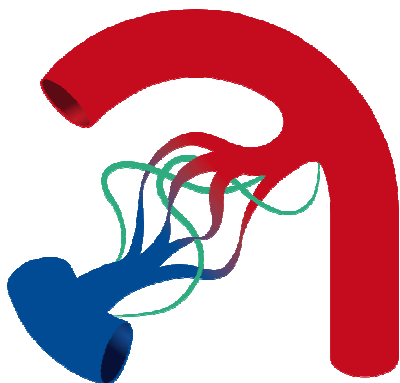


# European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)



# eHealth WG

Paris, Face-to-Face Meeting

October 12, 2018

# eHealth WG Monthly Call: Numbers

- 13 Monthly Meetings
- N. Participants = 9 (mean)

Month	N. Participants
May 17	9
June 17	13
July 17	11
Oct 17	8
Oct 17 (Paris)	29
Nov 17	11
Dec 17	9
Jan 18	8
Feb 18	9
Mar 18	8
Apr 18	10
May 18	8
Jun 18	9
July 18	8





# Agenda

Cross-Border pathway:  
Mobile Application

Pills of Knowledge  
(eLearning)

Conferences on YouTube

Communication advisory  
task-force

# Cross-Border pathway: Mobile Application



# Cross-Border pathway: Mobile Application



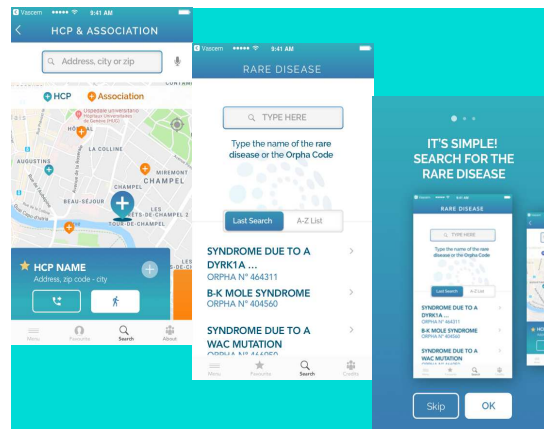
During EXPO2015 in Milan (Italy), Alessandro Pini (chair of the eHealth WG, VASCERN) developed a mobile app (ExploRare), to support patients with RDs to identify reference hospital and clinical centres located in Lombardy Region. The app was developed in 6 languages (IT, EN, ES, RU, ZH, AR)

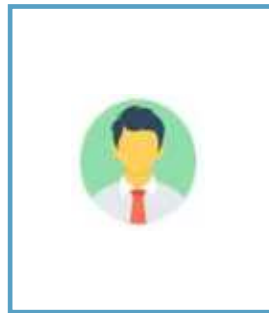


VASCERNApp was built on this pilot

## VASCERNApp

1. It will be officially launched in **Dec018/Jan019** and it will be in English at first
2. It will be made available in local languages to cover the whole EU area (version 2.1; 2019)
3. VASCERNApp is a modular platform, that will be developed incrementally during ERN lifetime through progressive updates and inclusion of new services
4. Is intended to become prospectively a gateway services for patients and for HCPs

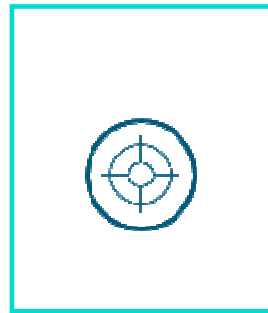




## WHO?

**Who  
is the Expert  
for my RD?**

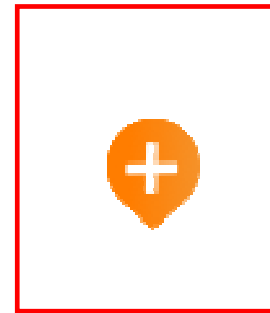
Just insert your  
rare disease and  
find the nearest  
Center of  
Expertise/Patient  
Organisation



## WHAT?

**What  
services  
(diagnostic,  
clinical) can I  
find?**

Look which  
services are  
offere by each  
Expertise Center  
and Patient  
Organisation



## WHERE?

**Where  
I have to go?**

Find the address  
of the Center of  
Expertise/Patient  
Organisation you  
have chosen and  
access directly to  
Google Maps.

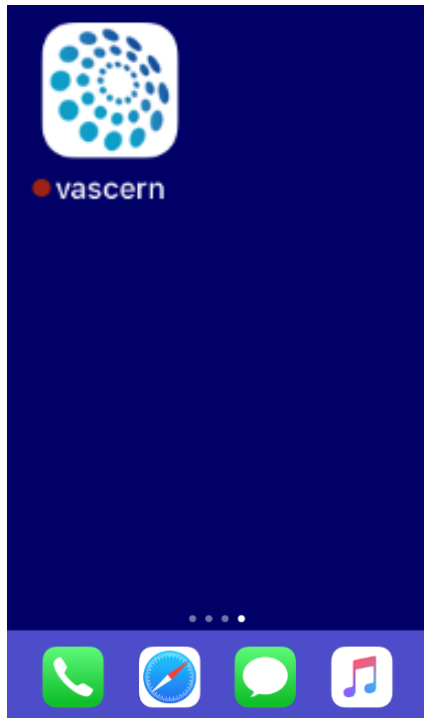
**YOU ARE  
GEOLOCALIZED**



## WHEN?

**When  
can I go?**

Look at the  
opening hours  
and how/when to  
contact the  
Center/Patient  
Organisation



In its first version, the app maps all the **37 CEs** and **40 POs** members of VASCERN from accross **15 EU Countries**

The information for each CE/PO includes:

- Practical details (name, address, contacts, opening hours, Coordinator details and specialization)
- Information about the diseases managed by the CE/PO
- List of medical specialization, core services and additional resources
- Functionalities as geolocalisation, direction, direct phone contact, messaging, email

***The app is now on trial phase on both platform (IOS/Android)***

***305 users among Clinicians and Patients are now testing  
VASCERNApp***

***A specific survey was created to ask feedback to ameliorate the  
app***



1. Search VASCERNApp on your **Google Play Store** and download it.
2. For **APPLE Store** the  $\beta$ -version for IOS need to go through TestFlight.
  - Ask the access code for the VASCERN App
  - Download TestFlight
  - You will receive an email from the developer saying “Alex Pini has invited you to test VASCERN App
  - Enter the access code into TestFlight
  - Download VASCERN App
3. Enjoy your new App
4. If any suggestion about the App, send me an email with details
5. We will try to solve every problem, the structural ones will be discuss on the vers 2.2
6. Fill the Survey to help us improve the app: [VASCERNApp Survey](#)

How to download  
the App





# Cross-Border pathway: Mobile Application

**Oct 2017**

- One DB for both HCPs and POs
- 16/31 HCPs
- 14/~70 POs DB
- Lots of missing information
- A list of diseases for each RDWG had not been defined

# Cross-Border pathway: Mobile Application



## 2017-2018

- Create a specific DB for: - HCP  
- ePAG
- Revise all the DBs (37HCPs+40POs):
  - 32 items x 37 HCPs = 1184 +
  - 19 items x 40 POs = 760 =

---

TOT **1944 info**
- We ask all HCPs/ePAG to check again their info:
  - **more than 124 emails sent**
- We create for each RDWGs a list of diseases (according to the VASCERN Official paper and interface with the RDWGs Chair): **from 16 Jan 2018 to 26 June 2018**
- Meet the developers to create the interface for the mobile App



