



Co-funded by
the European Union

PIANOFORTE Partnership

European Partnership for Radiation Protection Research

Horizon-Euratom – 101061037

D3.9 - Conclusions from the Proton Therapy workshops

Towards a European database - strengthening cooperation and data exchange between proton therapy centres”

Lead Author: Pawel Olko (IFJ PAN)

With contributions from: Ana Vaniqui (SCK-CEN), Alexandru Dasu (SKANDION),
Juliette Thariat (Ucaen)

Reviewer(s): Members of the Executive Board

Work package / Task	WP3	T3.5
Deliverable nature:	Report	
Dissemination level: (Confidentiality)	Public	
Contractual delivery date:	Month 20 31 January 2024	
Actual delivery date:	Month 20 31 January 2024	
Version:	1.0	
Total number of pages:	18	
Keywords:	Proton Therapy, Database,	
Approved by the coordinator:	Month 20	
Submitted to EC by the coordinator:	Month 20	

Disclaimer:

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.

Abstract

A dedicated workshop entitled “Towards a European database - strengthening cooperation and data exchange between PT centres” was organized in Kraków on 14-15 November 2023. The idea of the workshop was to bring together representatives of the major European PT centres involved to exchange information on the national solutions of clinical data storage and to discuss perspectives of a common European PT database.

The workshop provided a forum to review the status and discuss the needs of data sharing in PT. All presentations and the following discussion confirmed that the improved collaboration leading to coordinated clinical trials and preparation of a European database would constitute an essential tool for verifying the efficacy of PT.

Table of Contents

1. Introduction.....	5
2. The National Perspectives	6
3. The European perspective: ESTRO- EPTN and international projects.....	9
4. Position paper on the “European database - cooperation and data exchange between proton therapy centres”	11
5. Conclusions of the Workshop.....	12
6. Annex.....	14
6.1 Program of the Workshop.....	14
6.2 List of participants	17

1. Introduction

In the last decade, there has been a significant increase in the number of proton therapy (PT) centres in Europe. In 2018, the European Investment Bank (EIB), which financed in the past four hadron/PT projects, received an extraordinary wave of initial requests for financing of new centres, which raised some concerns, in particular in terms of indications approved at national level, referral systems, reimbursement tariffs, treatment vs research, collaborations among bordering countries etc. It was realized that PT requires considerable resources such as intensive investments, expensive equipment, infrastructure and highly specialized personnel. In addition, geographical coverage of PT centres was non-uniform; as small countries had too few patients to justify their own centres but the access for patients from other countries (regions) was limited. As the costs associated with PT are higher in comparison to photon-based radiotherapy, the EIB has suggested an investigation on the efficacy of PT. This includes receiving guidelines on the needed support for investment in PT.

Following this suggestion, the DG for Health and Food Safety (DG Santé) initiated a discussion on the strategy for further investment in PT in Europe. Therefore, in 2018 a Subgroup on PT Centres was created in the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases. The group was established with participants from Member States, the European Commission, European Particle Therapy Network (EPTN) and the EIB to address key questions for future funding decisions. The mandate of the sub-group was to examine the current state of play of availability and use of PT centres across the European Union (EU) and to identify options through which willing member states can cooperate sustainably to improve information exchange and avoid duplication of effort. The group underlined the need for the improved study design, improved metrology, closer networking between centres and improved patient registries and databases, to increase the knowledge and evidence bases. However, given the current state of evidence, the group advocated pausing investment in PT until the need for/benefits of PT were confirmed.

In a next step, DG Santé asked to continue the discussion on these topics from a broader stakeholder perspective in the framework of the PIANOFORTE partnership for radiological protection, which started in June 2022. The first report with the review on recommended clinical and research practices in modern PT was discussed on December 14 2022 during the Pianoforte online meeting with DG Santé, EBI and DG Research. The main conclusion of the meeting was that further work within the PIANOFORTE project should focus on the evaluation of the conditions to organize a common European clinical database of patients treated with PT.

