutions for 'safety/secure detention', which serve to protect the public from perpetrators who could be dangerous due to their mental condition.
- In England & Wales there are a number of prisons that only take convicted sex offenders.
- There are also a few prisons exclusively for foreign nationals in England & Wales.

All eight countries reported having separate institutions for young offenders, but again comparisons between countries are difficult because of the definition of 'young offender'; the age at which children and young people are classed as young offenders varies widely from country to country. Apart from young offender institutions, there was no evidence of segregation according to age; it therefore appears that prisons exclusively for older prisoners do not exist in these eight countries.

### 5.1.6 Security classification of prisons

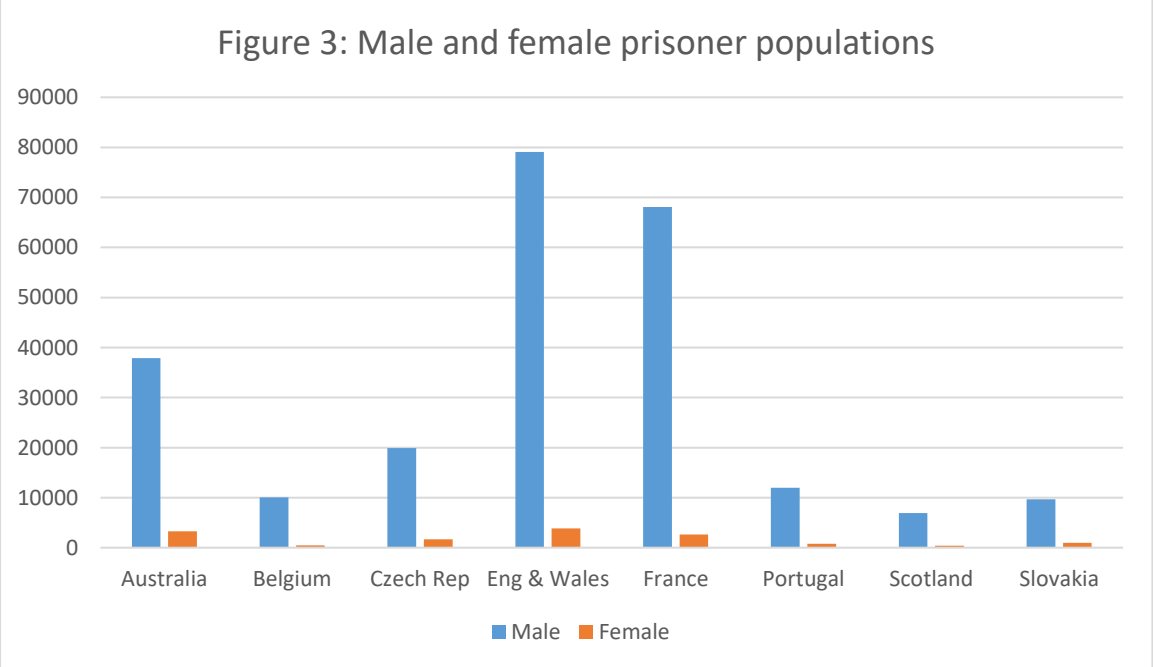
All countries reported classification of prisons according to security levels:

- In Scotland, apart from one open prison (where inmates can go outside to work each day in preparation for release), all other prisons are closed establishments with the same level of security.
- The Czech Republic has new legislation that has introduced two types of prison; those with security (the prison decides whether a prisoner needs minimum, medium or maximum security), and those with stricter security.
- Slovakia and Portugal have three security levels: minimum, medium and maximum security.
- Similarly, both France and Australia use a three-level system, but also have some prisons with mixed security levels.
- England & Wales have four security classifications from A to D, with Category A prisons being for the most dangerous prisoners, and Category D being open prisons for those working towards release.
- Belgium also has four levels of security: normal regime (continual detention), half freedom, limited detention and electronic surveillance (ankle band).