# Aug-Sept requests

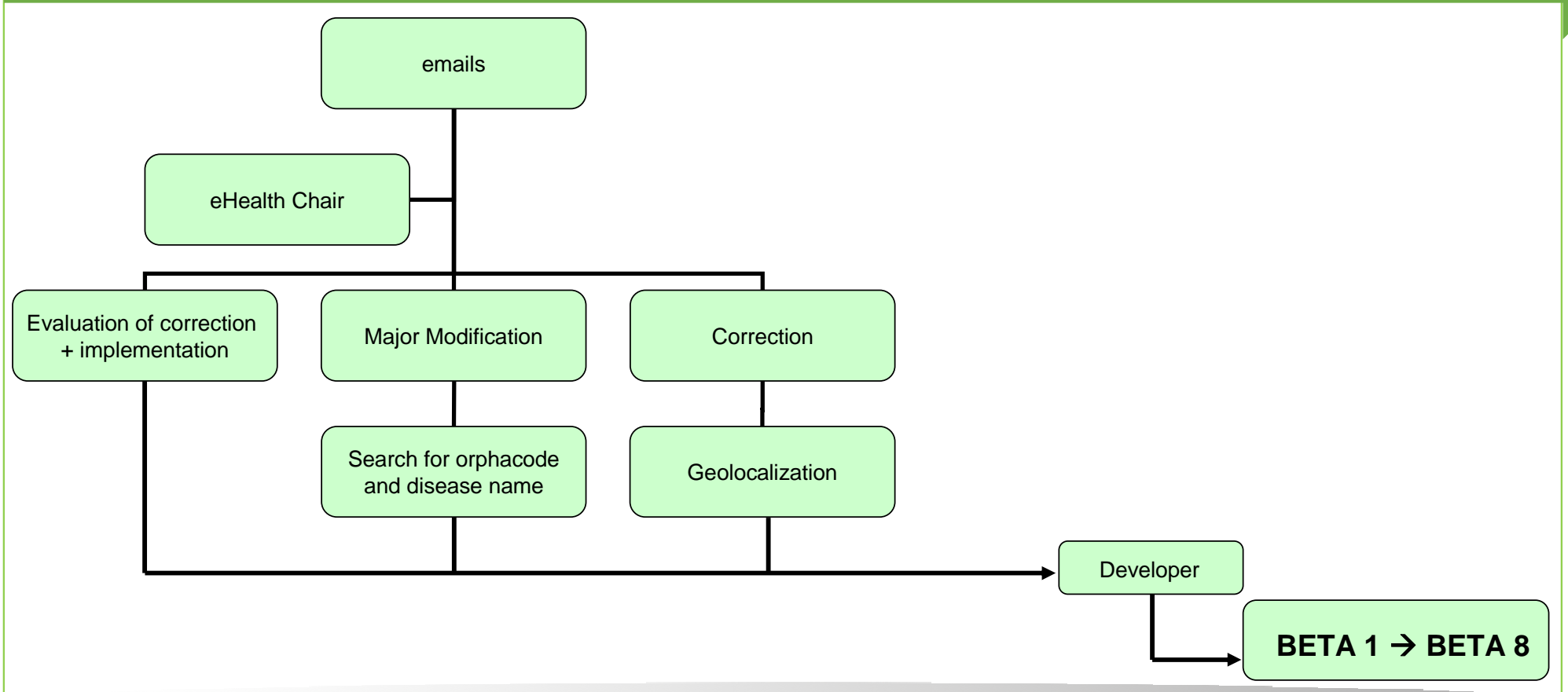
**More than 168  
request emails  
(HCPs+ePAG)**

Screen	August	September
<b>Tutorial</b>	<ul style="list-style-type: none"> <li>After 1<sup>st</sup> opening, the tutorial should not been shown</li> <li>Misspell SKYP→SKIP</li> </ul>	/
<b>Homepage</b>	The homepage should be the search screen not the menu' one	/
<b>Credits</b>	The size of the credits should be reduced	/
<b>Members</b>	<ul style="list-style-type: none"> <li>Not all the ePAG Members are shown</li> <li>Enlist the Country in alphabetic order</li> <li>Enlist the Countries with the possibility of expand them to see the members</li> <li>At the bottom of the page insert the possibility to select only HCPs or ePAG</li> <li>Mistakes in the definition of some HCPs</li> </ul>	<ul style="list-style-type: none"> <li>Enlist the Countries with the possibility of expand them to see the members</li> <li>At the bottom of the page insert the possibility to select only HCPs or ePAG</li> </ul>
<b>About</b>	<ul style="list-style-type: none"> <li>Remove the antispam message</li> <li>Add VASCERN Coordinator signature</li> <li>Improve text layout</li> </ul>	/
<b>Favourites</b>	<ul style="list-style-type: none"> <li>The saved cards should have a vertical scroll</li> <li>When you remove a saved card the screen should move to the remaining cards</li> </ul>	<ul style="list-style-type: none"> <li>The saved cards should have a vertical scroll</li> </ul>
<b>Search</b>	<ul style="list-style-type: none"> <li>Last search dos not work properly</li> <li>A-Z LIST of diseases are not in alphabetical order</li> <li>When you search a pathology change the "see orphannumber" button with "go on orphanet"</li> </ul>	/
<b>List of diseases</b>	<ul style="list-style-type: none"> <li>Check the list of diseases (expecially for PPL &amp; VASCA)</li> </ul>	Check the list of diseases (expecially for PPL & VASCA)
<b>HCP Cards</b>	<ul style="list-style-type: none"> <li>In the HCPs card, if no PO related open a screen that visualize "no related PO"</li> <li>Problem visualize the related PO</li> <li>Check the send email/call now button</li> <li>Is it possible to save the number associated to the "call now" button in the phone agenda</li> <li>Check the association between diseases &amp; HCPs</li> <li>Misspell mistakes</li> <li>If there are no information available insert in the description "no information available"</li> </ul>	Misspell mistakes (backend)
<b>ePAG Cards</b>	<ul style="list-style-type: none"> <li>Change in the contact section: HCP Coordinator with Personnel to contact</li> <li>Misspell mistakes</li> <li>If there are no information available insert in the description "no information available"</li> </ul>	Misspell mistakes (backend)
<b>Geolocalization</b>	<ul style="list-style-type: none"> <li>The geolocalization maps is street associated but this scale is too small</li> <li>There is no coherence between the geolocalization and the HCPs/ePAG shown on the maps</li> <li>Make the legend interactive with the possibility to select only HCP or EPAG</li> <li>The HCPs/ePAG that do not have a street address are not shown</li> </ul>	/
<b>Font &amp; screen</b>	<ul style="list-style-type: none"> <li>Possibility to enlarge the font</li> <li>Check the colours used in case of blind-colorness</li> <li>Possibility to zoom the screens</li> </ul>	
<b>HHT</b>	<ul style="list-style-type: none"> <li>Only the Bari HCP was shown</li> <li>For all the members insert in the Target diseases: HHT</li> <li>Associate the abbreviation to the complete name</li> </ul>	/