Based on this recommendation, a dedicated workshop entitled “Towards a European database - strengthening cooperation and data exchange between PT centres” was organized in Kraków on November 14/15 2023. The idea of the workshop was to bring together representatives of the major European PT centres involved to exchange information on the national solutions of clinical data storage and to discuss perspectives of a common European PT database. The workshop was conceived to fulfil subtask 3.5.2 of Pianoforte WP3 (Stakeholder engagement), with the goal of inviting speakers (within and outside the PIANOFORTE partnership) to discuss open questions from PT users. As gathering treatment data in a structured fashion was considered an important point to generate efficacy evidence, the workshop focused on strengthening cooperation and data exchange between PT centres towards a European database.

The following topics were propped for the presentations and discussion:

- What is the situation on data handling at your PT centre?
- What resources are needed (equipment, staff, organizational structure) to collect data at your centre?
- Is the cancer database (cancer register) at your country relevant for photon/PT inter-comparison?
- What is the country-based model for inter-comparison of photon and PT?
- What is an optimal photon/PT inter-comparison methodology? Is it cancer/technique dependent?
- What should be included in a minimal and a comprehensive dataset?
- How to standardize the definition of structures (nomenclature) in Europe?
- How to include the maturity of PT technology into a database?
- How to deal with the GDPR requirements when creating a database with clinical data? Who should do it? How to finance the European level database

2. The National Perspectives

The first day of the workshop was focused on presentations, whereas the second day was most mostly used for discussions.

Different PIANOFORTE members (J.C. Gariel - INFN, F. Rauser - BfS) stressed the need from the European Commission (EC) of understanding the benefits from PT. Moreover, they suggested that PIANOFORTE could support the field with funding opportunities through active calls throughout the partnership duration. P. Olko introduced the PIANOFORTE project and the background of the workshop.

The presentations moved towards the perspective from representatives of different European countries, i.e. Poland, Denmark, France, Belgium, Italy, Austria, Czech Republic, Switzerland, Sweden and Germany regarding how patient registries and databases are handled along with evidence from clinical trials.

Poland: Different Polish speakers (Renata Kopeć, Head of the Cyclotron Centre Bronowice at IFJ PAN Kraków, Tomasz Skóra, Head of Proton Therapy programme at National Institute of Oncology and Krzysztof Skłodowski, Director of the National Institute of Oncology at Gliwice) presented the national PT landscape. In Poland, protons have been used for ocular treatments since 2011 and from 2016 gantry-based treatments have been established. Nowadays about 50 patients per day are treated in Krakow using pencil-beam scanning (PBS) technology. A national list of approved PT indications mostly includes CNS, head-and-neck and brain tumours, sarcomas and lymphomas and 94% of the patient population is adult.

In Poland, the National Cancer Registry is a population-based medical register collecting data on the incidence of malignant tumours in Poland. The National Cancer Registry (KRN) is run by the National

Institute of Oncology on behalf of the Minister of Health, and the substantive supervision of the project is exercised by the Scientific Council composed by recognized experts. The tasks of the National Cancer Registry include collecting, updating and analysing data on diagnosed cases of malignant tumours in Poland necessary for the implementation of public tasks and public statistics. On their basis, the society's risk of cancer and the effectiveness of interventions in the field of public health and state health policy are assessed. However, there the database does not allow for comparing the effectiveness of radiation therapy techniques, in particular conventional (photon) and PT.

In Denmark (reported by Cai Grau), PT is performed exclusively at the Danish Proton Therapy Center (DCPT) in Aarhus. From 845 patients already treated with protons (status 1.07.2023) 650 (77%) had been included in 9 clinical proton intervention studies. These interventional studies are conducted for head and neck cancer (primary and recurrent), breast cancer, oesophageal cancer, thymoma, rectal cancer re-irradiation, anal cancer re-irradiation, prostate cancer, primary liver cancer and lung cancer (advanced stage NSCLC). The national model for collaboration is based on Danish Multidisciplinary Cancer Groups, responsible for guidelines and trials, Oncology departments responsible for selection and referral and DCPT, performing PT.

One of international clinical studies coordinated in Aarhus is the PROTECT trial (PROton versus photon radiation Therapy for Esophageal Cancer in a Trimodality strategy, website: protecttrial.eu). It is a multicentre international randomized phase III study of neoadjuvant proton based chemoradiotherapy in locally advanced oesophageal cancer looking for evidence of proton effectiveness in comparison to photon therapy.

