Important event in international ophthalmooncology

There is much that we can make together
and cannot accomplish on our own
Paul T Finger

A wide range of new methods for diagnostics and treatment, which are to be assessed clinically, are often performed simultaneously and independently of each other. As a result, the data existed already are duplicated since scientists neither acquainted with them nor have access to them. Besides, a lot of top specialists believe that investigations made in a separate centre are vulnerable due to systematic choice bias, and poor quality of both data harvesting and analysis. At the same time, a great amount of data harvested in the multicentre reduces the effect of choice bias and provides more heterogeneous data. Recently, both in Europe (e.g. EVICR.net) and America (e.g. COMS, *A Multicenter International Study*[1-2]), testing diagnostics and treatment methods by separate centers has been performed as part of the multicenter, managing and scientific requirements of which are concrete and severe.

Experience of multicenter investigations enabled to discuss the practicability and possibility of such investigations in the field of ophthalmic oncology at the one day meeting on the 15th of June 2015. The event called "The First Eye Cancer Working Day" with slogans "Working Together" and "Outreach, Fellowship, Collaboration, Education" was organized and funded by The Eye Cancer Foundation, The Curie Institute and The American Joint Committee on Cancer.

The meeting consisted of 6 sessions performing 39 oral presentations, 5 minutes each. Every session was concluded by discussion 20-30 min long.

Section 1: Multi-Center, International Studies, AJCC Validation, Registries, comprised 8 presentations:

1. The Power of Registries, *E. Rand Simpson, Canada*
2. The Uveal Melanoma Registry First Results, *Svetlana Saakyan*
3. Retinoblastoma Registry Update, *Brenda Gallie*
4. Ocular Adnexal Lymphoma Registries, *Steffen Heegaard*
5. Vitreoretinal Lymphoma Registry Update, *Sarah Coupland*
6. Eyelid Carcinoma - Lacrimal Gland Carcinoma Registries, *Bita Esmaeli*
7. A Metastatic Uveal Melanoma Registry, *Anna Pavlick*

The first of them determined entirely the purpose and tasks of the event. A presenter ***E. Rand Simpson (Canada)*** has pointed the main advantages of multicenter eye cancer registration program which *"..enables to determine cancer patient populations, measures outcomes of treatment and survival, and formulates plans for improvement"*.

He introduced the following *project approach* to be discussed:

- Staging Systems should function as "common language" to collect patient data;
- Eye tumour specific electronic medical records will facilitate multicenter data collection;
- Statistically significant outcomes will be used to allocate resources to improve patient care;
- Data bases for rare tumours are substantially empowered by multicenter participation (More powerful analysis over shorter time interval -10 centers with 40 patients per year provides 1000 cases in 2.5 years);
- Multiple institution experience and management policies captured,

Important terms and conditions were also presented:

- A Universal Staging System for Eye Cancer Required (OOTF was to provide anatomically based staging system
- (TNM) and practice guidelines for clinical data collection, including pathology);
- Evidence-based genetic and molecular biomarkers were to be included

The presenter E. Rand Simpson (Canada) named ***current databases*** (***DB)*** - Uveal Melanoma, Retinoblastoma, Conjunctival Melanoma, Vitreoretinal Lymphoma, Ocular Adnexal Lymphoma, Lacrimal Gland Carcinoma, Eyelid Carcinoma and ***possible DB****** - Conjunctival Carcinoma*, Orbital Sarcoma*.

Svetlana Saakyan, (Russia) has reported the results of international multicentre collaboration (10 centers, 4 continents) in a program for assessing different stage uveal melanoma (UM) patient mortality rate on the basis of general DB, including clinical and morphological data of 3 809 patients. It has been concluded that:

- This study validated the 7th Edition AJCC Staging for Ciliary Body and Choroidal Melanoma;
- There was a statistically significant increased risk of metastasis for each increased T-stage, Anatomic/Prognostic Stage as well as presence of CBI and EXE;
- Multicenter worldwide, internet-based data sharing is feasible in ophthalmic oncology;
- Decreases the impact of single-center selection bias by providing a more heterogeneous (robust) patient population;
- What's Next???

Brenda Gallie (Canada) has demonstrated the successful results when TNM classification is used in the analysis of clinical performance and treatment outcomes in retinoblastoma according to the combined DB from 6 centers. A World "registry" from bedside to a learning health system has been reported to be reasonable.