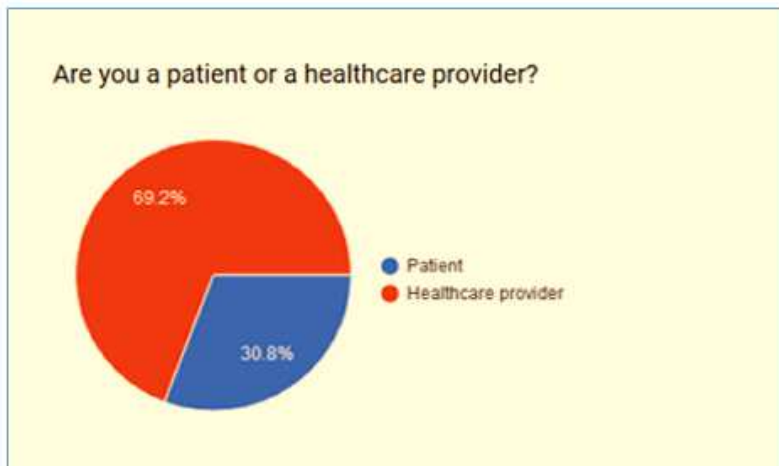
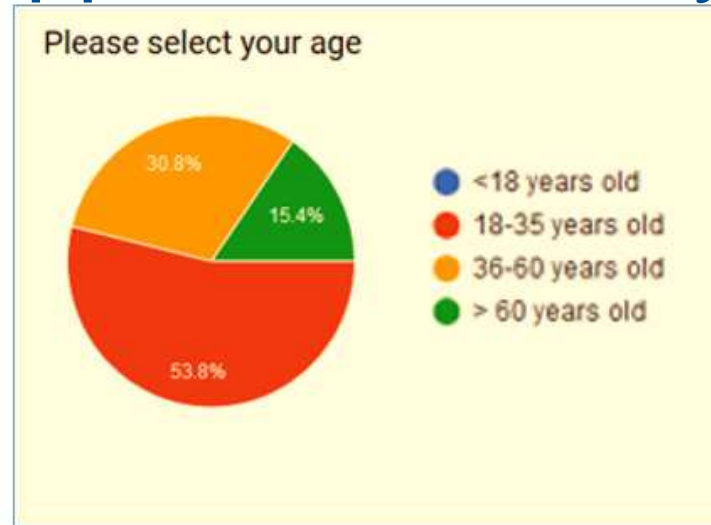
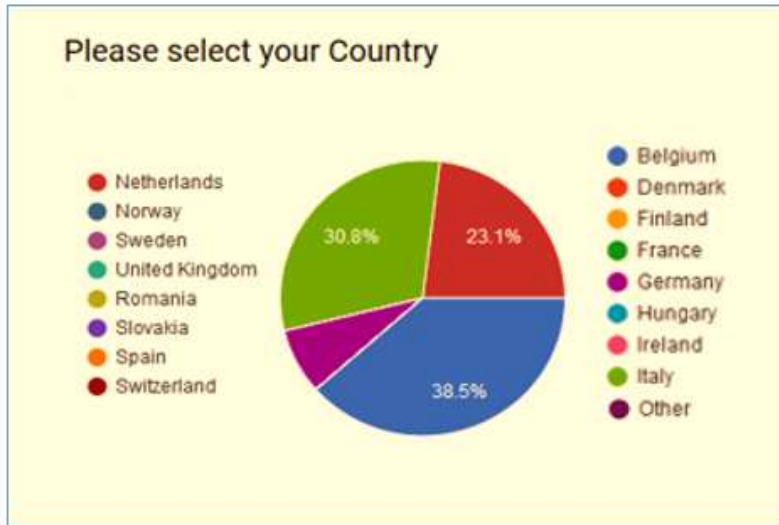
# Cross-Border pathway: Mobile Application



**Aug/Sept 2018**



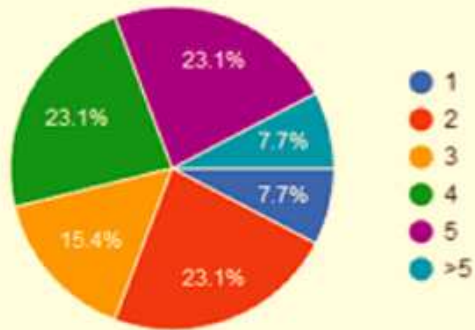
# Mobile Application Survey



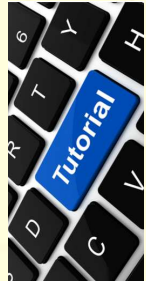
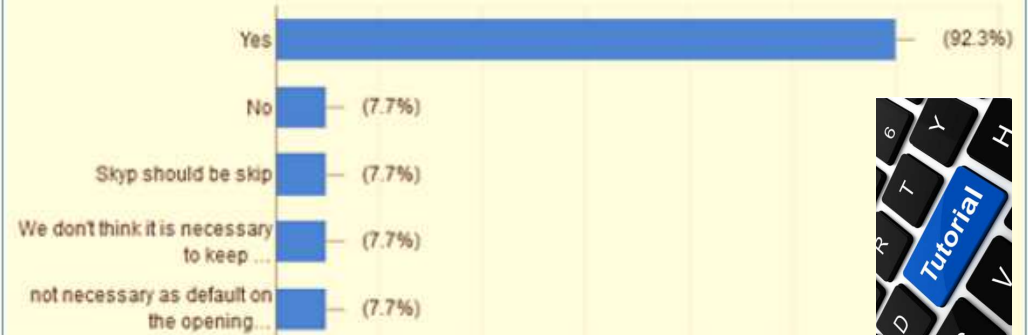
# Mobile Application Survey



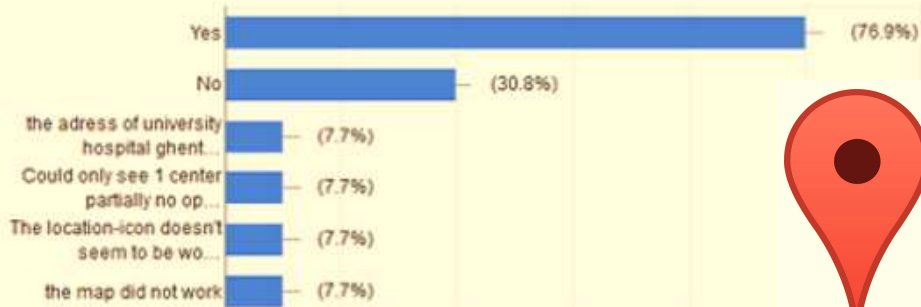
How many times have you tested the App?



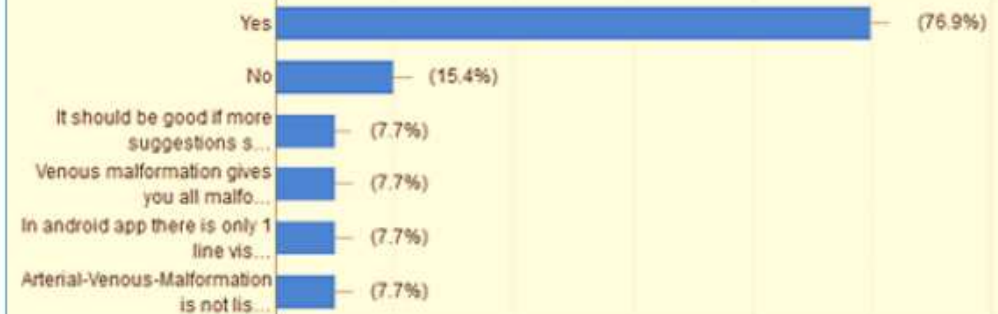
Is the Tutorial at the first opening sufficiently clear?



Was it easy to use Google Map?



Was it easy to find the disease/s of your interest?

