

Budapest Dissemination Workshop Minutes

Venue: Koos Aurel auditorium, 1st Dept. of Pediatrics, Semmelweis University, H-1083
Budapest, Bókay János u. 53-54.

Time: Jan 31 - Feb 01, 2019

Participants of the meeting:

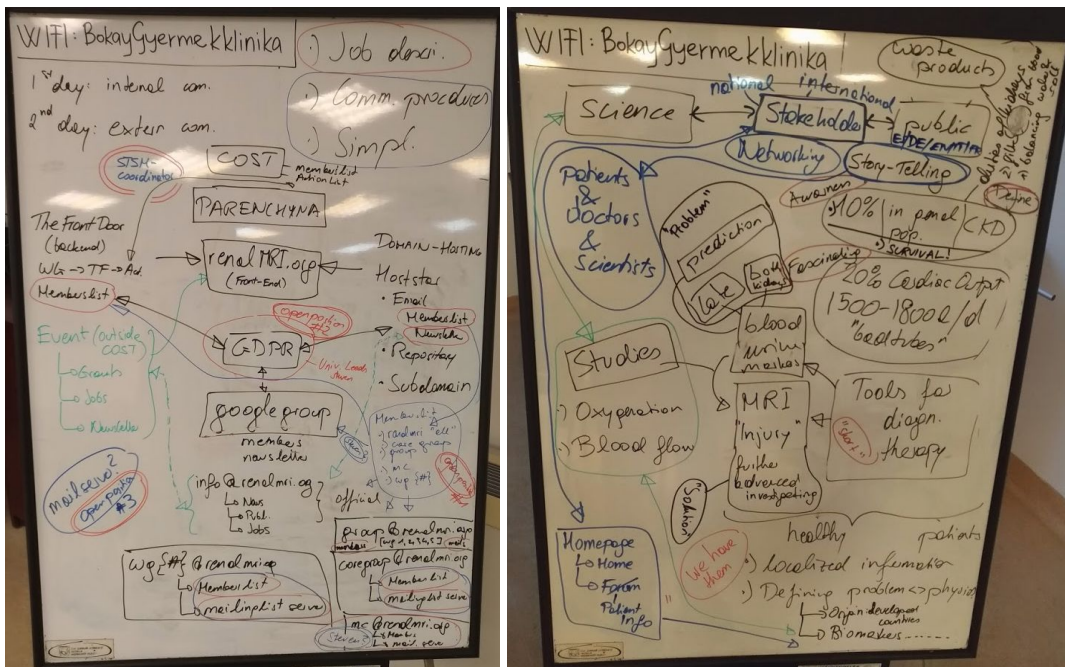
- Anna Caroli
- Antonio Goncalves Pinheiro
- Mitko Kostov
- Joey Moser
- Aghogho Odudu
- Sinisa Ristic
- Giulia Villa
- Marcos Wolf



Abstract

On the **first day** of the meeting internal communication procedures and tools were explored. The homepage structure (TheFrontDoor) as well as domain control (hoststar) were analyzed. The management of PARENCHIMA as well as Hoststar memberlist (email and contact storage) and GDPR regulations were put in context. The advantage and drawbacks of social media and google (google groups) communication tools were explored. Also new ways of communication were discussed, i.e. storytelling; training by COST would be highly appreciated. New communication paths (incl. new positions) were identified and simplified. Furthermore, the need for dedicated homepage management sessions and meetings is evident. Details can be depicted on the given plan for the following grand period.

On the **second day** external dissemination procedures were outlined. First, the need to disseminate our goal and results to patients and the general public was identified. Yet again, storytelling seems to be an appropriate and strong tool. Other dissemination tools should be considered (flyers and posters). In order to learn and synchronize with patient and public stakeholders, it should be considered with high priority to engage with stakeholders directly before or after future meetings. This might also help to get them involved in the future. Last but not least, our Action should be linked to different renal imaging and renal disease stakeholders (public-, patients-, medical-, scientific-groups), and we should ask them to link us.



Procedures for the future:

Person in charge are highlighted in yellow.

Open positions are in green.

Tasks associated with the WG5 Lead are highlighted in blue.

- **Story Telling** [Joey Moser, Giulia Villa, Aghogho Odudu]
 - A new tool to be used. If possible communication training by COST
 - Special Focus on patients and general public via Youtube, Twitter, LinkedIn
 - Get in touch with **renal societies** [Aghogho Odudu]
 - Change Homepage:Forum [Marcos Wolf - Dedicated homepage editing meeting]
 - **Create information area for patients and general public** [Joey Moser, Giulia Villa, Sinisa Ristic; @Marcos: create google document and share]
 - with links to stakeholders (preferably in different languages: ES/EN/DE/IT). Also collect and use patient information from WG3 study documentation repository. Draft structure:
 - **Abstract**
 - Definition
 - Key features / Duties of kidneys (“among others”)
 - Filtering waste products
 - Water balance
 - Raising Awareness
 - 10% Chronic Kidney Disease

