



Annual Congress 2018 – February 7, 8 and 9

The countless small deeds of the
unknown people

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‘Children with cancer and the need of patients and their parents’ (1)

Meeting at the VUMC with a 13 year old boy with leukemia, his father, Nicole van Leeuwen & Dennis van Vuuren (MD).

The boy told us about the inconveniences and side effects of the medication. He has to travel to the hospital in Amsterdam weekly for treatment and has to take several other medicines at home. He gets sick and inflated by the medication. He is not able to go to school and to live a normal life. He cannot practice any sport. He was very open to his friends from the beginning and told them about the disease. His friends fortunately still visit him and treat him like a normal healthy boy. He is most annoyed about the fact that his doctor didn't inform him immediately about his illness because he felt that something was terribly wrong. The doctors reaction was that he saw that as a lesson for the future.

Positive:

- There are several foundations that inform parents and organize excursions and holidays for children faced with cancer.
- Princess Maxima Center for Pediatric Oncology opens her doors officially in May 2018 in Utrecht. There will also be an office from the VOKK (foundation for parents of children with cancer) under the roof of the hospital to make it easier for parents to obtain information or assistance.
- There are 30 shared care centers under the organization of Princess Maxima Center for Pediatric Oncology throughout the Netherlands. They offer more generic treatment when necessary.

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‘Children with cancer and the need of patients and their parents’ (2)

To improve:

- It took a while for the parents to know where to go for information and subventions for travelling.
- Parents have the need to meet other parents.
- The child told us he would have liked a better guidance in the beginning of the disease and he needs contact with other children with cancer.
- Sometimes a parent has to stay in the hospital with the child, while the other parent is at home with the rest of the family. Better communication options would be nice to stay in contact with each other.
- Education of teachers at the schools could be better. Not all teachers are willing to cooperate and facilitate the online education of a child with an illness.
- Home care could be improved.
- Less side effects of the medicaments so that it is possible to live a normal life.

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‘What is the role of (healthy) gut flora in the prevention and treatment of cancer?’ (1)

A meeting at Winlove probiotics in Amsterdam Noord, with Barbara van Kesteren, Elke Lievens, Alisdair Scott, Maarten Pekelharing & Coen van Veenendaal.

- The International Cancer Microbiome Consortium studies the relation between the microbiota and cancer
- The human body contains as many bacteria as normal cells
- Humans have 23.000 genes, the bacteria in our body have 1.000.000 genes
- The bacterial genes (microbiome) are an integral part of our system
- Bad microbiota (dysbiosis) can cause cancer (H-Pylori, HPV etc) through chronic inflammation, genotoxicity and metabolites
- Certain bacteria can support anti-cancer treatments
- Bacteria can be used in prevention through vaccination (ie HPV)
- The microbiome can be used as a diagnostic tool
- Changes in the microbiome can be indication for treatment efficacy so useful as prognostic tool
- Microbiome can be used to reduce soide effects of chemotherapy treatments
- Role of probiotics in treatment of cancer needs further study but holds a mayor promise

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‘What is the role of (healthy) gut flora in the prevention and treatment of cancer?’ (2)

“Thoughts on developing microbiota management within oncology: from potential to performance”

Food for thought was presented by Dr. Alasdair Scott from Imperial College London and co-founder of the International Cancer Microbiome Consortium (ICMC) on the gut microbiota as a potential new frontier in colorectal cancer. The bacterial communities living in our body – also referred to as the microbiota – are known to be dynamic and resilient and to have oncosuppressive properties. Alterations of the gut microbiota, such as reduced bacterial diversity and increased abundance of specific pathobionts, are associated with colorectal cancers. However, it is difficult to establish if these alterations are causative of colorectal cancer or the result of cancer itself. Further longitudinal cohort studies are necessary.

Dr. Alasdair Scott presented the “interactome” model, stating that cancer might be a result of three interacting risk factors: the host, the environment and the microbiota. From this perspective, the possibility of microbiota manipulation for therapeutic benefit in cancer is emerging. For example, there is strong evidence that dietary manipulation can shift the microbiome towards a more oncosuppressive phenotype, potentially preventing carcinogenesis. The microbiome may also have prognostic uses, as the abundance of a specific bacteria (e.g. *Fusobacterium nucleatum*) appears to be correlated with cancer stage and survival. With respect to cancer treatment, the microbiome has been shown to influence the response to chemotherapy, in terms of both efficacy and side effects.

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‘The healthy city of Amsterdam’. (1)

Meeting at ‘Huis van de Wijk de Evenaar’ in Amsterdam Noord with Guan Schellekens, Jaap Seidell & Mark Vlaar.