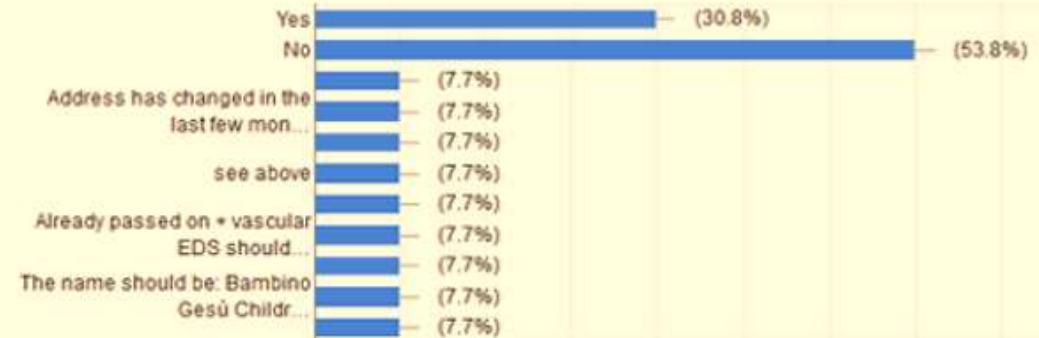


# Mobile Application Survey

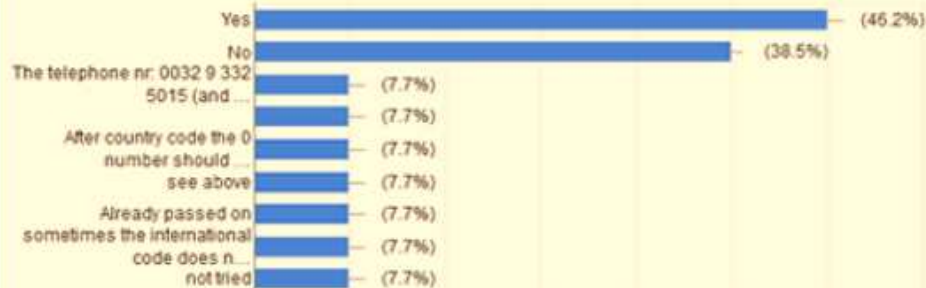


Enlist the Hospitals/Healthcare providers (HCP) you have tested

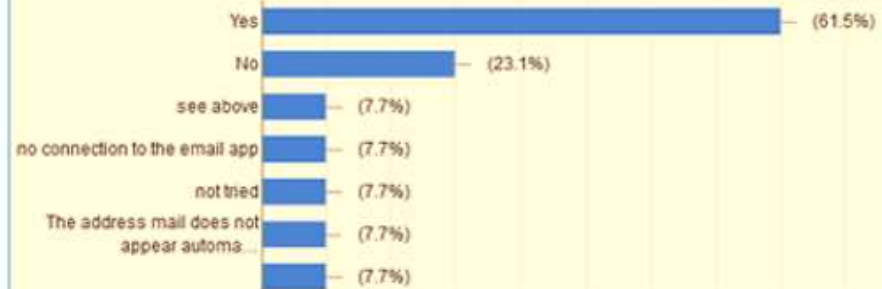

Is the information on the HCPs correct?



Does the "Call now" button work properly?



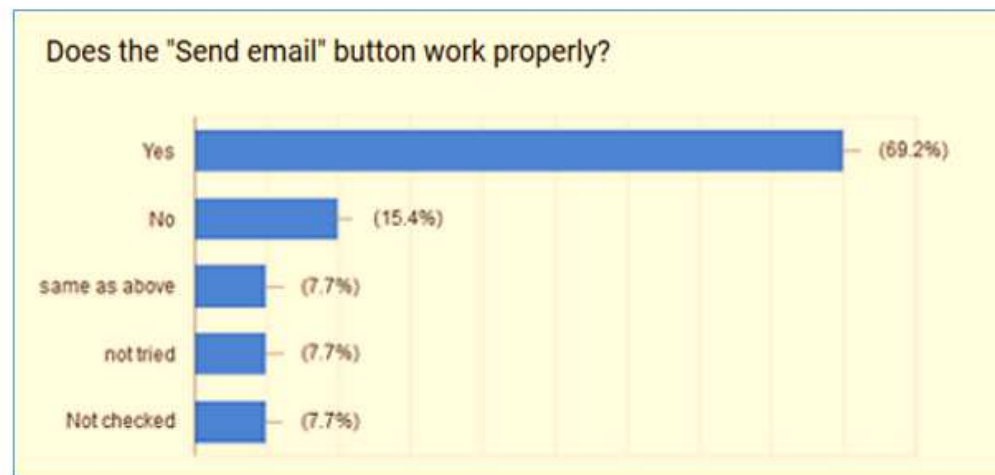
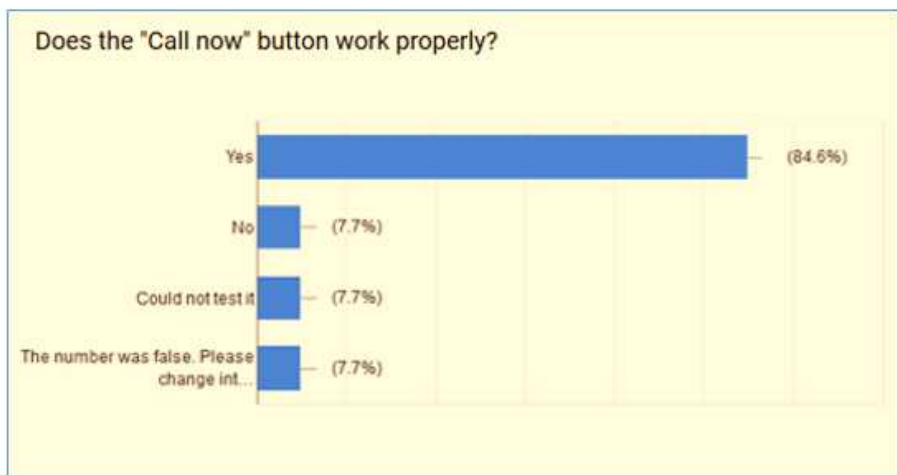
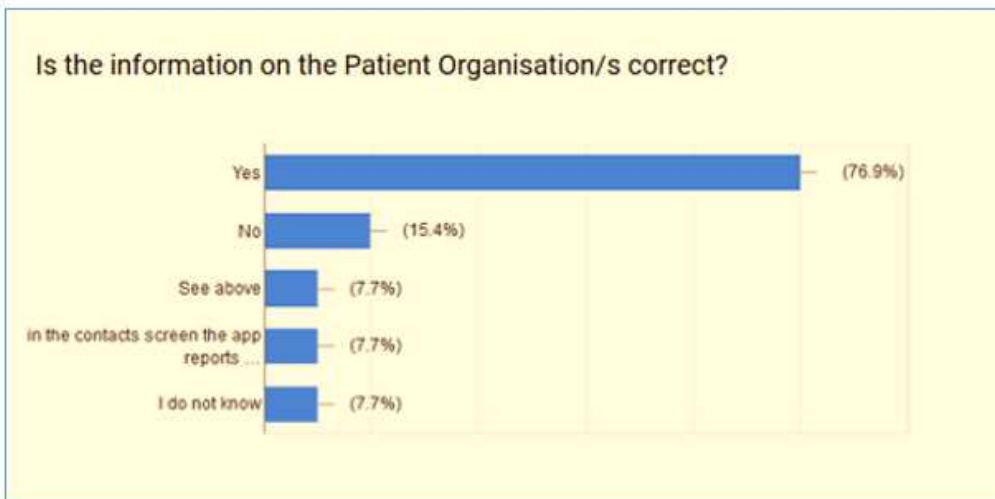
Does the "Send email" button work properly?