In France (reported by Juliette Thariat and Neige Journy) PT is performed in Nice, Orsay and Caen. There are limited possibilities for clinical trials due to the lack of funding but French centres can participate in international trials. The treatment of paediatric patients is the national priority. As a PT resource, the [ProtonShare website](#) enables the establishment of the demand for PT and consequently it helps determining if there is a need for the construction of new PT centres. Although no common database exists, local databases are available, e.g. HARMONIC project in Gustave Roussy and Caen or the private database of Caen.

In Italy (reported by Ester Orlandi), at the National Centre of Oncological Hadron Therapy (CNAO) a model-based approach for patient selection is under development. The REGAL (REGistry TriAL, NCT05203250) database for open-ended prospective and retrospective collection of real-world data has been established for supporting particle radiotherapy and generating evidence. The database uses the standardized oncological semantics (ICD-0, ICD-10, etc.) and follows EU regulations for observational studies. REGAL complies with anonymization and GDPR rules and it adheres to International Conference on Harmonisation of Good Clinical Practice standards. The database does not collect any personal identifiers and patient data is pseudonymized. CNAO also uses databases from the European Reference Network EURACAN, Italian Registry on Head and Neck Carcinoma (AIOCC) and Heavy Ion Therapy Research Integration (HITR). CNAO and the European Institute of Oncology in Milan plan to prepare a common database for proton patients in Italy – the Multicentre Proton Registry.

In Austria (reported by Carola Luetgendorf-Caucig), treatment reimbursement is case-based and there is no reimbursement for randomized clinical trials. There is not a national register for radiotherapy outcome. In Austria, it is particularly difficult to obtain information about a patient's death because there is no obligation to forward such information to the clinic that provided treatment. MedAustron has a dedicated office that handles databases and maintains the MedAustron register. There is an ongoing study based on the MedAustron Register focused on effectiveness and safety (NCT03049072).

In Czech Republic (reported by Pavel Vitek), a private PT centre in Prague has already treated over 10k patients. However, there are no patients currently subscribed in clinical trials. The results of treatment, particularly for prostate, Hodgkin lymphoma, H&N and anal cancer have been submitted to retrospective data analysis for efficacy and toxicity.

In Belgium (reported by Karin Haustermans), the PT data is stored in a national database that is linked to the patient's social security number and to the cancer registry. Although Belgium has a very well-established database, there are several issues with the list of indications for PT and treatment reimbursement. The current Belgian system does not allow participation in PT clinical trials.

In Sweden (reported by Alexandru Dasu), the Information Network for Cancer cAre (INCA) is available. This database is based on four pillars:

- a standardized national naming convention for RT structures to facilitate consistency in collected data. It is partly based on terminology from ICRU reports.
- a database solution for local storage of RT data to meet the requirements of automated data collection from TPSs/OISs on the national scale (Medical Information Quality Archive; MIQA). The MIQ was implemented to 17 oncological clinics around Sweden;
- a dedicated RT database (SKvaRT - Svenskt Kvalitetsregister för stRålTerapi) on the INCA platform, hosting most of the Swedish clinical cancer registers;
- a service for export of aggregated information including descriptors of structure doses and volumes from MIQA into the RT database on INCA (MIQA2INCA).

Proton treatment plans are handled by MIQA. PT dose objects, i.e. physical or RBE-weighted doses, require specific considerations for additional data that does not account for other parameters than dose. Several points still need to be addressed such as GDPR perspectives on data processing and transfer, responsibility for data in a distributed competence and workflow model and handling of treatment adaptation.

In the Netherlands (reported by Rianne Fijten) the ProTRAIT database (website: protraitinfra.github.io) has been structured to receive the data from the three different proton centres in a standardized fashion and allow for inter-comparisons. Selection of patients is based on Normal Tissue Complication Probability NTCP models ([J. Langendijk et al., 2013](#)) for six types of cancer: breast, lung, H&N, CNS, lymphoma and prostate. At present (Nov. 2023) circa 1500 patients were introduced into the database at the PT centre of Maastric Clinic. At this stage, ProTRAIT seems to be the most advanced database system linking several PT centres.

