

| <b>ECPDC FINAL EVENT – AGENDA</b>            |  |  |
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| <b>Monday, October 30<sup>th</sup>, 2023</b> |  |  |
| <b>Time</b>                                  | <b>Talk</b>  |  |
| 14.00-14.05                                  | <b>Opening</b>   | Charité & EC   |
| 14.05-14.15                                  | <b>Address from Cancer Mission and European Health Data Space</b>  | Barbara Kerstiens (DG RTD),<br>Guillaume Byk (DG SANTE)  |
| 14.15-14.25                                  | <b>Patients’ and Survivors’ needs for an ECPDC</b>   | Gilliosa Spurrier-Bernard (Patient Organisation)   |
| 14.25-14.45                                  | <b>Concept 1: ECPDC Information Portal</b>   | Roland Eils  |
| 14.45-15.10                                  | <b>Panel discussion</b> with relevant stakeholders   | STC + guests   |
|  | <ul style="list-style-type: none"> <li>• What is a good ECPDC? Where is the need highest?</li> <li>• How could KCC contribute to ECPDC and vice versa?</li> <li>• How could collaboration between different Cancer Information Services be deepened?</li> <li>• Why we use what is there.</li> </ul>   | Penilla Gunther/ Christine Chomienne (MOC Board)<br><br>Magdalena Stepien (KCC, DG JRC)<br><br>Susanne Weg-Remers (German Cancer Information Service)<br><br>Harald Wagener        |
| 15.10-15.15                                  | <b>BREAK</b>   |  |
| 15.15-15.35                                  | <b>Concept 2: ECPDC Personal Health Data Space</b>   | Harald Wagener   |
| 15.35-16.00                                  | <b>Panel discussion</b> with relevant stakeholders   | STC + guests   |
|  | <ul style="list-style-type: none"> <li>• Could ECPDC be foreseen as a use case of EHDS?</li> <li>• How could MyHealth@EU and HealthData@EU interact with data access and data management in ECPDC?</li> <li>• Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs) and EHDS: Why are they useful for patients / survivors? How do they fit together?</li> <li>• What features would a safe community space within ECPDC need to help mitigating social isolation and discrimination?</li> </ul> | Guillaume Byk (DG SANTE)<br><br>Guillaume Byk (DG SANTE), Zoltan Lantos (PATHeD / POTENTIAL)<br><br>Fabian Prasser (H2O), Jack Latteur (smartCARD)<br><br>Jack Latteur (smartCARD) |
| 16.00-16.05                                  | <b>BREAK</b>   |  |

| Time        | Talk   |   |
|-------------|--|---|
| 16.05-16.25 | <b>Concept 3: ECPDC Co-decision</b>  | Roland Eils   |
| 16.25-16.50 | <b>Panel discussion</b> with relevant stakeholders <ul style="list-style-type: none"> <li>• How to achieve patient agency?</li> <li>• Can we expect patients to making meaningful decisions on treatment? If no, what is missing?</li> <li>• Are researchers even prepared to explain their research to patients in a useful way? How can we help them?</li> <li>• How can we make sure that research results contribute to the ECPDC info portal in a timely manner?</li> </ul> | STC + guests<br><br>Gilliosa Spurrier-Bernard (PO)<br><br>Jan-Willem van de Loo (DG RTD)<br><br>Benedikt Westphalen (MOC Board)<br><br>Salvador Capella (EOSC4Cancer) |
| 16.50-17.00 | <b>Wrap-up</b>   | Roland Eils   |