# Mobile Application Survey

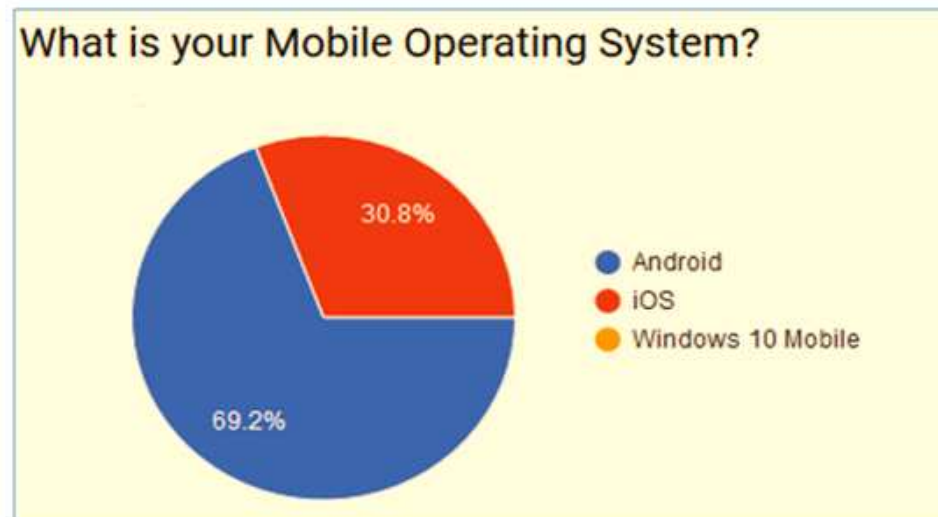
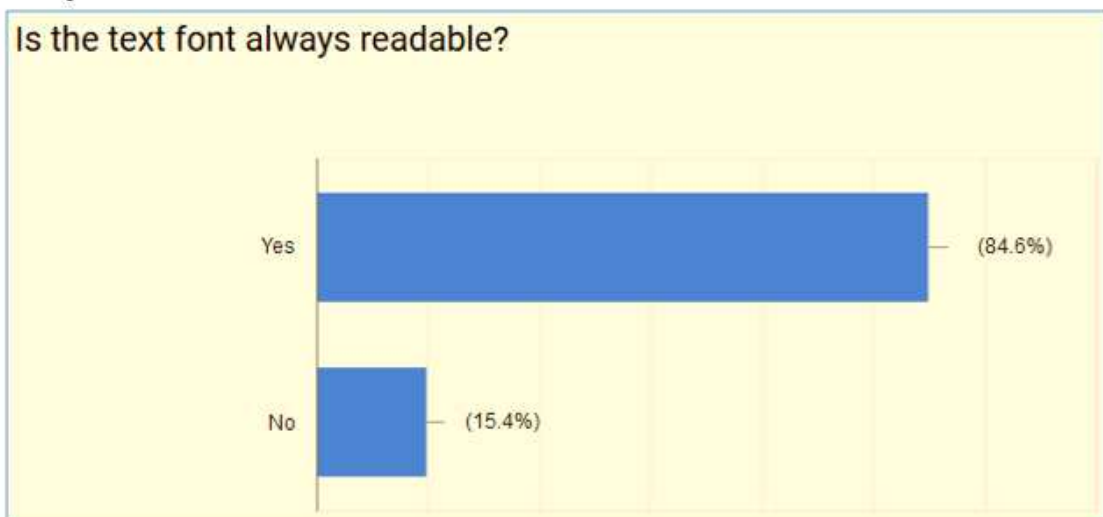
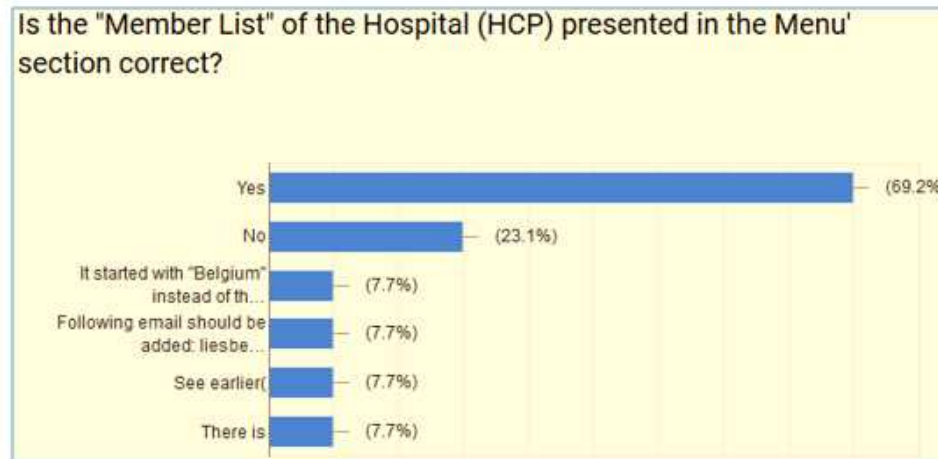
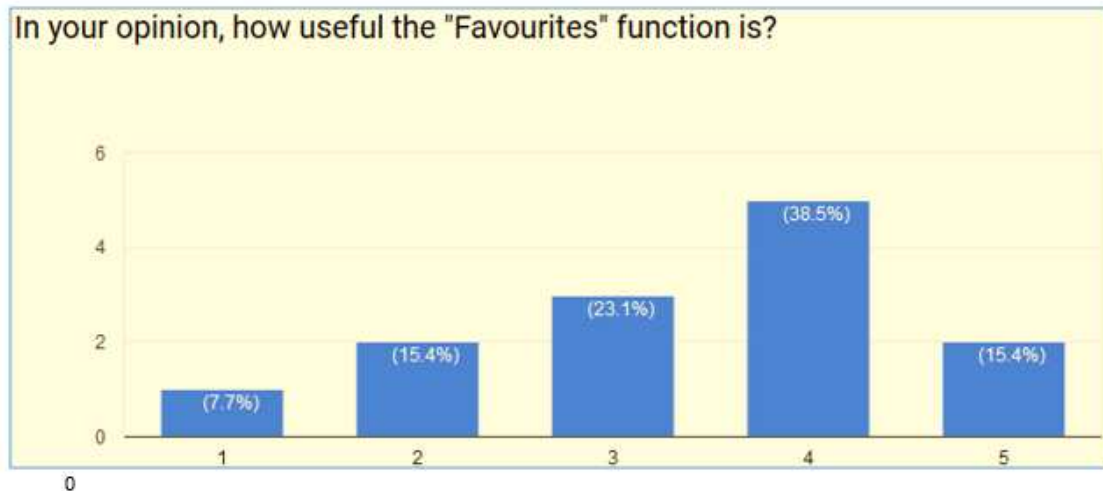


Enlist the Patient Organisation/s you have tested

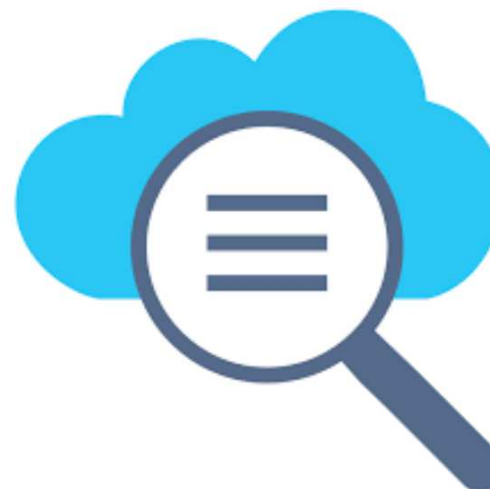
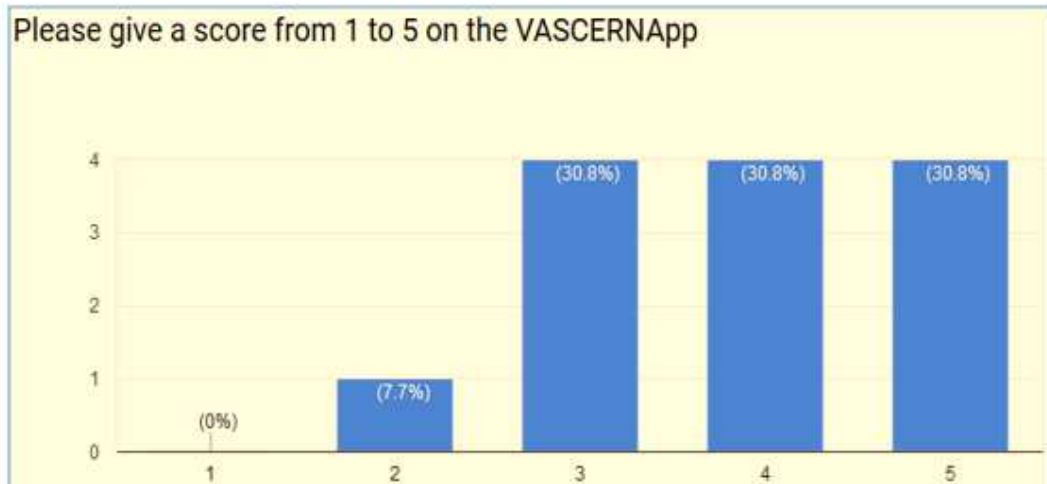