3. The European perspective: ESTRO- EPTN and international projects

ESTRO and the collaborating EPTN (reported by Cai Grau and Damien Weber) are the major promoters for a pan-European PT database and for the development of a European perspective on the sector. EPTN was established in 2015 as a Task Force of ESTRO to improve clinical evidence, quality assurance, education, image guidance, treatment planning, radiobiology and health economy in particle therapy. The mission of EPTN is to promote collaboration, and to ensure that particle therapy becomes integrated in the overall radiation oncology community.

One of the important tasks of EPTN is to support PT clinical trials. In a 2018 publication ([J. Langendijk et al. 2018](#)), the EPTN Working Package (WP) 1 summarizes the arguments for PT prospective data collection. The data collection should provide essential information on patient composition and treatment outcome, create a basis to discuss and harmonize the selection criteria for particle therapy and accelerate the evaluation of particle therapy efficacy in well-defined patient populations. Emphasis should be put on performing high quality trials with properly selected candidates and using relevant, validated clinical endpoints. A database would be particularly useful for proving efficacy PT for treating relatively rare tumours, such as base of skull tumours and paediatric malignancies. It can also help generate hypotheses for future clinical trials. In 2023, 31 proton interventional trials recruiting patients in Europe were active, out of which 20 were phase II and 11 phase III trials. The trials were performed in seven European countries, most of them in Germany and Denmark.

As stated at the introduction to this report, in 2018, a subgroup on PT centres was established with participants from Member States, the European Commission, EPTN and the EIB to address key questions for future funding decisions on PT. After an on-line meeting in October 2020, the group recommended the need for an EU PT patients registry, better data sharing and R&D collaboration among the existing PT centres. Addressing the identified issues will require an obligation to store and share data on the clinical outcomes of PT in an EU repository, but also to store and share data on conventional photon-based radiotherapy to have the possibility to compare the two.

In 2021, between January and March, EPTN performed interviews with nine European PT centres (PSI from Switzerland, DCPT from Denmark, The Christie from Manchester UK, Skandionkliniken from Sweden, CNAO from Italy, KUL-UCL from Belgium, UMCG from the Netherlands, OncoRay from Germany, Centre Léon-Bérard from France) with the objective to sense their participation in a pan-European data registry. The centres were chosen based on their geographic distribution and the magnitude of their clinical activities involvement in European networks (e.g. ESTRO, EORTC). All the centres agreed to share clinical data. However, automatic data transfer was not possible due to legal and ethical issues in different countries. A need of automatic data translation between the databases was identified.

One of the initiatives of ESTRO-EPTN (WP1) was to establish the ParticleCare (EORTC 1833-RP) cohort study with an objective to establish a uniform prospective data registration program for all patients treated with particle therapy in Europe. This is a model-based approach, open for all particle therapy

centres in Europe, collects data on primary tumours of H&N, CNS, lung, breast, prostate and oesophagus.

The other initiative of ESTRO-EORTC is the E2-RADiate (EORTC 1811, website: project.eortc.org/e2-radiate) database platform and the associated research protocol. It allows accruing patients with different tumours in open-ended prospective non-interventional non-therapeutic cohort studies. The database includes the recording of generic information, e.g., tumour site, tumour type, stage, previous cancer treatment, as well as specific data, e.g., radiation dose, acute and late toxicity, outcome data, and possible dosimetric data for various tumours. Data transfer tests to this database were successfully performed in few European PT centres.

KAYAC project (reported by Esther Troost). Recently, a new WP (EPTN WP8, led by Esther Troost) has been created to deal with data registration. In the summer of 2023, a proposal was submitted to the first PIANOFORTE funding call for collecting data across several centres (in Dresden - Germany, Aarhus - Denmark, Lyon - France, Pavia - Italy, Krakow - Poland, Leuven - Belgium, Barcelona - Spain, Groningen - The Netherlands, Uppsala - Sweden, Villigen - Switzerland) and generate knowledge on adolescent and young adult cancers (project KAYAC). The project aims to use the structure of the Dutch ProTRAIT database to collect treatment and follow-up data for outcome studies, including secondary cancers and side effects. Unfortunately, this initiative was not funded. Although some initiatives have been successful, the major hurdles are related to cost, as an investment of 0.5 full time equivalent (FTE) is expected for building and maintaining databases, and GDPR regulations that vary on a country basis.