## 5.2 Section B: Prison populations

### 5.2.1 Male and female prison populations

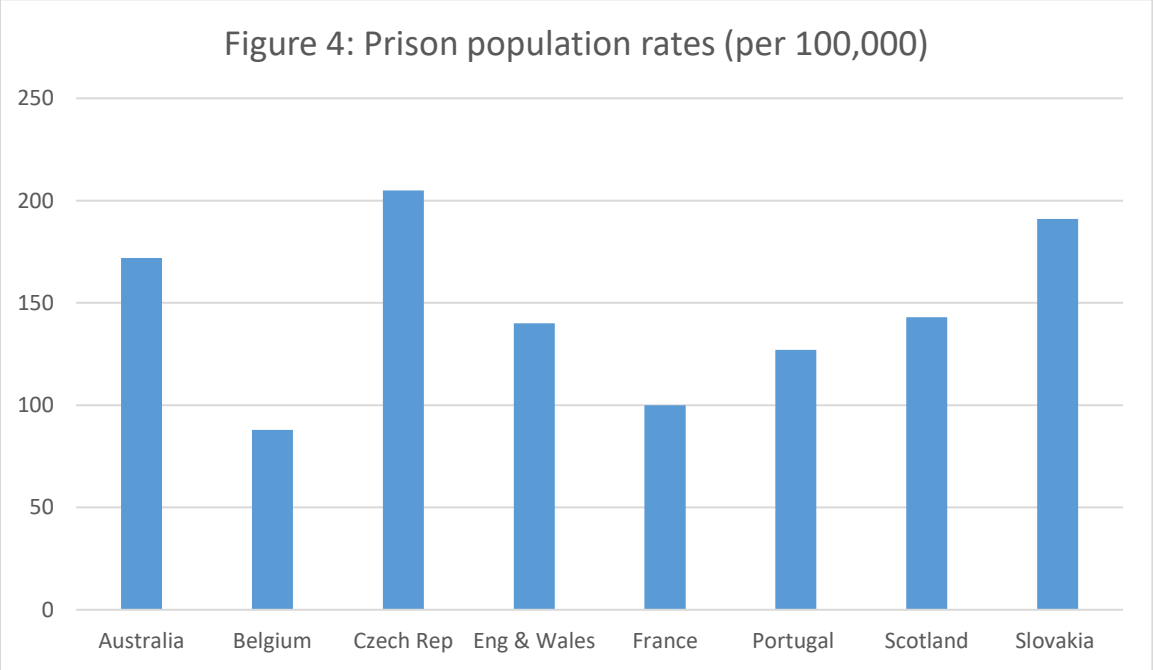
Figure 3 shows the numbers of adult male and adult female prisoners in each country. As the definition and age of young offenders varies between countries, only adults aged 18 and over have been included in these figures.



Of the total prison population, the percentage of female prisoners ranges from 3.7% in France to 8.2% in Slovakia. Across all eight countries the percentage of female prisoners is 5.4%; men therefore make up the vast majority of the prison population.

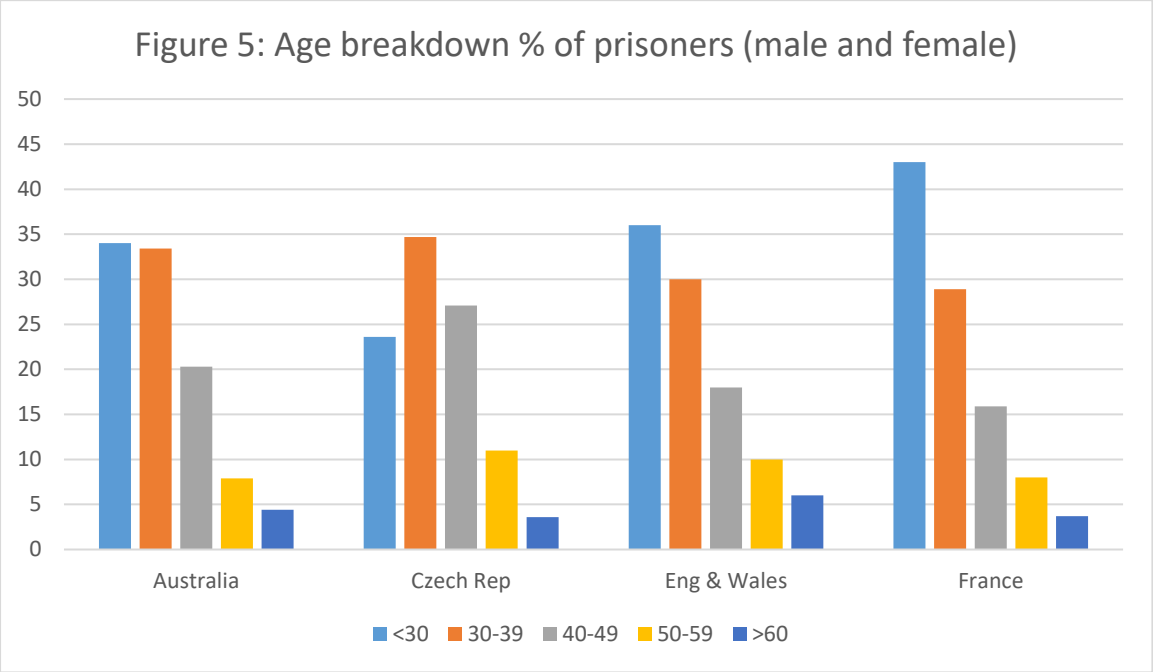
### 5.2.2 Prison population rates

It is important to consider the context of the numbers of prisoners, because the countries that took part in the survey vary considerably in population size. A world prison population list is produced each year (Walmsley, 2018), which shows the prison population rate in each country (i.e. the number of prisoners per 100,000 of the population). Figure 4 shows the prison population rates for the countries that participated in the Part A Survey. This reveals, for example, that although the Czech Republic has only 35 prisons (see Figure 1) it has the highest prison population rate of all the participating countries, at 205 prisoners per 100,000 of the population. Conversely, although France has the highest number of prisons (188), its prison population rate is only 100, which is relatively low.