# Mobile Application Survey



# Mobile Application Survey



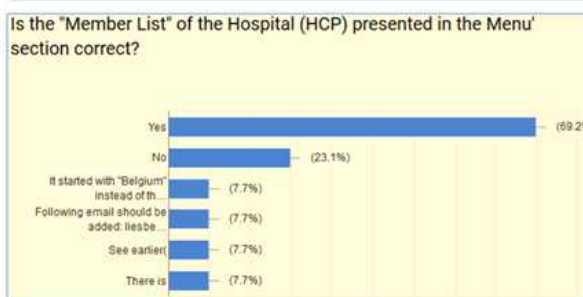
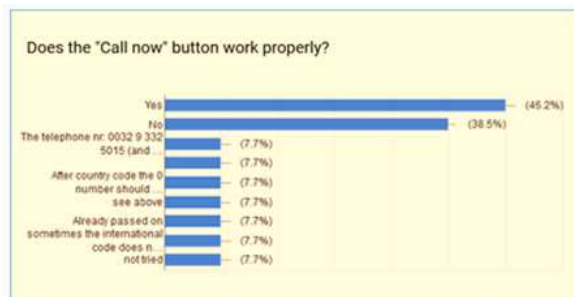
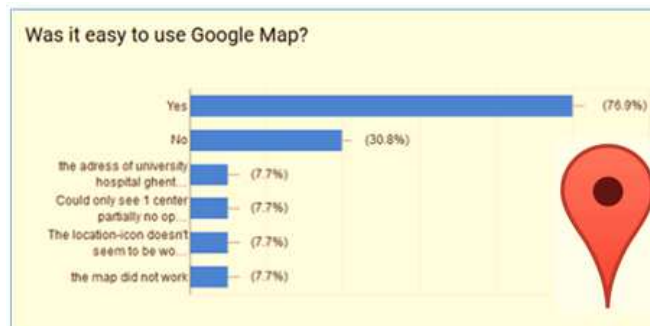
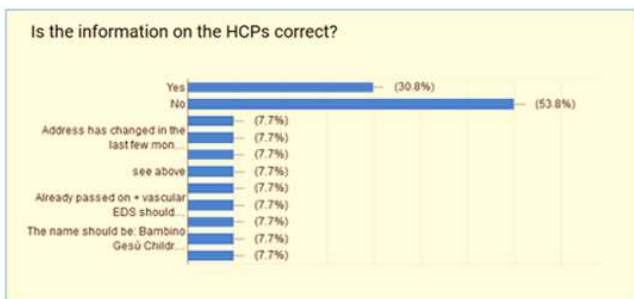
Could you please give us a general comment on the VASCERNApp?

After entering the search item, pressing enter to find it would be nicer then having to scroll down/remove the keyboard in the phone. After seeing the tutorial, it starts again. Shouldn't the app open the searchpart after that?

Very usefull

It's a great app to use if you're abroad and are experiencing health issues, or if you can't find any doctor's in your area

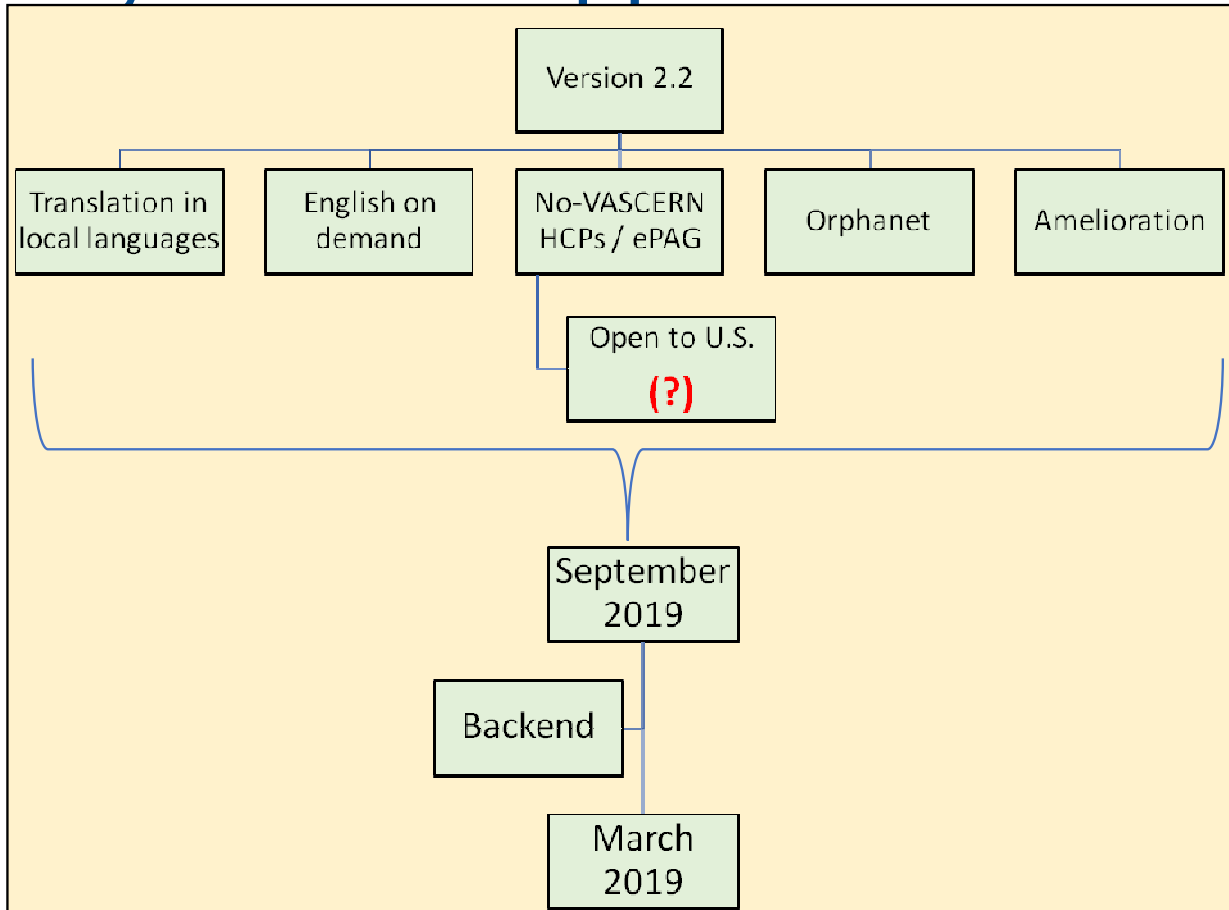
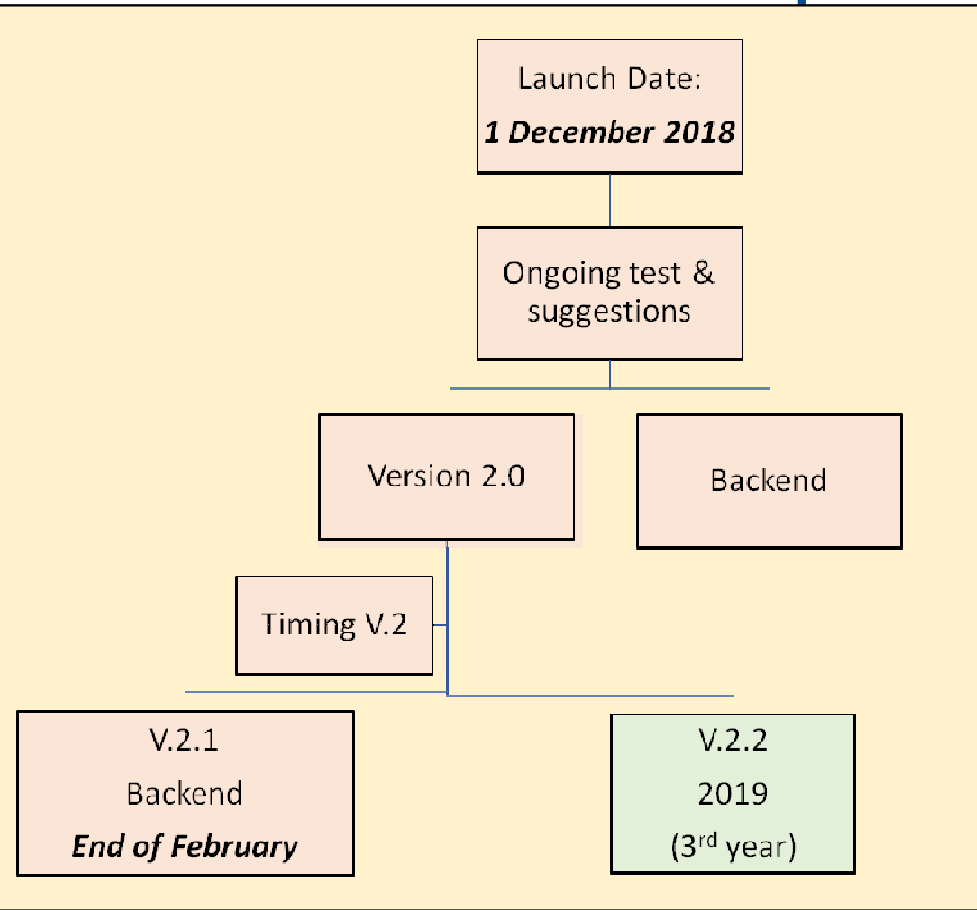
# Back end