The Harmonic project (reported by Neige Journy) was mentioned as a successful initiative, which generates evidence on paediatric medical exposures through an international data registry. The aim of HARMONIC (website: harmonicproject.eu) was to develop an infrastructure and conduct the pilot phase of a European registry (complemented by a biobank) of children, adolescents and young adults treated with modern radiotherapy techniques, and evaluate late outcomes.

The goal of the created database was to collect important factors for the investigation of late effects, minimize the requested overall information (scientific purposes, ethical requirement), collect data usually available in routine, make use of local IT systems as much as possible, develop Electronic Case Report Forms (eCRFs) and define variables to allow comparisons, data pooling and further collaborations, avoid efforts for re-coding at the centre level (e.g. cancer staging), and standardize units of quantitative parameters.

The Harmonic database is based on the EPTN guidelines for prospective data registration. It is connected to the national cancer registries and allows for international cohort studies. The database was built using Research Electronic Data Capture (REDCap) free software, which is a secure web application for building and managing online surveys and databases. The database considers patient registration and follow-up, clinical and socio-economic data, general health information and risk factors, etc. For retrospective inclusion, late morbidity and late mortality were placed in the registry, whereas for prospective inclusion biological markers and imaging markers were included. 1770 patients aged 0-21 were included in the study. The database is connected to OncoPlace, where pseudo-anonymized DICOM elements are stored.

The HARMONIC database assures interoperability with the existing databases such as EPTN clinical database (prospective data registration for the most important indications for PT), U.S. Paediatric Proton/Photon Consortium Study (PPCR), National cancer registries, National, European cohort studies on late effects of paediatric cancer treatment (e.g. PancareSurfUp). For its establishment, ethical approval was required in all countries and a specific consent was required for secondary data usage. A data sharing agreement was signed by all parties and differential access to the database was foreseen according to user status. This database structure is ready for dissemination and distribution to other PT centres.

4. Position paper on the “European database - cooperation and data exchange between proton therapy centres”

An important point of discussion and conclusion from the Workshop discussion was the need for a position paper aimed at summarizing the status of activities for preparation of a European PT database. The following topics were discussed and will be addressed in this paper:

1. Role of data registries in evidence generation for PT

- Phase II, III, IV methodologies for photon vs. proton inter-comparison (model-based approaches, etc.);
- Use cases and perspectives/rationale for a pan-European data registry (including indications not covered by ongoing phase II-III);
- DG Santé-EIB conclusions about networking, bridge knowledge gaps and databases.

2. Defining clinical datasets in a future European prospective data registry

- Update of the EPTN clinical dataset definitions.

3. Existing data sources and collaborative solutions

- Local and national registries, including imaging and treatment information (examples from the workshop, e.g. ProTRAIT);
- Relationship with existing registries e.g. cancer registries, HARMONIC, ASTRO database.

4. Nomenclature, treatment techniques, imaging, RBE in a future European prospective data registry

- Common nomenclature for definition of structures (standardization).
- Capture of treatment planning and technology information into database (e.g. EORTC,...).

5. Regulatory and governance issues

- Federated vs. central database model;
- How to deal with the GDPR requirements, when creating a database with clinical data;
- How to share data across institution and borders (data sharing agreement etc.);

- Governance of data registry;
- Collaborative relations, stakeholders PIANOFORTE – EPTN – EU;
- Costs and financing of a data registry.

The group will work on the initial draft of the paper and meet on January 15 and February 2nd to present and discuss the status.

5. Conclusions of the Workshop

The workshop provided a forum to review the status and discuss the needs of data sharing in PT. All presentations and the following discussion confirmed that the improved collaboration leading to coordinated clinical trials and preparation of a European database would constitute an essential tool for verifying the efficacy of PT.

EPTN has been involved in coordination of clinical studies in PT since the beginning of their activities in 2015. There is a need to develop, test and validate the methodologies (guidelines) for clinical trials. Model-based selection (as predictive biomarker) is a useful concept for NTCP based studies, and this concept should later be extended to incorporate also Tumour Control probability TCP. European guidelines could facilitate it and could follow the example of ASTRO guidelines – the number of indications has been ramping up in the USA.