Minutes:

The municipality of Amsterdam runs a successful [programme](#) to combat overweight among young people, in an attempt to minimize the risk factors that eventually lead to the onset of a diversity of diseases, among which cancer. Risk factors include families with low income, parents with low education, non-western ethnicity and growing-up in a major city. The workshop, with introductions by Prof dr. Jaap Seidell and Mark Vlaar, was held in one of the neighbourhoods in Amsterdam-Noord where the programme runs. Typical activities include food and awareness programmes on primary schools, sports and social activities in the neighbourhood, geared towards the youngsters but also involving the parents and the wider social environment.

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‘The healthy city of Amsterdam’. (2)

Recommendations:

- The cost effectiveness of prevention should not be measured against the cost for a specific disease, but to the cost of for all co-morbidities that might follow the first disease. In short, prevention pays off.
- An action-oriented, participatory research mode is needed to both acquire context-relevant data and speed forward the engagement of citizens with their own and public health.
- Healthy weight is a collective responsibility and the healthy option should be the easy option.
- It demands courage and strength to put and maintain clear public norms as to what healthy behavior is, as a counterweight to pervasive yet intangible market and social pressure to choose unhealthy options.

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'The need for randomized trials: can we accelerate the translation of novel targeted and immunotherapies to the clinic?' (1)

Meeting at the VUMC/Cancer Center Amsterdam and works with Margo Kitzen, Tanja de Gruijl & Bob Pinedo

Minutes:

- Tanja de Gruijl explains the state of the art from a scientist point of view on immunotherapy.
- After that Bob Pinedo shows his work as a physician and tells us his beliefs (for a long time) in the immunesystem in curing cancer.
- Bob set up treatments with Active Specific Immunotherapy (ASIT) in the nineties of the former century based on the scientific work (among others of course) of Tanja de Gruijl.
- The immunesystem is very complex but in the end it is now very succesful in treating (at least some) cancers.

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‘The need for randomized trials: can we accelerate the translation of novel targeted and immunotherapies to the clinic?’ (1)

- An intense and good discussion was initiated around the necessity of phase 3 trials. The example taken was melanoma treated with surgery and with or without CPG. Without CPG the disease relapses in 33% of the patients. With CPG almost never. Phase 2 shows no side effects other than red spots on the skin for 2 or 3 days after being treated with CPG. CPG cost little money (no patent). A relapsed patient is treated with expensive medicines and will not survive.
- The discussion is first between Tanja de Gruijl (we need a phase 3 trial) and Bob Pinedo (we can do without, it’s unethical not to treat).
- Richard Boucherie (PA at Inspire2Live and professor in mathematics) enters the discussion and tells us that we have (in this case) enough historical data to prove that we can do without phase 3).

Recommendations (action to be taken):

- Richard Boucherie, together with Tielo Jongmans (PA at Inspire2Live and mathematician as well) will work with epidemiologists and statisticians and try to write a paper in which they prove (or disprove) the hypothesis of Richard that we do not need for this case a phase 3 trial.

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Reallives.com (the workshop)

Parag Mankeekar (Neeti Solutions, Pune) & Ilona Schelle

The workshop was about showing with reallives.com (available for everyone) can do with empathy:

- Only the people behind technology can be empathic.
- You can learn empathy, it's like swimming.
- Vulnerability is key.
- Try making a you-ie instead of a self-ie.
- What we think we become.

Reallives is a technology, you ARE the person behind the screen, you make your decisions and can see how that works out in reallive!

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Data to the People – Patient Empowerment through Smartphones and Data Cooperatives

Olivia Gutziller, Andreas Invernizzi, Ernst Hafen & Hannes Hefty, ETH Zürich

Minutes:

Paternalistic way of the medical system will change.

Smartphones will open new possibilities in aspects like connectivity, diagnosis or ways to conduct scientific studies.

Patient empowerment through online networks and better accessibility of information.

Need for improvement in the medical IT-sector.

Idea of a cooperative data storing and sharing platform.

Use of the data for enhancement of therapy, early diagnosis and prevention of diseases.

Recommendations:

- Be open for changes in medicine.
- Don't be afraid to collect and use personal data.
- Take control over the data others collect of you.
- Participate in studies.
- Share your data under the appropriate circumstances.

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Enhancing Empathy in Healthcare

Chaitrali Pavnaskar, Pari Tawale, Parag Mankeekar & Vedang Ranade – Team Neeti Solutions, Pune, India

Minutes:

- Importance of data-centric empathy analysis of a healthcare system as empathy has a widely-proven effect on patient prognosis.
- Proposal for a better healthcare system which takes into account the well-being of all the stakeholders in the system to affect the entire ecosystem.
- Understanding requirements of emotional empathy at various stages in the many processes of the healthcare system.
- Leveraging architectural, design and systemic aspects to make the healthcare system more empathetic for the patients and caregivers.