**Survey is still ongoing** → Target 500 questionnaires among HCPs and ePAG



# Cross-Border pathway: Mobile Application



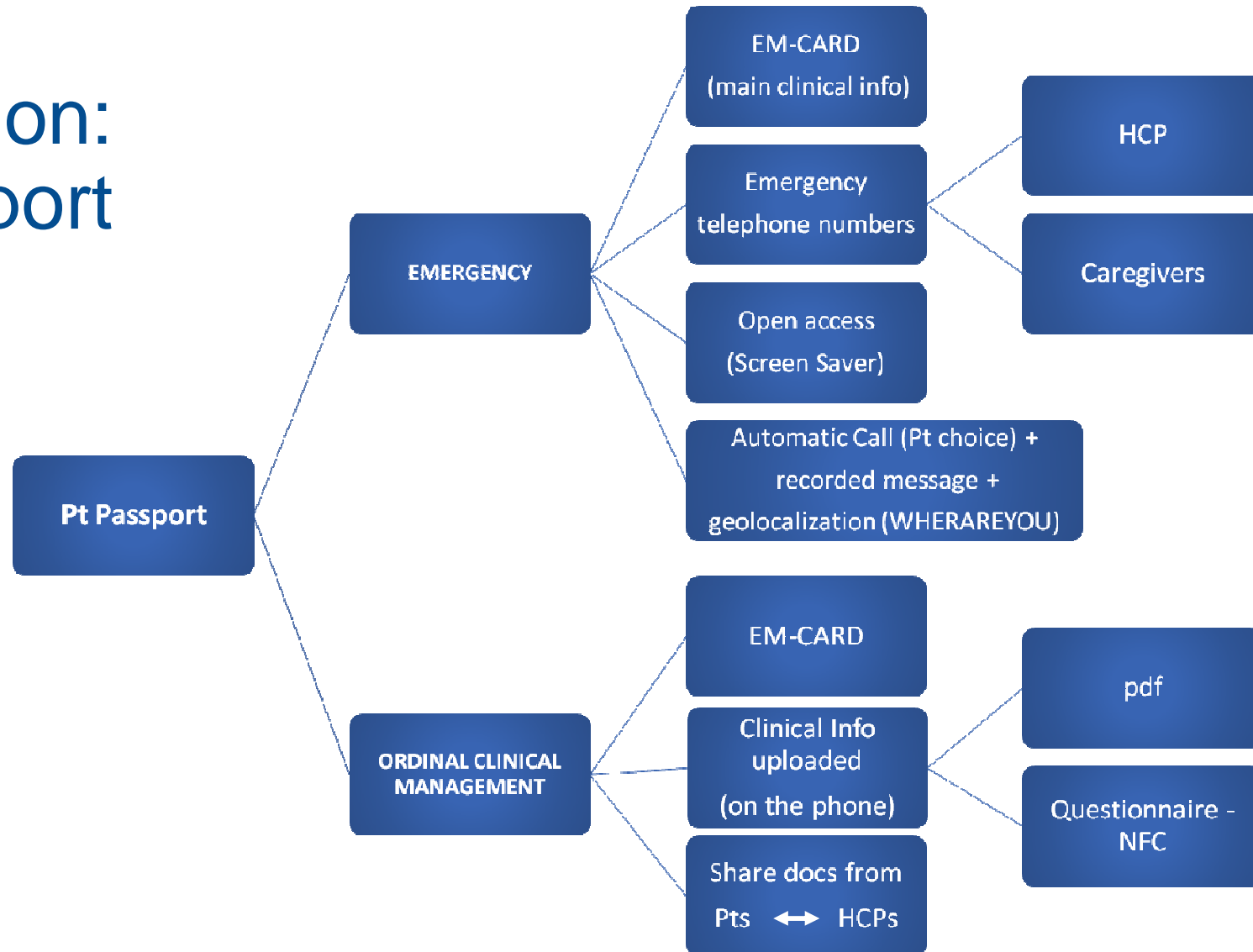


# Cross-Border pathway: Mobile Application

- 1** *Opening of VASCERNApp to no-VASCERN HCPs/ePAG*
- 2** *Overlap of diseases between RDWGs*
- 3** *List of diseases not always related to VASCERN pathologies*
- 4** *Link to ORPHANET*