### 5.2.3 Age of prisoners

Data on the age of prisoners posed some specific challenges in analysis. First, not all countries use the same age bands in reporting prisoners' ages, making comparisons difficult. For this reason, data from Belgium is not included in Figure 5. Second, in some countries (Scotland and Portugal) no data on age could be found, and in Slovakia the available data were very limited and more than five years old. Third, data on age by gender were only found in two countries (Australia and the Czech Republic); Figure 5 therefore shows the age breakdown of male and female prisoners together for the four countries in which comparable data were available.




### 5.2.4 Prison population trends and projections

Table 1 shows the current population trends (upwards and downwards) where evidence for this could be found, and any projections for the numbers of prisoners over the next 5-10 years. Although some countries show either stable overall populations or slight downward trends, there is clear evidence of rising older prisoner populations in Australia, Czech Republic, England & Wales and France.

**Table 1: Prison population trends and projections**

| Country | Prison population trends | Prison population projections |
|---|---|---|
| Australia | Increasing older prisoner population:<br>- Age 50 and over up by 84% from 2,400 in 2005 to 4,400 in 2015<br>- Age 65 and over up by 170% from 312 in 2005 to 842 in 2015. | No data available |
| Belgium | Slight downward trend in total prison population since 2013. | No data available |
| Czech Rep | - Age under 18 numbers decreasing<br>- Age 25-45 numbers fluctuating (up from 12,853 in 2015 to 13,891 in 2016, and down to 13,567 in 2017<br>- Age 50-60 up from 1,283 in 2013 to 2,233 in 2017<br>- Age 65+ up by 120 since 2013 | In 2015 the projected growth in total population was to 21,740 by 2024; however, by 2018 the total population had already reached 21,804. |

| | | |
|---|---|---|
| Eng & Wales | Increasing older prisoner population:<br>- Age 50 and over up from 7% in 2002 to 16% in 2018. | - Total population projected to increase from 83,165 in August 2018 to 86,400 by March 2023.<br>- Age 50-59 projected to decrease from 8,607 in June 2018 to 8,500 by June 2023.<br>- Age 60-69 projected to rise from 3,328 in June 2018 to 3,600 in June 2023<br>- Age 70+ projected to rise from 1,681 in June 2018 to 2,000 by June 2023 |
| France | Increasing older prisoner population: Age 50 and over up over the past 30 years from 4.5% in 1980 to 11.8% in 2014. | High projection: 76,254 by 2025<br>Low projection: 67,137 by 2025<br>(Current: 70,710) |
| Portugal | No data available | No data available |
| Scotland | The trend appears to be stable. | Current projections to 2022-23 suggest the population will remain stable. |
| Slovakia | Increase in the number of women (no information about age) | No data available |

## 5.3 Section C: Healthcare in prison

### 5.3.1 Healthcare funding in prison

In all eight countries, healthcare funding in prison is provided by the state. In most countries, the delivery of all prison healthcare is also the responsibility of the state, apart from in Australia and England & Wales, where a small proportion of healthcare provision is contracted out to private providers.

### 5.3.2 Types of healthcare services

The survey revealed that all prisons in each of the participating countries provide some sort of healthcare (mainly primary care), apart from Portugal, where only 41 of the 55 prisons have healthcare units. The survey asked specific questions about whether or not prisons have in-patient beds, and whether they provide mental health care and palliative care as specialist services. Table 2 gives a summary of the responses to these questions. It is interesting to note that there are relatively few prisons with in-patient facilities, and dedicated palliative care units are only found in one country (England & Wales). Most prisons provide some sort of mental health care, but details about the type of care and staff providing it were difficult to find.