Steffen Heegaard (Denmark) and 13 co-authors have presented data on clinical, pathomorphological and immune histochemical features, on the treatment and its results according to the TNM classification of combined DB for adnexa oculi lymphoma (7 centers and 4 continents). They concluded that:

- Highly recommendable to perform multicenter studies
- Hard work !!
- Define early what information you need from the collaborators
- High scientific impact
- High scientific production – provide spin offs

Sarah Coupland (England) has presented *"Vitreoretinal lymphoma and the TNM staging system: can we create a TNM staging system for this tumor?"* and pointed the difficulty of lymphoma differentiation and different treatments due to various subtypes causing the problems in DB forming.

Bertil Damato (UCSF USA) has presented *"Conjunctival Melanoma Registry Update"*, and introduced carefully developed and periodically improved DB for conjunctiva melanoma with details about clinics, treatment and follow up. A topographic scheme of TNM tumor location has been also demonstrated.

Bita Esmaeli (M.D. Anderson Cancer Center Houston, Texas USA) has reported on the collaborative investigation of orbit oncology at 10 academic centers on the interinstitutional DB of American Society of Plastic and Reconstructive Surgery (ASOPRS), put on the secure server MD Anderson Cancer Center. Since October 2014, 692 patients have been included into the DB and conclusions as follows have been made:

- 7th edition of AJCC used as basis to capture data on tumors of eyelid, orbit, conjunctiva, and intraocular tumors;
- Once database populated, various study questions can be explored;
- Need a common "protocol" to gather and disseminate information; particularly for rare cancers;
- Multi-institutional studies add to our knowledge base;
- The "universal" protocol for the database has to be IRB-approved at every participating institution;
- Data share agreements must be in place with each participating center;
- Security check on server.

Anna C. Pavlick, (NYU Cancer Center Clinical Trials Office, USA) has had a presentation *"Metastatic Uveal Melanoma: A Prospective Tumor Registry"*. She has pointed the relatively low incidence of this ocular cancer and, thus, large combined BDs and investigations as the single response to disease and its result. It is especially important since such patients, as a rule, are excluded from the investigations of skin melanoma, and ophthalmologists are rare informed of such cases. Thus, tasks are:

- Understand biology: Why liver, bone, skin, lungs?
- Little natural history information:

Determine patterns of metastasis and progression;
Determine relative efficacy of methods for detection;
Record and publish the results of failed treatments;

- Lack of clinical trials;
- Fast Data Acquisition = Survival 6-18 months.

Probable approaches are:

- Open multicenter, international model;
- Scale of information will be determined;
- Database fields will be generated by consensus;
- Online forms will be approved by the group;
- Informed consent and privacy templates will be distributed to participants for editing to satisfy institutional requirements.

The main conclusion is that DB demands efforts, but it is the only way to achieve the high statistically significant quality of this cancer medical finding.

The session was ended by 20 min discussion on issues:

- Other possible registries?
- Standards for data collection, privacy?
- Qualifications for who enters the data, centers?
- Writing, internal peer-review and authorship?
- Cost, funding, can all the eye cancer foundations help?
- Retrospective to prospective, are we ready yet?

The discussion confirmed the interest of participants in widening and most qualified performance of such projects.

Section 2: "Radiation Side Effects Staging" consisted of presentations as follows:

1. Why Stage Radiation Side Effects, *Wolfgang Sauerwein*
2. Lids, Conjunctiva, Limbus and Cornea, *Henrike Westekemper*
3. Staging Radiation Cataract, *Jens Kiilgaard*
4. Radiation induced Neovascular Glaucoma, *Carlo Mosci*
5. Posterior Segment Radiation Complications, *Norbert Bornfeld*
6. Maximal Tolerated Doses to Ocular Structures, *Lawrence Tena*
7. Specific Side Effects After Radiotherapy in Children, *Remi Dendale*

Wolfgang Sauerwein (Германия) has demonstrated the necessity of determining the stages of irradiation side effects on the basis of deep analysis of radiotherapy physical factors.

Why:

- Radiotherapy plays an important role in ophthalmic oncology but there are some challenges in ophthalmic tumors radiotheraphy;
- It's application is an interdisciplinary challenge;
- Different modalities are available, leading to different dose distributions;
- Very often at one center only one technique;
- A common language for reporting does not exist;
- Very small treatment volume;
- Absolute dosimetry difficult/not done;
- Very close to important functional structures;
- Treated in (few) dedicated centers, which have a different equipment.

