PATIENTS AND THE DIGITAL REVOLUTION
Development of the VASCERN Mobile APP

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ePAG co-chair – HHT WG – VASCERN
VASCERN – eHealth WG

VASCERN — Vascular Diseases

Transversal WG: eHEALTH

Chair

Dr. Alessandro PINI
Centro Malattie Rare Cardiologiche – Marfan Clinic
Azienda Socio Sanitaria Territoriale Fatebenefratelli – Sacco
Milan, Italy

ITALY
Crossborder Mobile App
Part 1: The Proposal - May 2017

• A rapid guide to identify the Hospital that can offer the best diagnostic and clinical assistance for each rare disease within VASCERN.

• Very simple to use. Clicking on the rare disease the App reveals the hospitals around you that can offer the right answer to your clinical need.

• Clicking on a single hospital the address, telephone number, email of the selected rare disease centre appears.

• Direct dial option, direct road directions
VASCERN e-Health Transversal WG
Dataset information to be included

- HCP name
- VASC Specialization
- Hospital Name
- Department
- Complete Address
- City and ZIP code
- Country
- Director/Coordinator
- Telephone Number (Direct)
- FAX Number

- Email
- Opening Time
- Core services
- Other specialist evaluation
- Dedicated Emergency Department (Y/N)
- 24/7 Call Center (Emergency)
- Patient Association Point
- Website and/or Social media account
<table>
<thead>
<tr>
<th>HCP name</th>
<th>Centro Malattie Rare - MarfanClinic</th>
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<tbody>
<tr>
<td>VASC</td>
<td>Marfan Syndrome, Loeys-Dietz Syndrome, Ehlers - Danlos Syndrome, Bicuspid Aorta, Aortic Aneurism Diseases</td>
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<tr>
<td>Specialization</td>
<td></td>
</tr>
<tr>
<td>Hospital Name</td>
<td>Luigi Sacco Hospital - ASST Fatebenefratelli Sacco</td>
</tr>
<tr>
<td>Department</td>
<td>Cardio-Neuro-Angio Department</td>
</tr>
<tr>
<td>Complete Address</td>
<td>Via GB Grassi, 74</td>
</tr>
<tr>
<td>City</td>
<td>Milan</td>
</tr>
<tr>
<td>ZIPcode</td>
<td>20157</td>
</tr>
<tr>
<td>Country</td>
<td>Italy</td>
</tr>
<tr>
<td>Coordinator</td>
<td>Alessandro PINI</td>
</tr>
<tr>
<td>Telephone number (direct)</td>
<td>+39 02 39</td>
</tr>
<tr>
<td>FAX number</td>
<td>+39 02 39</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:alessandro.pini@asst-fbf-sacco.it">alessandro.pini@asst-fbf-sacco.it</a> @asst-fbf-sacco.it</td>
</tr>
<tr>
<td>Opening time</td>
<td>Monday to Friday 07.45-17.00</td>
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<tr>
<td>Core Services offered</td>
<td>Cardiovascular and Clinical genetic evaluations - Psychologist evaluations - Molecular genetic evaluation</td>
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<tr>
<td>Other specialistic evaluation offered</td>
<td>Cardiac and Vascular Surgery - Ophtalmology - Pneumology - Orthopaedic - Obstetric and Gynecology</td>
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<tr>
<td>Emergency Dpt Dedicated</td>
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<td>24/7 Call Center (Emergencies)</td>
<td>+39 348</td>
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<td>Patient Association Point</td>
<td>YES</td>
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<td>Website and or Social Media</td>
<td><a href="http://www.marfanclinic.it">www.marfanclinic.it</a> MarfanClinic (Facebook) Marfan Clinic Milano(Youtube)</td>
</tr>
</tbody>
</table>
- Dedicated section for Patient Organization contact information in the APP.

- PO section independent from Rare Disease Center

The proposal IMMEDIATELY was accepted.
What this PART 1 tells us

• That many POs have acquired the awareness of our independent viewpoint and value yet we can constructively work towards improving this awareness in the HCP environment.

• That working with Clinicians in the ERNs, is a great opportunity for POs to get the message through and to be of help.

• That we need delegates that are aware of what patient engagement is and that are aware of the value of patient advocacy on a peer to peer basis. (Training)

• Our proposal was very easily accepted: we are heard.
Part II – Actually becoming part of the APP
Collecting Datasets: Feedback issues

The task of collecting datasets from other ePAGs was easier said than done:

• Lack of responses from ePAGs that had always had low levels of participation
• Difficulties in explaining the usefulness of the APP.
• Many disease group co-chairs still haven’t got connections with all patient organizations.

All added up: lots of work and incomplete results
Collecting Datasets: Incomplete contact info

- Collected PO datasets presented many incomplete fields
- Many do not have a dedicated phone number
- Many are not accessible through social media
- Not all have websites or official emails

All added up: not all organizations are equally findable.
The advantages for Federated POs

The HHT ePAG group benefitted greatly from the existence of the HHT Federation:

- The HHT ePAG co-chair personally knew all the delegates
- Feedback was immediate and accurate
- Trust in the ePAG co-chair favoured adherence to the project
- The Federation had already encouraged many organizations to develop dedicated helplines and social media pages
What does this tell us?

- ePAGs communities are a growing reality yet PO delegates that are not in the front line don’t always grasp the opportunities.
- Some POs on our lists are inactive, we begin to question up to what point we should struggle to get responses.
- Many POs could benefit from federated activities to share knowhow and resources and grow at the same pace of other European realities.
- Do we need to decide what characteristics a PO needs to have to be in the ePAG community? Can we train those behind to assist them?

All summed up:

**In a digital world we need to improve:**

**our findability and reliability**
The Crossborder Mobile App is a great opportunity that we are happy to be a part of. If you think it would work for your ERN please encourage your ERN coordinator and eHealth WG chair to contact:

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alex_pini@libero.it
Thank you….

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Managing Director – HHT Europe
ePAG co-chair – HHT WG - VASCERN

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