**Table 2: Types of healthcare services provided in prison**

| Country | No of prisons with some sort of healthcare | No of prisons with in-patient beds | No of prisons with specialist mental health | No of prisons with dedicated palliative care |
|---|---|---|---|---|
| Australia | All | 8* | All | None |
| Belgium | All | 2 | 12 | None |
| Czech Rep. | All | 2* | All (psychologist or psychotherapist) | None |
| Eng & Wales | All | Some* | All | A few* |
| France | All | 26 | All | None |
| Portugal | 41 | 8 | 2 | None |
| Scotland | All | None | All | None |
| Slovakia | All | 1 | All | None |

*= exact numbers not known

### 5.3.3 Deaths

In order to ascertain the need for palliative care in prisons, the survey asked about the numbers of deaths in the last year for which figures are available, and how many of these were from natural causes (as opposed to suicides or homicides). Table 3 summarises these data where available. The timeframes for reporting deaths differ between countries, again making comparisons difficult.

**Table 3: Deaths from natural and non-natural causes**

| Country | No of deaths | Year | No of natural cause deaths | No of non-natural cause deaths |
|---|---|---|---|---|
| Australia | 74 | 2016-17 | 45 | 29 |
| Belgium | 44 | 2017 | 31 | 13 |
| Czech Rep. | 34 | 2017 | 24 | 10 |
| Eng & Wales | 310 | 2017-18 | 173 | 137 |
| France | 168 | 2016 | 62 | 104 |
| Portugal | Not available | - | Not available | Not available |
| Scotland | 26 | 2018 (Jan-Oct) | 9 | 17 |
| Slovakia | 15 | 2018 (Jan-Nov) | 11 | 4 |

## 5.4 Section D: Policies and practices

### 5.4.1 Compassionate release

The survey revealed a range of different approaches to release on compassionate grounds at the end of life. Table 4 summarises the policies in relation to compassionate release.

**Table 4: Policies on compassionate release**

| Country | Policy details |
|---|---|
| Australia | The medical management and healthcare of all prisoners, regardless of age, are dealt with on a case-by-case basis. Formal policy or guidance documents were found in different jurisdictions, each with a primary focus on outlining care and/or release options for prisoners who have been diagnosed with an end of life illness or terminal medical condition. Within each state/territory jurisdiction application processes and guidelines exist for requests for compassionate release.<br>For compassionate release decision processes, consideration may be given to relevant factors that include (but are not limited to): the prisoner's sentence status; the nature of the prisoners' offence(s) and their offending history; the safety of the community; the safety and well-being of any victims; the safety and well-being of the prisoners; the suitability of the intended non-custodial setting if released; and views of medical, correctional and other related professionals involved in the care of the prisoner. |
| Belgium | As of 2015, the criminal court judge has the final decision over the temporary release of a prisoner with terminal illness. Prisoners are required to file a written request for temporary release for medical reasons with the prison registry. The registry sends the request to the criminal court and the prison director receives a copy. The criminal court judge makes a decision within 7 days based on the advice of the prison director, including the opinion of the treating physician, the leading civil-servant physician of the penitentiary health service and potentially a physician chosen by the prisoner. The prosecution also sends in an advice, of which the prisoner and prison director receive a copy. The prisoner receives notification of the decision via court letter within 24 hours.<br>The court cannot grant this request if a real risk exists that the prisoner will commit serious crimes, would not have a place to live or would bother his victims. Additional terms may be added. |
| Czech Republic | No specific policy. A pardon can be granted according to the Constitution. This can be granted by the president mainly in the case of serious illness or incurable imminently life-threatening illness. There is legislation on possible suspension of execution of the sentence and on possibility of dropping the execution of the sentence completely in the case of serious illness of a convicted person. |
| England & Wales | Prison Service Order 6000: Parole, Release and Recall. Chapter 12 of this PSO sets out the procedures for early permanent release on compassionate grounds. The main principles are that:<br>1. The release of the prisoner will not put the public at risk<br>2. A decision to approve release would not normally be made on the basis of facts of which the sentencing or appeal court was aware<br>3. There is some specific purpose to be served by early release.<br>Early release may be considered where a prisoner is suffering from a terminal illness and death is likely to occur soon. There are no set time limits but 3 months may be considered to be an appropriate period. It is therefore essential to try and obtain a clear medical opinion on the likely life expectancy. The Secretary of State will also need to be satisfied that the risk of reoffending is past and that there are adequate arrangements for the prisoner's care and treatment outside prison. |