What for: how to select the optimal radiation technique?

- The possibility of a choice between different treatment modalities has not been sufficiently investigated;
- Published literature does not give any advice to answer the question: what is the best solution for an individual patient
- All authors report excellent tumor control (and good functional outcome);
- Any optimization of ophthalmic radiotherapy has to focus on side effects;
- Side effects and damage to normal structures are often not mentioned;
- In contrast to other anatomical sites, a standardized reporting system of side effects after ophthalmic radiotherapy does not exist.

To sum up, "a standardized reporting of side effects is overdue".

The author has supported the project of the ISOO (International Society of Ocular Oncology) to create ***The Radiation Side Effect Staging*** (active members are Norbert Bornfeld, Ямі Dendale, Jens Kiilgaard, Carlo Mosci, Clare Stannard, Lawrence Tena, Henrike Westekemper).

Lawrence B. Tena (Israel-USA) has reported the relevance of studying radiation side effects:

- Early vs. Late effects;
- Modulators of Radiation Effects: Total dose, Fraction size, Duration of time, Dose rate, Specific organ, Volume.

Analyzing the data of the six significant papers there has been noted the success in minimizing radiation side effects, the prospects of use of possible complication models in healthy tissues in clinics and concluded:

- Ocular structures inherently have different maximum dose tolerances to radiation;
- Dependent on total dose, fraction size, time, dose rate, and volume;
- Minimize late effects - Protons, IMRT, VMAT, electrons, SRS, brachytherapy, 3DCRT

Jens Folke Kiilgaard (University of Copenhagen), in his paper *"Staging radiation cataract – A complex and challenging task"* and on the basis of analysis of 9 significant papers (2000-2015) and his own observations, has demonstrated the development of cataracts and vision acuity in dynamics and depending on the radiation type (A-bomb, Proton beam, Ruthenium-106, Iodine-125) as well as made an effort to stage this process. The conclusion was made in questions which require answers:

- Cataract formation is multifactorial - Can the individual effect be isolated?
- Ionizing radiation causes cataract in a dose dependent fashion - Can the treatments be optimized?
- Systems for cataract grading is available - Can the systems be used to differentiate cataracts?
- Surgery:

1. VA vs Clinical follow up?
2. Is radiation a complicating factor?

Carlo Mosci (Italy) has presented an original discussion presentation *"Radiation induced neovascular glaucoma"*, the purpose of which was not a discussion of preventive methods and treatment for neovascular glaucoma, but the analysis of its incidence after radiation (Double face of the same coin: efficacy - damage), especially uncontrolled in small tumors. The presenter has also specified risk factors for neovascular glaucoma (tumor size, proximity to the optic disc/macula, uveal involment anterior to the equator, presence of serous retinal detachment) and its aetiopathogenesis:

- angiogenic factors secreted because tumor and or radiation – induced inflammation
- retinal ischemia following serous retinal detachment or retinal tumor invasion

According to the data of The Collaborative Ocular Melanoma Study (COMS) that survival rates are similar not depending on the treatment method, the presenter has concluded that:

- Is it possible a screening to treat smaller intraocular tumors?
- Do we have to review our indication of radiotherapy treatment?

The notes on specialized therapy:

- Following the needs, wishes, fears and personal situation of the patient
- Ocular melanoma could give an important visual and aestethic handicap (enucleation).

The presentations were followed by 20 min discussion on issues:

- Should staging be purely based on anatomic changes or eye function?
- Separating brachytherapy from teletherapy for staging?
- Betas, gammas, protons, electrons – should they be treated differently?
- How to stage radiation cataract, location, visual acuity, contrast sensitivity?
- Staging iris neovascularization or just neovascular glaucoma?

- Staging radiation retinopathy, papillopathy and optic neuropathy?
- Formation of committees and a road map

The participants agreed with the necessity to solve these problems as well as with the possibility for their realization at adequate time terms only in the conditions of multicenter collaboration.

Section 3: Doctor Reported Outcomes (DRO) Project.