- Survival
 - Fascinating facts
 - 20% Cardiac Output
 - Blood Flow per day: 1500 - 1800 Liter (10 “bathtubs”)
 - Existing tools for diagnosis and therapy exist
 - Blood & urine biomarkers
 - “Problems:” only both kidneys; low sensitivity and specificity; only advanced injuries
 - Novel Biomarkers
 - Why are they potentially better?
 - Why is further research necessary?
- Thereafter, longer version with more details (but still for general public and patients; thus, keep it simple!)
 - Defining problems <> physiology <> pathology
 - Localized information of renal imaging
 - Biomarkers (examples)
 - Oxygenation >> Link to NDT publications
 - Blood Flow >> Link to NDT publications
 - Structure >> Link to NDT publications
 - Short description of current stakeholders >> Link to “Blog”/“News”
- Create **scientific information package** (to be used for communication with external stakeholders) [WG leads, Steven Sourbron]
 - @Marcos: create shared document
 - Short general information about us (can be used also for other parts of the homepage; can be seen as an “update”)
 - Describe us and our structure: groups
 - Fundings
 - Use “old” information from meetings!
- Create **Master Slides** Powerpoint [Anna Caroli, Mitko Kostov, Marcos Wolf]
 - @Marcos: Google slides, COST Acknowledgements
 - Introduction (fixed)
 - Free Slides
 - Free Acknowledgement
 - Acknowledgement (partly fixed)
- Find **external stakeholders** [share with PARENCHIMA]
 - @Marcos: create shared document
 - List of Links and Contacts (Communication officers)

- Science
 - Public / Patient
 - Contact them when the information block is done
- **Newsletter** [Marcos Wolf]
 - info@renalmri.org (complete memberlist of renalMRI)
- **Memberlist** - Sync TheFrontDoor and Hoststar [OPEN POSITION]

Automated script @Marcos: is it possible? [OPEN POSITION]

@Marcos: Manage User Rights

@Marcos: Ask TheFrontDoor how to export the list of participants (e.g. excel sheet)

 - Apply COST Groups and standardize member details
 - Working Groups
 - Task Forces
 - Job Title (e.g. “Radiologist” vs “Radiology”)
- **Create emailing-list server** [OPEN POSITION]

@Marcos: Hoststar plugins?

 - group@renalmri.org (parenchima)
 - coregroup@renalmri.org
 - mc@renalmri.org
 - wg{#}@renalmri.org
- **Privacy Notice (PN)** [OPEN POSITION]
 - Update PN status of previously signed PN at hoststar info@renalmri.org (send copy to WG5 Lead) [Steven Sourbron]
 - Currently unsigned and new members
 - Request participants to follow Social Media together with PN request (share links!)
- **All STSM** should be mentioned on Homepage [Olivera Nikolic]
 - Reports should include (for social media; public)
 - One Image
 - One title: 140 characters
 - One description/”story”: 80 words
 - Forward appropriate reports to social media leads (Mitko Kostov, Aghogho Odudu)
- **Resorting homepage** [Joey Moser, Marcos Wolf]

Organize dedicated homepage editing meeting

@Marcos: get in contact with Marcel

 - a. *Home* >> Optimize Introduction for all (scientists and public)
 - If possible add social media content
 - If possible add “storytelling”
 - b. *Working Group*
 - c. *Events* >> Rename to Actions (COST Actions)



- Keep track of Actions [OPEN POSITION, Steven Sourbron, Marcos Wolf]
 - Sync with COST tools
 - Add pictures and stories
- d. News >> (outside COST; Backend “Blog”) “Scientific content”
 - Dissemination activities [still link to TF 5.1<>News]
 - Symposium
 - Talks
 - Collaborators
 - Other stakeholders
 - Newsletter
 - Publications
 - Clean up / Make Order
- e. Forum >> make general public and patient information
 - Also add patients’ stakeholders
- **Google Analytics** [Mitko Kostov]
@Marcos: Share content
 - What can we learn from Google Analytics?
- **LinkedIn** [Aghogho Odudu]
 - Make it open
 - Connect more with stakeholders
 - Share link to other social media
- **Twitter & Facebook** [Mitko Kostov]
 - Facebook will go active/online
 - Connect more with stakeholders
 - Share link to other social media
- **Research Gate:** [Giulia Villa]
We identified substantial security issues (all collaborators can edit everything)
 - Add Logo (Parenchima)
 - Share link to other social media
 - Update should include
 - Meeting informations (incl. description)
 - Results should focus on:
 - Project
 - Publication (min. 2 centers/partners)

Tasks for WG5 Lead: Marcos Wolf

- **Contact Nick** to update **International Meeting** information on our homepage
 - Ask to link us on their Meeting homepage



- Fix link on newsletter and pdf
- **Homepage**
 - Update Admin Rights and User Rights (e.g. permissions only for Actions, TF,...)
 - Promote info@renalmri.org on homepage
 - Join Newsletter (Ask Marcel: autom. System >> Sending Privacy Notice)
 - Social Media
 - Show last twitter postings
 - Top bar fixed with social media links, or
 - Right bar?
- **Link social Media**
 - Homepage (*Home, About*)
 - Ask COST to follow us
 - On all documents (including Privacy Notice)
- **Hootsuite**
 - Create account and share with Aghogho Odudu and Mitko Kostov
 - Use official renalMRI email address => "randomtextandnumber"@renalmri.org
- Clarify with COST whether **external sponsoring** is allowed; they could help with
 - Mailserver
 - Social media management
 - Etc.

Upcoming Budget Plans:

- Budget **Next Year**:
 - **Meeting with patient/general public stakeholders** [1day]
 - Before or after Nottingham meeting (maybe already planned? Contact Nick?)
 - Optimize storytelling
 - **Dedicated homepage editing workshop/meeting** - Re-sorting [1day]
 - Together with TheFrontDoor (maybe close by?)
 - Manage members list (see above)
 - Invite from each WG a dissemination officer to join and learn how to edit
 - Posters and Flyers
 - Contact Nick for the international meeting
 - Stakeholders
- Budget **Last Year**
 - 1000 € left for design of **logo** (last year, change: PARENCHIMA to renalMRI)
 - Estimated **1500€ left for last year** of the project for the homepage
 - We have to maintain the homepage for 2 years after COST Action



Acknowledgement

This meeting was based upon work from COST Action PARENCHIMA (CA16103), supported by COST (European Cooperation in Science and Technology).

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation. www.cost.eu



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