| | |
|---|---|
| | Early release may also be considered where the prisoner is bedridden or severely incapacitated. This might include those confined to wheelchairs, paralysed or severe stroke victims. Applications may also be considered if further imprisonment would endanger the prisoner's life or reduce his or her life expectancy. Conditions which are self-induced, for example following a hunger strike, would not normally qualify a prisoner for release. |
| France | Law No. 2002-303 dated March 4, 2002, on patients' rights and quality of the health system. The goal is to allow prisoners to obtain optimal treatment under better conditions and, in the case of terminal illness, to die outside the prison environment before their sentence is completed (other solutions could be proposed, such as parole or electronic bracelets). This compassionate release can be granted in two situations, namely, when patients are terminally ill or when their health situation is not compatible with continued detention. In comparison with compassionate release, it is actually a suspension of the sentence, which means that if the inmate who gets out of prison then recovers, he will return to serve the remainder of his sentence. |
| Portugal | No policy found. |
| Scotland | GMA 054A/16 explains the guidance for an application for release on compassionate grounds. The main criteria for an application is on medical grounds (where death is anticipated, or the prisoner is confined to bed or seriously incapacitated), the risk of re-offending must be low and can be managed, appropriate arrangements are in place for supervision, care and treatment within the community and early release will bring some benefit to the prisoner and their family. An application can also be made in the event of tragic family circumstances, however, it must be demonstrated that the family circumstances have changed to the extent the hardship of the family would be significantly greater than foreseen by the court. |
| Slovakia | No policy found. |

### 5.4.2 Compassionate release requests

The survey sought information on the number of requests for compassionate release, and how many of them were granted. Data on compassionate release could only be found in three countries, as shown in Table 5.

**Table 5: Requests for compassionate release**

| Country | Number of applications for compassionate release | Number of applications granted |
|---|---|---|
| Czech Republic | 747 prisoners or their kin applied for a pardon/clemency in 2017. | 2 were pardoned; 118 had their sentence suspended for health reasons |
| France | 296 requests made between 2002-2012 | 253 were granted (85%) |
| Scotland | 5 applications received during 2017 | 2 released |

### 5.4.3 Other options for end of life care

In cases where compassionate release was either not applied for or not granted, the survey sought information on what other options were available to prisoners. Data were not available in Belgium, Czech Republic, Portugal or Slovakia; Table 6 shows the findings from the other four countries.

**Table 6: Other options for end of life care**

| Country | End of life care options |
|---|---|
| Australia | 1. Transfer to an inpatient bed at another prison within the same state/territory jurisdiction and receipt of in-prison healthcare services<br>2. Transfer to a tertiary hospital providing healthcare for prisoners within the respective state/territory<br>3. Remain in the same prison<br>4. Some state/territory prisons use existing community palliative care services to provide in-prison care appointments |
| England & Wales | Prison Governors can also grant temporary release on compassionate grounds, whereby the prisoner can be recalled to prison if circumstances change. For those who need to remain in custody, they can be cared for in their usual prison, be transferred to another prison (e.g. one with in-patient beds), or be moved to an outside facility such as a hospital or hospice (usually with 2 prison officers to stay with them at all times). |
| France | 1. Transfer to another care facility in one of the eight secure inpatient care units (UHSI) in university hospitals.<br>2. Remain in the same prison.<br>3. Ask for a parole or an electronic surveillance.<br>4. Request an “emergency compassionate release” (the procedure is simplified). |
| Scotland | If the criteria are not met in terms of risk to allow an individual to be released on compassionate grounds the other option is to transfer to a care home/hospital/ hospice and remain under guard |

### 5.4.4 Other policies related to palliative care for prisoners

In general, it was difficult to find specific policies relevant to prisoners with palliative or end of life care needs (e.g. policies about older prisoners, frailty, disability or the provision of social care) through online searches; in most of the participating countries, therefore, they do not appear to exist. Two examples were found: in France, there is a policy about parole for older people; and in England & Wales there are detailed rules, regulations and guidelines by which prisons are run, known as ‘Prison Service Orders’ (PSOs) and ‘Prison Service Instructions’ (PSIs), some of which relate to older people and disability.

## 5.5 Section E: Examples of good or innovative practice

The survey asked for any examples of good or innovative practice in relation to palliative care in prisons, whether in just one prison or across the whole country. In some countries

(Australia, Belgium, Czech Republic, Portugal and Slovakia), little or no evidence was found of such initiatives. The survey from France reported that some prisons organise additional help inside the prison, one example being 'life support workers', who come in to help old and frail inmates.

In Scotland, a national project is underway that has employed a specialist palliative care nurse to support the implementation of palliative and end of life care standards in all prisons; this project is funded by Macmillan Cancer Support, a national charity. Macmillan Cancer Support has also funded a project in the North East of England, and there are other local initiatives ongoing in various prisons, but there is currently no national project across England and Wales.

### 5.6 Section F: Regulatory approvals for the Part B questionnaire

All countries (apart from Portugal) provided detailed information about what permissions will be required for the next part of the Task Force project, and how to apply for approvals in each country (these details are not included here).