Recommendations:

- Need to collect and utilize data in order to perform effective empathy analysis of a healthcare system.
- Need of focused efforts to enhance empathy in a healthcare system from design perspective.
- Create a strong force to oppose the factors which are working against empathy.

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Our health data can save lives – Are we willing to share?

Lisa Moris, Sara Jane MacLennan, James N'Dow & Kostas Dimitropoulos

Belief that:

- Medical data represent sensitive information
- Medical data are confidential

They are not:

- Pharmaceutical companies analyze prescription data.
- Data analytics companies process data and expose previously invisible patterns – then, they sell their findings to various buyers.
- Easily accessible by hackers, they get stolen and sold on dark web.

In reality, YOU cannot access them

In reality, WE cannot access them

In reality, WE ALL LOSE because of the limited access

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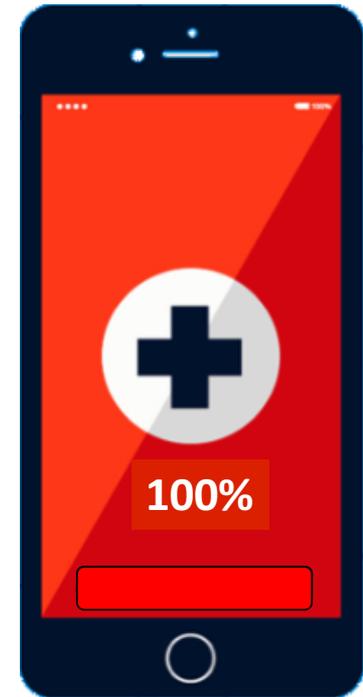
**Imagine what we could achieve with the data that already exist...
If we can facilitate appropriate access.**

Cooperation/ transparency between scientists – clinicians – patients.

- National and international.
- Academy and industry.
- Opting out system.
 - Donating data unless clarified objections.
- Providing safe systems to store data but keep it accessible.
- Patient = Center and the purpose.

Recommendations:

- High profile celebrity to front campaign around access to stored research data to aggregate and address important questions.
- Raise public awareness of the benefits of big data for research and the loss of knowledge around lack of access to existing research data.
- Role of non-profit organisations in facilitating awareness campaigns and lobbying activity.
- Lobbying at national-level to change governmental regulations around consent to use existing research data in a regulated manner.
- Lobbying at an international-level to change governmental regulations around consent to use existing research data in a regulated manner.



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The fundamental research perspective (1)

Arina Puchkina, Marjolijn Ladan & Dik van Gent (ErasmusMC)

Minutes (more communication):

- Between clinicians and researchers to set the right goals for research (so researchers know what needs are there in the clinic and clinicians know what research can do for them).
- Between patients and researchers (so the main problems for patients will be addressed in the research projects and to raise patient awareness of what is possible in research).
- National medical record system + patient education and awareness: Data should be made available in a standard format in order to be useable for meaningful analysis (the same elements should get the same name and content should be available in a standard format).
- It will be better to have a central repository for patient data than to ask patients to upload their information, because this would allow updating the patient files when new information becomes available and it prevents accidental disclosure of personal information that should not be shared. This set up would also have the possibility to restrict access to for example the research community and/or patient organizations.
- Keep in mind both patient safety as well as the drive to develop new therapies: Quick access to novel therapies should be balanced with safety and the possibility to objectively measure responses to the therapy (one should be able to draw conclusions about effectivity and side effect at the end of an experimental period). It is important to prevent loss of quality of life due to experimental treatments.

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The fundamental research perspective (2)

Recommendations (More communication):

- Organize meetings between clinicians, patients and researchers (talk to each other). Start from the assumption that everybody has the best intentions for the patient and optimizing cure; work together to formulate solutions. In general dialogue works better than debate (don't debate, communicate!)
- National medical record system + patient education and awareness: A standard format for medical records that is used in all hospitals. Everybody should be educated to fill out these lists in a reproducible way. The patient should get the option to put these data in a repository that is maintained by a central organization. Access to these data could be limited to researchers and data can be anonymized correctly. Updates will be uploaded automatically by the hospital.
- One should avoid a bias for patients with e.g. higher education levels (that may have a healthier lifestyle). For this purpose it may be better to have an 'opt out' procedure rather than an 'opt in' procedure. Patient education is important to involve all classes of patients in this endeavor.
- Keep in mind both patient safety and the drive to develop new therapies: Therefore, it's advisable to start a dialogue with oncologists, surgeons, researchers, patients, ethical committees and regulatory bodies to explore alternative strategies to conduct clinical trials. Just abandoning phase III trials is not a feasible option now. A valid alternative may convince medical doctors and regulatory bodies to change procedures. An instrument could be the creation of research grants to explore alternatives (similar to what 'proefdiervrij' has done to fund research on alternatives for animal experiments).

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