The initiative of ESTRO/EPTN for an EU database has been already green-stamped by the EU DG Santé-EIB. The existing examples of databases, which merge clinical data from the different PT centres, are encouraging. The HARMONIC database for children, adolescents and young adults treated with modern radiotherapy techniques is operational and demonstrated interoperability with the existing databases. Considering the information shared by the HARMONIC participants from over ten countries, it became clear that local and national initiatives exist but a European organization is lacking. The ProTRAIT database, developed to merge results of PT centres in the Netherlands is functional and allows for the automation of data transfer (collection). The structure of ProTRAIT allows for its use with machine learning purposes which can further increase functionality of such projects. Extending the database to other centres is more a legal and financial problem rather than a technical one. Also, in other EU Member States national/local PT databases are well advanced e.g. in Italy, Sweden and Belgium.

Several issues were identified which have to be addressed in the development of an EU database for PT. Two of them seems to constitute the major problems:

- **Funding mechanisms** for development and maintenance an EU database are currently lacking. Dedicated, highly qualified personnel is needed at each PT centre to assure regular update. At the level of individual clinics, there are no dedicated personnel and funding to maintain the database.
- **Legal issues** are probably the most difficult problem. Introducing the European General Data Protection Regulation (GDPR, 2016) additionally complicated situation, partly due to different

implementations of the directive in EU Member States. This should be solved at the European level.

Other conclusions:

- **Technical issues** (data transfer) in most cases can be nowadays easily tackled. It was shown that the cost free software (e.g. Research Electronic Data Capture, REDCap) was useful for development of clinical databases. The challenge is an automation of data translation from one database to another.
- **Vendors** producing Treatment Planning Systems and Oncology Information Systems can introduce software options to facilitate export of selected data to the database. This would be possible if such an export option is specified in international/national regulations (recommendations).
- Results of the treatment may also constitute a valuable scientific and commercial result. Therefore clinics could not be interested in sharing the data. In some cases, a PT centre would not be interested in publishing their results which may show a "suboptimal" treatment of the patient.

6. Annex

6.1 Program of the Workshop

Pianoforte Workshop: Towards a European database - strengthening cooperation and data exchange between proton therapy centres

Date: 13 November 2023 (14:00) – 14 November (13:00)

Venue: Seminar room of the Cyclotron Centre Bronowice, Institute of Nuclear Physics Polish Academy of Sciences, Radzikowskiego 152, Kraków, Poland

Link on-line

Time: 13 Nov. 2023 02:00 PM - 06:30 PM

14 Nov. 2023 08:45 AM – 01:00 PM

Join here: <https://zoom.us/j/98964213631?pwd=N1Z0dmN1SUJhY3JkZU5JNSs0Tmludz09>

Meeting identifier: 989 6421 3631

Access code: 988160

Program

13 November. 2023			
13:00-14:00	Working lunch		
14:00- 14:01	Tadeusz Lesiak,	Director General IFJ PAN	Welcome address
14:01 - 14:10	Renata Kopec	Head of the Cyclotron Centre Bronowice	Cyclotron Centre Bronowice – the first Polish PT center
14:10- 14:20	Tomasz Skóra	Head of Proton Therapy programme at NIO, Kraków	Clinical activities at the CCB
14:20 - 14:25	Jean Christopher Gariel	Deputy Director General IRNS, Pianoforte coordinator	Welcome at the Pianoforte project –(on-line)

14:25- 14:30	Florian Rauser	Deputy Director Bundesamt fuer Strahlenschutz	Towards the Pianoforte stakeholders (on-line)
14:30 –14:40	Pawel Olko	Head of the Division of the Applications of Physics, IFJ PAN	Why proton therapy in Pianoforte – the background of the Workshop
14:40 - 15:00	Cai Grau	Head of research, The Danish Centre for Particle Therapy	Building clinical evidence of proton therapy – the perspective of clinician and the Danish experience
15:00-15:15	Juliette Thariat	Professor in Radiation Oncology at Centre Baclesse/ ARCHADE	Situation in France (on-line)
15:15-15:30	Neige Journy	French Institute of Health and Medical Research	Establishing a European registry to assess late outcomes of advances in radiotherapy for paediatric cancers: the HARMONIC-RT project
15:30- 15:45	Coffee break		
15:45-16:00	Krzysztof Skłodowski	Director of the National Institute of Oncology, Gliwice	The organisation and infrastructure of radiotherapy in Poland
16:00 16:15	Karin Haustermans	Medical director Proton Therapy, PARTICLE – Particle Therapy Interuniversity Center Leuven, Belgium	Cooperation and data exchange between proton therapy centres: Belgium in Europe (on-line)
16:15 –16:30	Ester Orlandi	Head of the Clinical Department CNAO	Current status of particle therapy in Italy, approaches for collecting patient data and clinical and research networking (on-line)
16:30- 16:45	Carola Luetgendorf-Caucig	Clinical director radiooncology MedAustron	Particle therapy in Austria – databases of clinical data (on-line)