1. Why Should We Periodically Report Our Outcomes? Tero Kivela
2. Is Peer Review Publication Reporting Good Enough? Stefan Seregard
3. The Risks and Benefits of Open Access Reporting, Bertil Damato
4. The Risks and Benefits of Closed Access Reporting, Santosh Honavar
5. Data collection and patient privacy, Carol Shields

Tero Kiveld, (Finland) in his report *"Why Should We Periodically Report Our Outcomes?"* has presented his own design for the basis and structure for reporting outcomes:

- Record outcomes - To create a tumor registry for your service;
- Analyze outcomes - To transfer data to a statistical program to get an overview;
- Report outcomes - To publish the data or upload them in a repository;
- Benchmark outcomes - To compare with other publications or with peers.

A repository of meaningful, comparable outcome data stratified by main tumor charateristics and treatment type. The author believes that the difficulty is that at the initial stage there appears additional working stress, which should be minimized. However, the time spent on data loading is compensated by easy search.

The author has pointed that *"..anonymized open access to participants and in part to outside peers allows comparison of own outcomes against an international standard"*.

The problems that may occur when creating such registers:

- Finding the extra time needed
- Maintaining confidentiality
- Achieving standardization
- Balancing simplicity vs applicability
- Maintaing commitment

Bertil Damato (UCSF, USA) in his presentation *"The Risks and Benefits of Open Access Reporting"*, has pointed the certain risks in case of open access common DB when data are loaded by unskilled physicians:

- Poor data - inaccurate/incomplete information
- Lack of patient consent, ethical approval, security
- Problems exporting/transferring incompatible data
- Insufficient 'bandwidth' to populate multicenter registry
- Loss of patient/doctor/institution confidentiality
- Improper use of shared data

The author has presented the main data (team, principles) of two registers: AREV, a computer register of Liverpool Ocular Oncology Centre (LOOC) and APEX, a register of University of California, San Francisco, which have the common purpose to simplify clinical, investigational and administrative work. The difference is that in AREV register, managers load the data from the paper forms, while in APEX register they only control the completeness and quality of loading.

The presenter sees the proper use of the data in:

- Contractual arrangements before release of data
- Regulation by host organization
- Inter-society cooperation

He believes that it is possible to avoid the risks following the number of conditions:

- Patient consent and ethical committee approval must be obtained before collecting data.
- Patient and doctor confidentiality must be protected.
- Computers and memory devices must be secure.
- Data must be collected concurrently and must be used for clinical care, administration and research.
- Data managers are needed to ensure that database is complete and correct.
- Data export/transfer must be fully or semi-automated.
- Use of shared data must be regulated by host organizations

Santosh G Honavar, (Hyderabad, India) in his report *"The Risks of Keeping Outcomes Secret"* has demonstrated a dilemma of "wide-ranging practices " or "open access to no access!".

The types of wide openness of outcomes have been proposed:

- Internal audit;
- External audit;
- Podium presentations/posters;
- Non-peer reviewed publications/reviews;
- Peer-reviewed publications;
- Open-access peer-reviewed publications;
- Open access reports,

and Health Care Accountability:

- All the stake-holders;
- Patients;
- Department;
- Hospital;
- Funding sources;
- Society at large;
- Peers.

The author has presented the negative sides of keeping outcomes secret:

- Outcomes – one of the critical parameters to judge quality against established benchmarks;
- Most established management protocols and surgical procedures should be comparable to the benchmark;

- Sunrise technologies and treatments under trial may not have benchmarks to control but still can be;
- Compared with the existing standard of care;
- Rare diseases,

... as well as examined the risks of keeping outcomes secret:

- Suspect quality;
- Poor accountability to stakeholders;
- Patients no scope to exercise choice;
- No scope to compare, analyze, change and improve;
- Loss of trust,

... and following possible barriers: "lost time and resources; outdated technology; and mindset - status-quo and dubious intent".

Stefan Seregard (Sweden) in his presentation *"Is Peer Review Publication Reporting Good Enough?"* rather hard and compelling (paper copies presented) has noted the the flaws of the peer review system of manuscripts:

- Nepotism and sexism in peer-review
- Lack of transparency of review process
- Bias among reviewers, editors and publishing companies
- Promotes amateurism
- Maintains publication bias (negative results tend not to be published)
- Data are not standardized

The presenter has introduced the real incident of a manuscript specially created by **Science** (a group of scientists) on behalf of fictional institute and author which was published in 157 journals around the world. This reveals little or no scrutiny peer-review at many open-access journals. One of initiators of this affair ***John Bohannon*** has pointed that *"...the data from this sting operation reveal the contours of an emerging Wild West in academic publishing"*.