## 6. Discussion

### 6.1. Key findings

The findings from this survey reveal that there are wide variations in prison systems and prison populations across the eight participating countries. When the prison population rate in each country is taken into account, some countries appear to have much more punitive systems than others; for example, the number of people per 100,000 of the population incarcerated in Czech Republic is more than twice the number in Belgium or France. Different cultural attitudes and approaches to crime and punishment mean that there are also likely to be wide variations in sentencing, with the same or similar offences attracting very different sentences in different countries.

In all countries, the number of female prisoners is small in comparison with male prisoners; this creates the potential for the specific needs of female prisoners to be secondary to those of male prisoners, who present far greater challenges in terms of their numbers. All prisons in the eight countries segregate prisoners according to gender (whether in separate prisons or separate units within the same prison), but this is limited to either male or female units/prisons; no evidence was found in the survey of any prison units that cater for transgender prisoners, or those who identify as neither male nor female.

In line with ageing populations across the world, the survey provided clear evidence of ageing prisoner populations. This is a trend that is likely to continue in the foreseeable future, which adds weight to the contention that the healthcare needs of older prisoners need to be addressed (Heidari et al, 2017).

In all eight countries, both prisons and prison healthcare are funded by the state. Most of the healthcare delivered in prisons is in the form of general practice or outpatient care; only a relatively small number of prisons provide in-patient services. Therefore, prisoners who require in-patient care often need to be transferred either to another prison with in-patient facilities or to a hospital. This presents particular challenges for the prison authorities, as prisoners have to be escorted by prison officers, usually in restraints (e.g. handcuffs or shackles). For the prisoners themselves, this can present challenges in that care is often fragmented, and they are removed from their friends and support networks in their usual prison.

The survey provides evidence of increasing numbers of deaths in custody in some countries, and although some of these deaths are from suicide, increasing numbers are from natural causes, some of which can be anticipated. The increase in older prisoners also brings burgeoning numbers of those with multiple and complex health needs, and consequently an increased likelihood that they will die in custody. This highlights the growing need for palliative and end of life care to be provided in custodial settings.

However, it is clear from our survey that as yet there are no palliative care units in prisons in any of the participating countries except England & Wales, and even there they are few and far between. The few examples of good practice we uncovered do indicate that informal links are starting to be developed between prison healthcare and external palliative care services, but there is no formal strategy, policy or programme to address the needs of dying prisoners in any of the countries involved in this project.

Policies for early release on compassionate grounds also vary widely between the different countries. With the exception of France, in the countries where data were available on how many prisoners applied for and were granted compassionate release, the numbers were generally small; this echoes findings from Handtke et al (2017). For prisoners who either do not apply or are not granted compassionate release, the options for their end of life care are limited; in general, depending on individual circumstances, they can either remain in the same prison, or be transferred under guard to another prison, an outside hospital or other care facility.

The findings from this survey point to manifold inequalities experienced by prison populations in the participating countries. These inequalities exist on multiple levels: between prisons in different countries; between prisons within the same country; between prisoners within the same prison; and between prisoners and the general population outside prison. It has been argued that older prisoners are particularly disadvantaged and face the ‘double burden’ of imprisonment and poor health (Turner et al, 2018). One example concerns prisoners who are awaiting sentencing; they are often held in custody for many months before their case comes to court, and if they develop a life-limiting condition during that time they are unlikely to have the same access to early release on compassionate grounds as a sentenced prisoner.

Although we were able to find some examples of good practice in relation to prisoners and palliative care, these were limited in number, *ad hoc* and localised. This further support the argument for national policies and strategies about palliative care for prisoners.

## 6.2. Limitations of this project

This project was subject to a number of limitations. To begin with, it was unfunded, so all the work was undertaken by members of the Steering Committee in their own time, which inevitably limited the amount of time available for searching the internet for the data. The survey was completed by a different person in each country, thus raising the possibility of different interpretations of the survey questions. In most countries, the survey was conducted in English, but in Slovakia for example, it was translated into Slovak, completed in Slovak and then the findings were translated back into English; again, this introduces the possibility of inconsistency in interpretation.

The poor quality of the data in some areas also raises questions about reliability and validity. The survey was not piloted or validated as it was very much the first stage of an exploratory scoping project; this limits the extent to which the findings can be generalised to other settings. Data were also held in different formats in the different countries (e.g. different age bands), making international comparisons extremely difficult. In addition, some of the data sought could not be found in the public domain so therefore could not be accessed.

Despite these limitations, however, this project has uncovered some very important issues in relation to palliative care in prisons, and represents to our knowledge the first attempt to understand these complexities from an international perspective.