16:45 – 17:00	Pavel Vitek	Radiation oncologist, Prague PTC	PTC Prague – ten years, thousands of patients and reasonable data collection and assessment
17:00- 17:15	Alexandru Dasu	Chief Medical Physicist at the Skandion Clinic, Uppsala	National Radiotherapy Register in Sweden Miqa– the perspective of medical physicist
17:15-17:30	Rianne Fijten	Assistant Professor Clinical Data Science Maastricht University / Maastro Clinic	The ProTRAIT (PROton Therapy ReseArch regIsTry) project (on-line)
17:30-18:00	Discussion: Alexandru Dasu		
19:30	Working dinner		
14 November 2023			
8:45-9:15	Esther Troost	Co-Chair of Department of Radiotherapy and Radiation Oncology of University Hospital Carl Gustav Carus Dresden	The ongoing European Particle Therapy Network efforts to create a data registry and KAYAC - how to gather evidence on proton therapy in the lively radiotherapy environment" (on-line)
9:15 -9:30	Damien Weber	Head and Chairman Radiation Oncologists PSI Villingen	ESTRO-EORTC- EPTN ParticleCare experience : lessons for the future
9:30-10:00	Brainstorm the outline of the position paper (moderator Cai Grau)		
10:0 –12:30	Coffee and breakout sessions in smaller groups, work on the sections of the paper		
12:30-13:00	Plenary session, wrap up		
13:00	Working lunch		

6.2 List of participants

No	Name	Institution
1	Daniela Alterio	European Institute of Oncology, Milan (IT)
2	Agnieszka Chalaszczyk	CNAO - National Center for Oncological Hadrontherapy (IT)
3	Alexandru Dasu	Skandion Kliniken (SE)
4	Katarzyna Drosik-Rutowicz	National Institute of Oncology, Gliwice (PL)
5	Rianne Fijten	Maastrro Clinic (NL)
6	Jean-Christophe Gariel	IRSN (FR)
7	Tiziana Golme	CNAO - National Center for Oncological Hadrontherapy (IT)
8	Cai Grau	Danish Center for Particle Therapy (DK)
9	Leszek Grzanka	Institute of Nuclear Physics PAN (PL)
10	Karin Haustermans	UZ Leuven, KU Leuven (BE)
11	Barbara Alicja Jereczek-Fossa	European Institute of Oncology, Milan (IT)
12	Neige Journy	Inserm (FR)
13	Renata Kopeć	Institute of Nuclear Physics PAN (PL)
14	Dawid Krzempek	Institute of Nuclear Physics PAN (PL)
15	Carola Lütgendorf-Caucig	MedAustron Ion Therapy Center (AT)
16	Paweł Olko	Institute of Nuclear Physics PAN (PL)
17	Ester Orlandi	CNAO - National Center for Oncological Hadrontherapy (IT)
18	Maciej Pelak	MedAustron Ion Therapy Center (AT)
19	Paweł Polanowski	National Institute of Oncology, Gliwice (PL)

20	Florian Rauser	Bundesamt für Strahlenschutz (DE)
21	Antoni Rucinski	Institute of Nuclear Physics PAN (PL)
22	Krzysztof Składowski	National Institute of Oncology, Gliwice (PL)
23	Tomasz Skóra	National Institute of Oncology, Kraków (PL)
24	Juliette Thariat	Centre Baclesse - Cyclhad - LPC Caen IN2P3 CNRS (FR)
25	Filip Vanhavere	SCKCEN, KULeuven (BE)
26	Ana Vaniqui	SCK CEN (BE)
27	Pavel Vitek	Proton Therapy Center Czech, Prague (CZ)
28	Damien Charles Weber	Paul Scherrer Institute, Villingen (CH)