**Supplementary File 2: online survey sent to PACE participants**

**Patient and Clinician Engagement (PACE) Evaluation**

**Patient and clinician views and experience about medicines for rare conditions (orphan medicines), very rare conditions (ultra-orphan medicines) and conditions associated with a short life expectancy (end of life medicines) are gathered during Patient and Clinician Engagement (PACE) meetings. The output of a PACE meeting is the PACE statement, which is a consensus statement that describes the added value of a new medicine from the perspective of the patient/carer and clinician. More information about the PACE process can be found on the SMC** [**website**](https://www.scottishmedicines.org.uk/media/4731/pace-overview-document.pdf)**.

When making a decision about PACE medicines (i.e. orphan, ultra-orphan or end of life medicines), SMC committee members consider a range of evidence, including information in the PACE statement. As part of our evaluation of the PACE process, we are undertaking a survey of  participants to find out how important they think different factors identified in this process should be to SMC decisions.**

**Did you attend the PACE meeting as a : ( select all that apply)**

|  |  |
| --- | --- |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Patient Group Representative |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Patient (with experience of the condition being discussed) |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Carer |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Clinician |

**How many PACE meetings have you attended?**

|  |  |
| --- | --- |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | 1 |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | 2 |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | 3 or more |

**Please indicate the type of medicine(s) that was discussed at the PACE meeting you participated in. (select all that apply)**

|  |  |
| --- | --- |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Rare Condition (orphan) |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Very rare condition (ultra-orphan) |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | End of life |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Don’t know |

**In general, how important do you think information relating to each of the following factors should be to SMC decisions on these medicines?**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Very important  | Important  | Of lesser importance | Not important  |
| Impact on quality of life | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Impact on life expectancy | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Addresses an unmet need | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |

Comments:

|  |
| --- |
|   |

**The PACE statement provides committee members with information about the impact of a new medicine on aspects of quality of life. A review of PACE statements in 2016 identified 8 key quality of life themes. In general, how important do you think information relating to each of these themes should be to decisions on these medicines?**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Very important | Important | Of lesser importance | Not important |
| Ability to take part in normal life (including work, education, social and family activities) | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Convenience of administration | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Health benefits (for example improved physical health and better symptom control) | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Impact on patient’s family or carer | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Opportunity for treatment choice | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Providing hope for the future | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Psychological benefit (for example improved emotional well-being, reduced stress, reduced anxiety and improved self-esteem) | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |
| Tolerability (relating to side-effect profile) | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   |

Comments:

|  |
| --- |
|   |

**If you were a committee member making a decision on these medicines, would you rate the importance of the information relating to quality of life differently depending on whether it is an orphan, ultra-orphan or end of life medicine?**

|  |  |
| --- | --- |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Yes |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | No |
| https://app.smartsurvey.co.uk/images/ico/print/checkbox.png   | Maybe |

Please explain your answer:

|  |
| --- |
|   |

**Is there any other information relating to aspects of a patient’s quality of life that you feel should be an important factor in SMC decisions on these medicines?**

|  |
| --- |
|   |