## 6.3. Recommendations

A number of recommendations arise from the Part A Survey in relation to policy, practice and research:

- **Policy**. There is a clear need for national policies and strategies concerning palliative and end of life care in prison. Options other than custodial sentences (including early release on compassionate grounds) should be considered where appropriate, and where it is not possible to release prisoners at the end of life, policies need to be developed about how best to provide appropriate care in the prison setting, in order to ensure more equitable treatment and care.
- **Practice**. The resources to care for dying prisoners need to be provided, and staff should receive adequate training and support to enable them to deliver palliative and end of life care. There is further scope for sharing ideas and good practice initiatives for different countries, so it is important to use existing networks (e.g. Europris: https://www.europris.org/ and the Worldwide Prison Health Research and Engagement Network (WEPHREN): https://wephren.tghn.org/) and develop new networks to this end.
- **Research**. Further research is needed, both national studies where little or no evidence exists, and international studies to explore comparisons. There is an urgent need to develop appropriate interventions for prisoners with palliative care and end of life care needs, and evaluate the effectiveness and cost effectiveness of these.

## 7. Conclusions

The first part of the project to map palliative care provision for prisoners, the Part A Survey, has provided valuable information on prisoners and prison systems in each of the eight participating countries and has therefore achieved its main objectives.

The findings of the survey have provided the foundations for the next stage of the mapping project. The Task Force Steering Committee now aim to undertake more detailed work in selected prisons in the participating countries, in order to explore some of the challenges and issues in greater depth.

## References


Handtke, V., Wangmo, T., Elger, B,. & Bretschneider, W. (2017) New guidance for an old problem: Early release for seriously ill and elderly prisoners in Europe. *The Prison Journal* 97(2); 224-246.

Heidari, R., Wangmo, T., Galli, S., Shaw, D.M., Elger, B. on behalf of the Agequake group. (2017). Accessibility of prison healthcare for elderly inmates, a qualitative assessment. *Journal of Forensic & Legal Medicine* 52; 223-228.

Pazart, L., Godard-Marceau, A., Chassagne, A., Vivot-Pugin, A., Cretin, E., Amzallag, E., Aubry, R., and the PARME Study Group. (2018). Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national study. *Palliative Medicine* 32(1); 6-16.

Turner, M., Peacock M., Payne, S., Fletcher, A., & Froggatt, K. (2018). Ageing and dying in the contemporary neoliberal prison system: exploring the 'double burden' for older prisoners. *Social Science & Medicine* 212; 161-167.

Walmsley, R. (2018). World Prison Population List (Twelfth Edition). Available from: www.prisonstudies.org/sites/default/files/resources/downloads/wppl_12.pdf. Accessed 21 May 2019.

## Appendix 1: Part A Survey


***European Association for Palliative Care***

***EAPC Onlus: Non profit-making Association***

***Non Governamental Organisation (NGO) recognised by the Council of Europe***

***Wesiteb:*** http://www.eapcnet.eu

EAPC Head Office, Istituto Nazionale dei Tumori, Fondazione IRRCS, Via Venezian 1, 20133 Milano, ITALIA
Email: julie.ling@eapcnet.eu


**EAPC Task Force: Mapping palliative care provision for prisoners in Europe**

**Survey Part A: Prisons and prison systems**

**Introduction**

This survey is being undertaken as the first part of a mapping project supported by the European Association for Palliative Care (EAPC) to develop understanding about the provision of palliative care for prisoners in Europe. The information sought should be in the public domain, so ethical and governance approvals are not required for this survey.

Sources of information can include national statistics from ministries of health and justice, prison administrations, national prison advocacy organisations, networks, and so on. Please provide as much information as possible in answer to each of the questions below. Please also ensure that you record the source of the information as well as the date on which it was collected.

The survey has six sections: Types and categories of prisons; Prison populations; Healthcare in prison; Policies and practices; Examples of good or innovative practice; and Regulatory approvals for the Part B questionnaire. Some questions require numbers, others require a more detailed description; however, you are encouraged to make comments as appropriate in answer to any of the questions.

If you are unsure about how to answer any of the questions or would like to discuss the survey, please contact Mary Turner, co-chair of the EAPC Task Force on mapping palliative care provision for prisoners in Europe. Please also email your completed survey to Mary Turner: m.turner@hud.ac.uk by **31 October 2018**

**Thank you for your help in completing this form**

## Country details

| | |
|---|---|
| **Name of country** | |
| **Name and email address of person completing this form** | |
| **May we contact you if we have any queries about any of your responses to the questions below?** | Yes / No (please delete as appropriate) |

## Section A: Types and categories of prisons

Please describe the types and categories of prisons in your country (please note the boxes will expand).

