# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

# INTERVENTIONAL PROCEDURES PROGRAMME

## Equality impact assessment

## IPG666 Reducing the risk of transmission of Creutzfeldt–Jakob disease (CJD) from surgical instruments used for interventional procedures on high-risk tissues

The impact on equality has been assessed during guidance development according to the principles of the NICE Equality scheme.

## Briefing

| 1. Have any potential equality issues been identified during the briefing process (development of the brief or discussion at the committee meeting), and, if so, what are they? |
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| The incidence of any type of Creutzfeldt–Jakob disease (CJD) (based on published surveillance studies) is 1 to 2 cases per million of the population worldwide. The CJD Research and Surveillance Unit in Edinburgh estimated that since 1990 there have been 3640 referrals and 2284 deaths of definite and probable CJD (data as at 2nd May 2017).<br>There are 4 aetiological CJD categories: sporadic CJD, inherited CJD, variant CJD, and iatrogenic CJD.<br>Sporadic" CJD (sCJD) is the most common type of CJD and accounts for 85 to 90% of cases worldwide. It has an annual incidence of 1 to 2 deaths per million of population per year. The general rate of age-adjusted detection of sCJD is increasing in the UK. Reasons for this include improved case ascertainment and an ageing population (where there is a higher incidence).<br><br>Inherited (genetic or familial) CJD accounts for 5 to 15% of cases or about 10 deaths in the UK per year. It is associated with pathogenic mutations in the prion protein gene.<br><br>Iatrogenic CJD accounts for less than 1% of cases in the UK and globally. It is the transmission of prions through surgical or medical procedures (especially from tissues with the highest concentration of prions including brain and spinal cord, pituitary gland, cranial nerves and posterior eye) or human derived products (growth hormone, gonadotropin, dura mater grafts, and packed red blood cells).<br><br>Variant CJD (vCJD) is a novel form of human prion disease, first found in the |

UK in 1996. By 2016 there had been 178 cases of vCJD (classified as definite or probable) in the UK. Three cases are considered to have occurred through blood transfusion and 175 cases were related to consumption of food derived from cattle infected with bovine spongiform encephalopathy (BSE). The age profile at onset of symptoms is a median of 28 years in the UK. None of them had a date of birth after 1989. There is potential for under-reporting of vCJD amongst elderly patients, though its extent is not known.

The prevalence of non-clinical vCJD (abnormal prion accumulation in tissues without clinical symptoms) in the general UK population is estimated to be 240 per million, based on retrospective analyses of appendix specimens. In the UK after 1996 a series of measures were put in place to reduce the risk of people being exposed to BSE (including the intention to protect the younger age group who are unlikely to have been exposed to BSE from food or have not have undergone high risk procedures). Over the past 8 years there have only been 0 or 1 deaths per year in the UK attributed to vCJD.

An epidemic has not occurred since the original guidance and to date there has been no evidence of vCJD transmission by surgery. However, abnormal prion accumulation in the appendices of low risk cohorts (those born after 1996) was found.

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| 2. | What is the preliminary view as to what extent these potential equality issues need addressing by the committee? (If there are exclusions listed in the brief (for example, populations, treatments or settings), are these justified?) |
| This was not thought to have an impact on the assessment of the procedure. No exclusions were applied. | |

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| 3. | Has any change to the brief (such as additional issues raised during the committee meeting) been agreed to highlight potential equality issues? |
| No | |

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| 4. | Have any additional stakeholders related to potential equality issues been identified during the committee meeting, and, if so, have changes to the stakeholder list been made?’ |

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| No |

**Kevin Harris**

**Approved by Programme Director and Clinical Advisor**

**Date:** 08/10/2019

## Consultation

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| 1. | Have the potential equality issues identified during the briefing process been addressed by the committee, and, if so, how? |
| No specific data relating to [potential issues mentioned earlier] was identified in the literature presented in the ScHARR report. | |

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| 2. | Have any other potential equality issues been raised in the overview, specialist adviser questionnaires or patient commentary, and, if so, how has the committee addressed these? |
| The guidance is based on evidence from the ScHARR report and advice was taken from the CJD advisory subcommittee. Organisations representing patients provided submissions and representation at the CJD advisory subcommittee meetings. No equality issues have been raised. | |

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| 3. | Have any other potential equality issues been identified by the committee, and, if so, how has the committee addressed these? |
| No | |

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| 4. | Do the preliminary recommendations make it more difficult in practice for a specific group to access a technology or intervention compared with other groups? If so, what are the barriers to, or difficulties with, |

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| | access for the specific group? |
| No | |

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| 5. | Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability? |
| Not applicable | |

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| 6. | Are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 4 or 5, or otherwise fulfil NICE's obligation to promote equality? |
| Not applicable | |

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| 7. | Have the committee's considerations of equality issues been described in the consultation document, and, if so, where? |
| No | |

**Kevin Harris**

**Approved by Programme Director and Clinical Advisor**

**Date:** 08/10/2019

## Final interventional procedures document

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| 1. | Have any additional potential equality issues been raised during the consultation, and, if so, how has the committee addressed these? |

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| No |

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| 2. | If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access a technology or intervention compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group? |
| Not applicable | |

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| 3. | If the recommendations have changed after consultation, is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability? |
| Not applicable | |

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| 4. | If the recommendations have changed after consultation, are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 2 and 3, or otherwise fulfil NICE's obligations to promote equality? |
| Not applicable | |

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| 5. | Have the committee's considerations of equality issues been described in the final interventional procedures document, and, if so, where? |
| No | |

**Mirella Marlow**

**Approved by Programme Director**

**Date:** 28 October 2019