Seregard has also pointed disadvantages of cancer registers which capture a wealth of information on diagnosis and survival, and some information on the first round of treatment, but nothing related to recurrence or to subsequent surgery or other treatments).

The presentations were followed by lively discussion on issues:

- How do we ensure the best quality data is collected?
- Who is collecting the data, EMR data vs. retrospective analysis?
- How can we provide a mechanism to report our outcomes?
- Can we perform an internal, society generated quality review?
- Should our goal be an anonymized central registry?
- Organizing a DRO exploratory committee to make recommendations to the group.

The issues discussed have proved the difficulty of program's purposes and tasks. There was demonstrated the experience of some clinics in Cleveland, the USA and Toronto, Canada in the field of personnel training and correct reporting on treatment outcomes. It was pointed that it is possible to minimize clinical variants and improve the quality of reporting at the level of DB manager.

Section 5: Basic Surgical Techniques, Project

7 presentations have shown main current treatments, including surgical and therapeutic ones, pretending to be standards:

1. The Need for an Open-access Eye Cancer Surgical Technique Guide, *Santosh Honavar*
2. Eyelid Tumors Excision, *Fairooz P Manjandavida*
3. Conjunctival Tumor Excision, *Carol Shields*
4. Plaque Brachytherapy, *Paul T Finger*
5. Enucleation and Exenteration, *Santosh Honavar*
6. Orbital Tumor Biopsy/Excision, *Bita Esmaeli*
7. Effect of Histopathology on Surgical Technique, *Hans Grossniklaus*

In a presentation *"The Need for an Open-access Eye Cancer Surgical Technique Guide"*, ***Santosh Honavar (Hyderabad, India)*** has given the reason for standardization of surgical methods of treatment and pointed its benefits:

- Wide variation in techniques;
- Amalgamation of best of clinical practices;*
- Varying training background;
- Evidence-based; *
- Ocular Oncology as a stand-alone facility
- Current standard of care;* exists in very few centers;
- Easy to learn and teach;*
- Varied results, often suboptimal;
- Optimization of outcome;*
- Poor outcome;
- Cost-effective treatment strategies;*
- Comparison of data;*

The author supposed that standardization of the greater part of clinical practice in ocular oncology will provide *"...immense scope to increase outcome – local tumor recurrence; regional and systemic metastasis; life-eye-vision salvage"*. The tasks, realization of which will lead standardization project to success, are:

- To provide standard guidelines;
- Standard surgical techniques;
- Easy to tech, learn, and replicate;
- Evidence-based management protocols;
- Peer-reviewed document;
- Video on demand;
- Discussion forum;
- Part of training curriculum,

When creating the project, it is important "NOT to be prescriptive but participatory". The strategy is like:

- Discuss variations and reasons for the same;
- Form interest groups;
- Dig up literature for evidence in support or against;
- Meta-analysis, analysis of pooled data, publish!
- Online guide with video on demand, online discussion group;
- Amalgamation into training curriculum, accrue data, analyze, revise and refine – stop not!

The author has pointed the barriers on the way of standardization as *"wide variation in training background, Infrastructure, Cost of care, Regional and local circumstances and demands"*. The group of participants to coordinate project's efforts in different fields of ophthalmooncology has been presented:

Eyelid – Fairooz PM
Ocular Surface – Carol Shields
Plaque Brachytherapy – Paul Finger
Enucleation and Exenteration – Santosh Honavar
Orbit – Bita Esmaeli
Pathology – Hans Grossniklaus

The issues discussed in this section:

- Set up writing committees
- Equipment standards
- Internal peer review
- External peer review
- Publication

Of them, the most relevant for us was discussion of possibility for open access to publications on surgical and reconstructive treatment in ophthlmooncology.

Fairooz P Manjandavida (China, Shenzhen) in his report *"Basic Surgical Techniques and Protocols Eyelid Tumors"*, has reminded that recurrence incidence in suboptimal surgical excision of eyelid tumor is more than 30.0 %, thus increasing the incidence of regional/ systemic metastases and invalidity; while in incision with control of frozen section edge, the recurrence incidence is only between 0.0% and 10.0%. The standard of surgery for eyelid tumor can be as follows:

- Primary wide surgical excision- 'gold standard';
- Surgical protocols reduces recurrence;
- Pathological evaluation of margin clearance;
- Alternative chemotherapy;
- Adjuvant treatment modalities if indicated.