| **Question** | **Description / comments** | **Sources for the information provided** | **Date information was accessed** |
|---|---|---|---|
| 1. Please provide the total number of prisons in the country | | | |
| 2. How many prisons are funded solely by the state? | | | |
| 3. How many prisons are funded solely by the private sector? | | | |
| 4. How many prisons are jointly funded by the state and the private sector? | | | |
| 5. How many male prisons are there? | | | |
| 6. How many female prisons are there? | | | |
| 7. How many mixed prisons are there with both male and female units? | | | |
| 8. How many immigration detention centres are there? | | | |
| 9. How many prisons are there for people awaiting sentencing? | | | |
| 10. How many prisons are there for people serving long sentences? | | | |
| 11. Are prisons classified according to security level? If so, please provide a description of this. | | | |

| | | | |
|---|---|---|---|
| 12. How many prisons are there for young offenders? (Please specify the age at which people are classed as young offenders) | | | |
| 13. Are there any other specific types of prison? If so, please provide details. | | | |

## Section B: Prison populations

| Question | Description / comments | Sources | Date |
|---|---|---|---|
| 14. What is the total prison population in this country? Please specify whether or not people in immigration detention centres are included in this number. | | | |
| 15. How many adult male prisoners? | | | |
| 16. How many adult female prisoners? | | | |
| 17. How many young offenders? (Please comment on the age of young offenders) | | | |
| 18. Please provide a breakdown of the ages of male prisoners as far as possible. | | | |
| 19. Please provide a breakdown of the ages of female prisoners as far as possible. | | | |
| 20. Are there any current population trends (upwards or downwards in any age group)? If so, please provide details. | | | |
| 21. Are there any projections for the numbers of prisoners over the next 5-10 years? If so, please provide details. | | | |

## Section C: Healthcare in prison

| Question | Description / comments | Sources | Date |
|---|---|---|---|
| 22. How many prisons have healthcare units providing a | | | |

| | | | |
|---|---|---|---|
| range of services but not including in-patient beds? | | | |
| 23. How many prisons have healthcare units providing a range of services that include in-patient beds? | | | |
| 24. How many prisons have specialist staff providing mental health care? | | | |
| 25. How many prisons have a dedicated palliative care unit? | | | |
| 26. In how many prisons is healthcare funded by the state? | | | |
| 27. In how many prisons is healthcare funded by the private sector? | | | |
| 28. In how many prisons is there a mix of state and private funding for healthcare? | | | |
| 29. How many prisoners have died in the last year for which figures are available? (Please state which year) | | | |
| 30. What is the number of natural cause deaths in the last year for which figures are available? (Please state which year) | | | |
| 31. What is the number of non-natural cause deaths in the last year for which figures are available? (e.g. suicide, murder) (Please state which year) | | | |
| 32. Are there any current trends about the numbers of deaths? If so, please give details. | | | |

## Section D: Policies and practices

Please provide a detailed description of any policies or practices that relate to prisoners with palliative care needs. If there are no policies in a particular area, please write 'none' in the description / comments box and if possible record the sources that you have searched.

| Question | Description / comments | Sources | Date |
|---|---|---|---|
| 33. Is there any policy or guidance about compassionate release for prisoners approaching the end of life? If so, please provide details about the main elements of this policy (e.g. eligibility criteria) | | | |
| 34. How many prisoners applied for compassionate release during the last year for which figures are available? (Please state which year) | | | |
| 35. How many prisoners were granted compassionate release during the last year for which figures were available? (Please state which year) | | | |
| 36. For prisoners who do not apply for or are not granted compassionate release, please describe the options at the end of life (e.g. transfer to another care facility; remain in the same prison). Please describe the process and any eligibility criteria for each option. | | | |
| 37. Is there any policy or guidance related to palliative or end of life care in prison? If so, please provide details) | | | |
| 38. Please provide details of any other policies or guidance relevant to prisoners with palliative or end of life care needs (e.g. policies about older prisoners, frailty, disability, the provision of social care, etc) | | | |

## Section E: Examples of good or innovative practice

| Question | Description / comments | Sources | Date |
|---|---|---|---|
| 39. Please describe any examples you know of that represent models of good or innovative practice and could be shared | | | |

| | | | |
|---|---|---|---|
| with other countries. These might be national initiatives or local to just one prison, and may include cross-boundary working, palliative care support and facilities within prisons, the use of prisoners as volunteers, advance care planning, team working etc. | | | |

## Section F: Regulatory approvals for the Part B questionnaire

In the next stage of the scoping work, we plan to distribute a questionnaire to all prisons in the participating countries, to find out how many prisoners there are with palliative and end of life care needs, and what their needs are. We anticipate that in order to do this we will need approval from the prison service in each country. In the box below please provide a description of the approval processes that will be required in this country. Where possible, please include information about and links to the regulatory bodies that we will need to approach.

| |
|---|
| |

**Thank you for your help in completing this survey**

Please email your completed survey to: m.turner@hud.ac.uk.