Carol Shields (Philadelphia, USA) has presented the report *"Conjunctival Tumor Excision"*, and her experience of treatment of 1 643 melanocytic and non-melanocytic conjunctiva tumors. She has introduced the no touch incision technique as a treatment standard for malignant melanocytic and epithelial conjunctiva tumors.

Paul T Finger (NY, USA) in the presentation *"Basic ophthalmic plaque radiation surgery"* has introduced the main requirements for eye applicator radiotherapy, one of the leading treatments for intraocular melanomas.

- Trained ophthalmologist;
- Experienced radiation oncologist - medical physicist;
- Plaque (gold-seeded or solid ru-106, sr-90);
- Transilluminator;
- Indirect ophthalmoscopy;
- B-scan ultrasound imaging.

The author has pointed the necessity to compare the intraocular dosimetry in each case of brachytherapy as well as its difficulty, requires training, requires equipment, quality assurance and regulation.

Section 6: Patient Reported Outcomes (PROs) Project

The section was rather lively since the difficulty of patient question formulation in order to achieve comprehensive answers not disturbing his private life principles was criticized. The section included four reports:

- What are PROs? *Bertil Damato;*
- The Liverpool Experience, *Laura Hope Stone;*
- The Los Angeles Experience, *Tara and Colin McCannel;*
- The San Francisco Experience, *Andrea Villaroman;*
- PRO future directions: How working groups can be used to standardize data collection for sharing and comparing reported outcomes. *Tara McCannel.*

Bertil Damato in his presentation *"What are Patient-Reported Outcomes? And who wants them?"* has given the analysis of answers of patients treated UM with different methods (Departments of Ophthalmology and Radiation Oncology University of California, San Francisco) to the questions (The EORTC Ophthalmic Oncology Quality of Life Questionnaire Module (QLQ-OPT30) about the quality of life, in particular:

- During the past week, were your activities limited in any way by your vision?
- During the past week, were you worried about tumor recurring in other parts of the body?
- During the past week, how would you score your quality of life?

The author has concluded that:

- Uncertainty in the context of uveal melanoma is a complex and multifaceted experience that is not easily resolved by prognostication (Genetic Tumor Type);
- Additional approaches are needed to help patients with the uncertainty that persists despite prognostication.

That' why, on-line questionnaire of Ocular Melanoma Foundation includes the questions facilitating new ways to help UM patients, in particular:

- How would you rate your psychological counseling?
- Do you wish you had been given better information regarding the different treatment options?
- Were you informed about the possibility of prognostic tumor biopsy?
- How could your care have been better?
- What do you wish your optometrist, ophthalmologist, ocular oncologist, medical oncologist or primary care physician did differently?

... questions for patients with other tumors:

- help patients predict the impact of disease on their life;
- inform patients about disparities in standards of care at different centers;
- inform doctors about patients' unmet needs and levels of satisfaction with their care;

- enhance the evaluation of clinical services and rival treatments.

Laura Hope Stone (Liverpool, UK), with presentation *"Patient Reported Outcomes: The Liverpool experience"*, has argued in favor of specialized psychological assistance to examined UV patients treated in England, Germany, Sweden and Netherlands. Analyzed the responses of such patients, medical psychologists (Institute of Psychology, Health & Society University of Liverpool UK; Liverpool Psychology Service for Cancer RLBUHT) have revealed factors of psychological vulnerability and developed psychological actions, in part or in whole releasing patients from apprehension, depression and improving the life quality. Thus, patient reported outcomes help us):

- Provide a comprehensive view of issues and concerns that patients report over time;
- Determine how we can best help and support patients in the future.

In paper *"Patient-Reported Outcomes at the University of California, San Francisco"*, the aim of which is to collect patient reported outcomes (PROs) and match them to clinician reported outcomes (CROs), ***Andrea Villaroman*** has presented approaches for this comparison, problems in loading and processing the data, advantages and disadvantages of on-line connection with a patient and assessment of preliminary outcomes of this approach. In particular, the author has noted a good rating of questions, time limits and convenience of on-line connection by patients.

To conclude, the author has pointed the importance of PROs integration as an essencial part of clinical and psychological assistance to patients; however, investigators can face some problems:

Workflow changes

- Who enters the clinical data?
- Where do we incorporate recruitment in a busy clinic schedule?

Funding challenges

- How much effort do you need from your coordinator?
- Once established, who will follow up with patients in a long term study?
- Who pays for the data scientist?
- How do you keep true to "philanthropic goals"?

Institutional Protection of Data

- How do you maintain open access and protect privacy?
- Who houses the data? Third party players or the institution?
- Security protocol?

Due to the complexity of this problem, the discussion in this section was highly active and concerned issues as follows:

- How have these influenced your practice/ improved your patient care?
- How to get started in your center?
- Data collection and patient privacy?
- What to do with the data?
- Giving your patients feedback;
- Data sharing (local, governmental and publications);
- Multicenter PRO data comparisons.

Bertil Damato et al have proposed seven steps to create "Universal Eye Cancer Database" which have been taken as the future basis. The seven steps are:

1. A common AJCC -UICC language to define tumors on a clinical and pathologic basis.
2. Define parameters (data points) that must be derived from each tumor: e.g. Epidemiologic / Clinical Diagnostic / Photographic / Ultrasound Angiographic / Ultrasonographic / Radiographic / Pathology / Genetic / Treatment / Outcomes.
3. Each database will be the responsibility of the previous section leaders to coordinate. Parameters will be devised and shared for comment within the committee (and outside reviewers as needed).
4. Software development: Commercially available software is available. It must be internet - based, open source, password protected, and privacy compliant.
5. Implementation: Once constructed, this software will be shared with the network of participating physicians. It is essential that each physician or institution have complete control over their patient data sets. Multi center cooperative research (data - sharing) will only be performed at the discretion of each physician/center.
6. EMR Overlay: This database is a necessary step towards building an ophthalmic oncology specific electronic medical record (EMR) system. It is possible to create an overlay EMR that can rest upon each institutions proprietary EMR, extracting and sharing the data it needs (while collecting the information we require).
7. EMR-based data collection allows for the most pure form of data collection, directly from the treating physician at the time of the patient encounter.

Thus, at the event, two important projects have been discussed: the creation of 8 edition of cancer stage system under the guidance of American Joint Committee on Cancer, as the basis for "common language" of future multicenters, and fundamental principles providing serious co-investigations on the basis of the multicenter. The event participants have rather serious organizational and professional experience and this anticipates the project's success. The project has been partially started: DB in some fields of ophthalmology as well as multicenters and bioinformatics nets (BIG) have been created and are developing; the process of open access to the literature on eye cancer surgery techniques has been initiated. Statements determining the structure of report on patient examination and questionnaire are coming soon.

It should be pointed that, in EU over several years, there has been a program "Translational research in ophthalmology and vision science" which involves 72 centers from 16 European countries. Translational research is considered as a five-phase model of interventional research which is used to describe the continuity of biomedical investigation from fundamental to applied science (a laboratory table- a patient's bed) and inversely. In patient-oriented translational research there is permanent exchange between fundamental and applied sciences. Clinical trial opens the question and verifies the decisions proposed.

Finally, the event was not formal; it was an open discussion of problems and ways for their solvation. It was seen that specialists were closely communicated in the bioinformatics nets, which connect fundamental scientists such as pathologists, epidemiologists and clinicians, determining the medical practice on the basis of the data proved. The interest in attraction of new participants into the project was also noted.

Taking into account all said above, we should think what and how we can do to participate in this project.

Refernces

1. Clinical and Pathologic Characteristics of Biopsy-Proven Iris Melanoma A Multicenter International Study. Available at:http://www.archophthalmol.com/ on October 16, 2011
2. International Validation of the American Joint Committee on Cancer's 7th Edition Classification of Uveal Melanoma. Available at: http://archopht.jamanetwork.com/ by Paul Finger on 01/02/2015
3. Craig McFadyen, MD, Sara Lankshear, PhD, Dimitrios Divaris, MD, Mark Berry, MA, Amber Hunter, MBA, John Srigley, MD, Jonathan Irish MD. Physician level reporting of surgical and pathology performance indicators: aregional study to assess feasibility and impact on quality.

Meeting attendee
A. S. Buiko, Dr Sc (Med), Professor
(Filatov Eye Diseases and Tissue Therapy Institute)