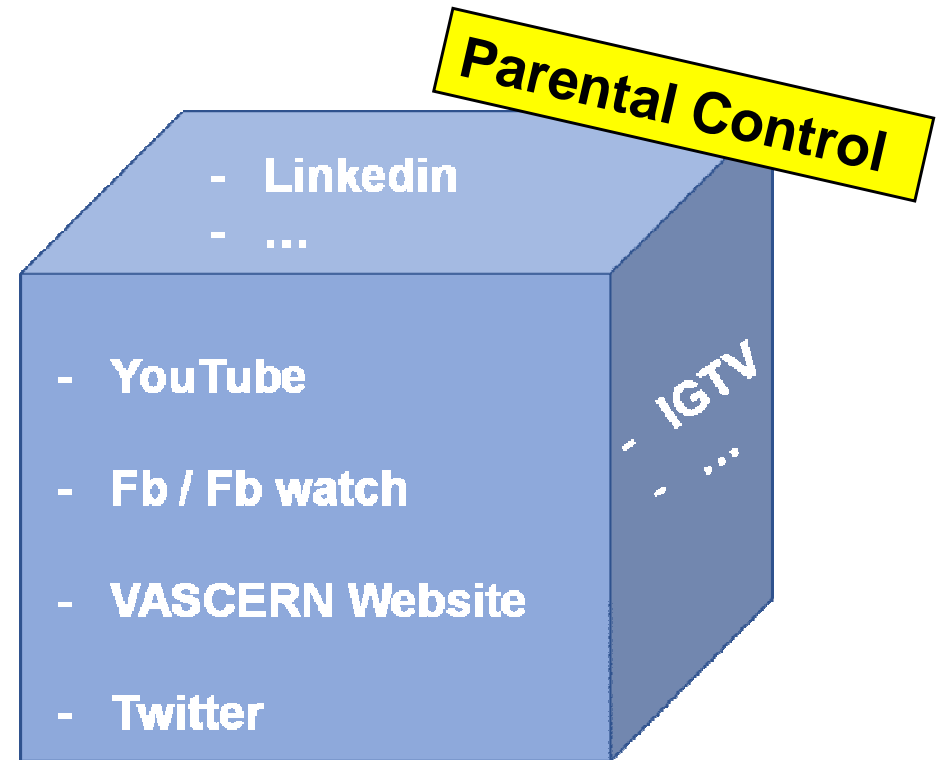
# Mobile Application: Pt Passport





# Mobile Application: Pt Passport

**All VASCERN materials  
linked to  
VASCERN Cube**





# Pills of Knowledge (eLearning)







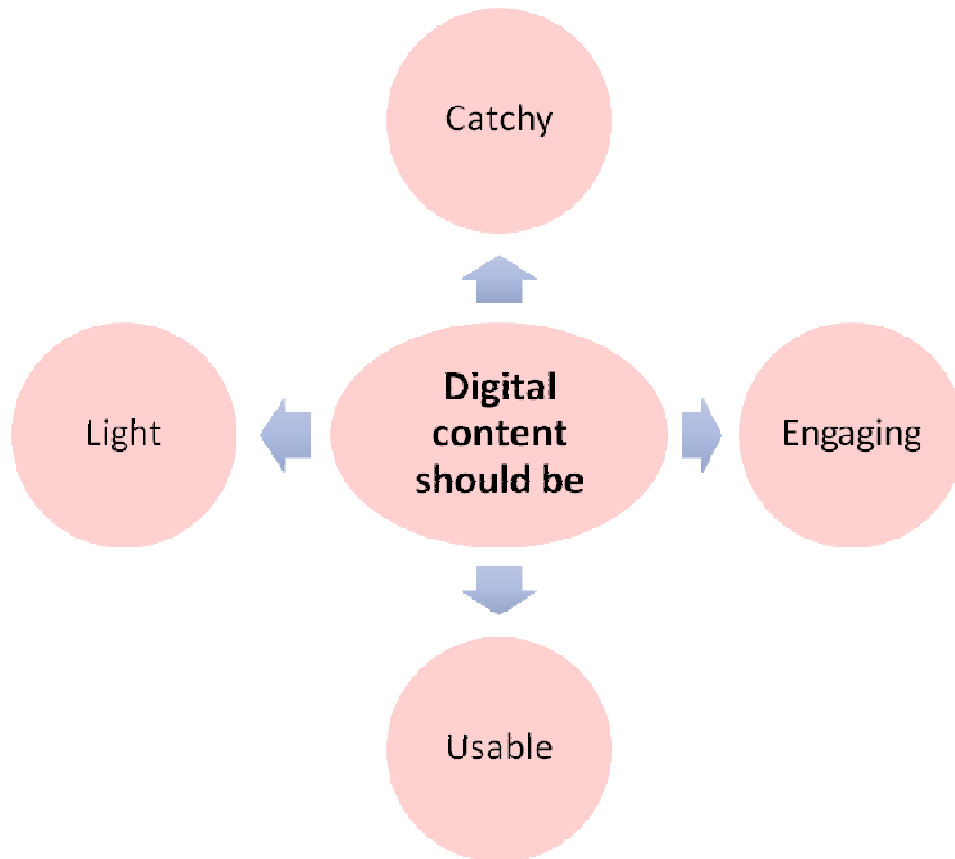
# Pills of Knowledge (eLearning)

OBJECTIVES	sharing of knowledge, improve knowledge via eLearning
WP4 Pills of Knowledge	D4: Pills of knowledge: 15 Video lessons available for e-Learning (obj: 3/ RDWG, 100 views/video) and Pills of Knowledge available on the website (text, links, translated patient info material) (including information on document translated)

- According with the definition of the RLO-CETL (Reusable Learning Objects-Centre for Excellence in Teaching and Learning) **a learning pill is a “reusable learning objectives”**, that is, a digitized entry, which can be used, reused or referenced during technology, supported learning.
- Learning objects are much smaller units of learning.
- Each learning object can be taken independently and reusable a single learning object may be used in **multiple contexts for multiple purposes**.
- Learning objects can be **grouped into larger collections of content**, including traditional course structures.
- By the using of audio/video tools, short lessons can be disseminated during hospital meetings or to stimulate a conversation/discussion/interactive lesson.
- These “pills” of rare disease knowledge will be available on a **mobile-friendly platform**



# Pills of Knowledge (eLearning)



## Advantages of POK:

- Training everytime/everywhere
- Greater continuity in the learning experience
- Reuse
- Cost reduction
- Up-to-date learning materials
- Flexible way to learning
- World-wide learn society
- Support know-how
- Easier way to learn by observation

# Pills of Knowledge (eLearning)



RDWG	n. Viewers from Jan2018 to Oct2018
HHT	1335
	231
HTAD	763
PPL	204
VASCA (both in Dutch)	53
	34
Tot	2620

**POK are the most-viewed videos on our YouTube Channel**

# Pills of Knowledge (eLearning): Improvement



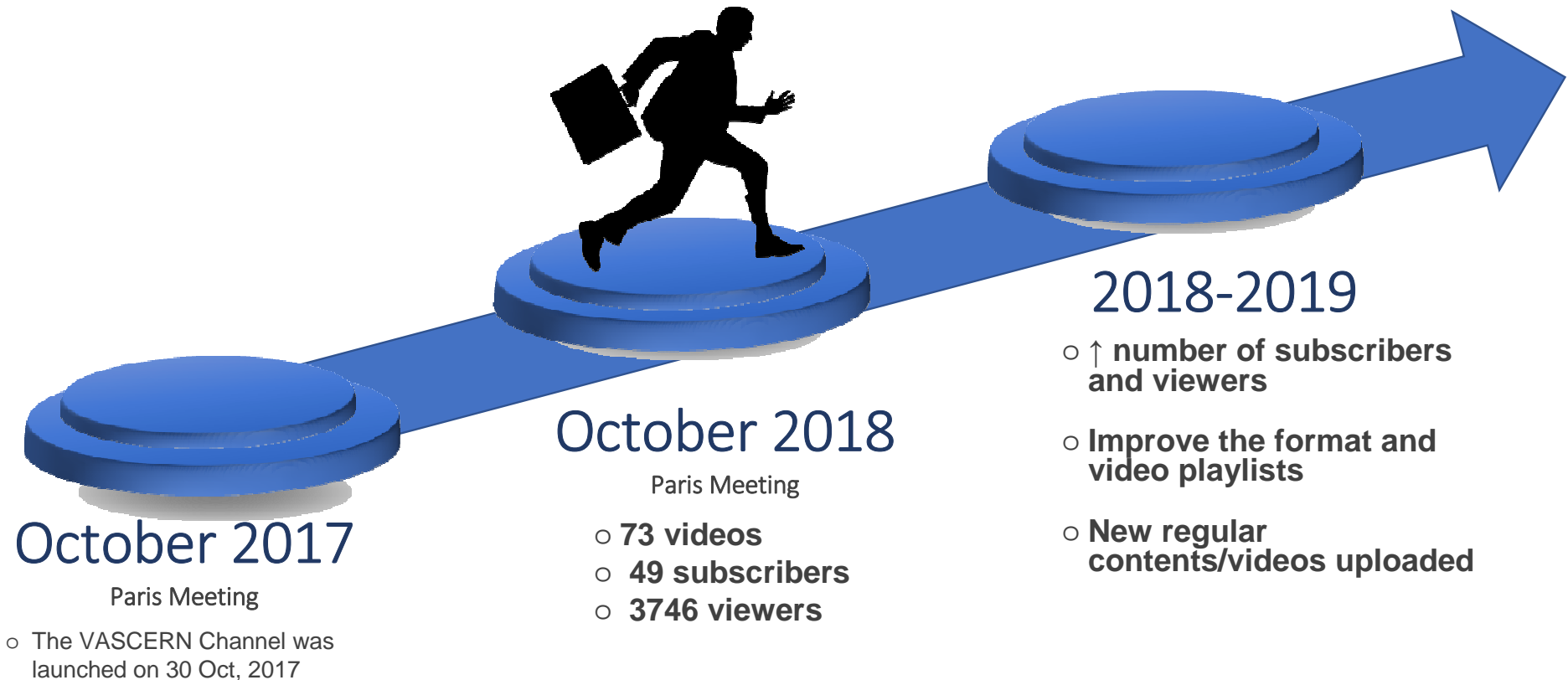
1. Create clear playlists for each RDWGs that will contain POK fold
2. Define an official thumbnail for all the POK
3. Use correct tags and keyword to spread the video on Social platform
4. Translate them in as much languages as possible
5. Create different type of format
6. Spread it on different Social Media platform (YouTube, Fb watch, ..., IGTV)



# Conferences on YouTube



# Conferences on YouTube: Trend & Target



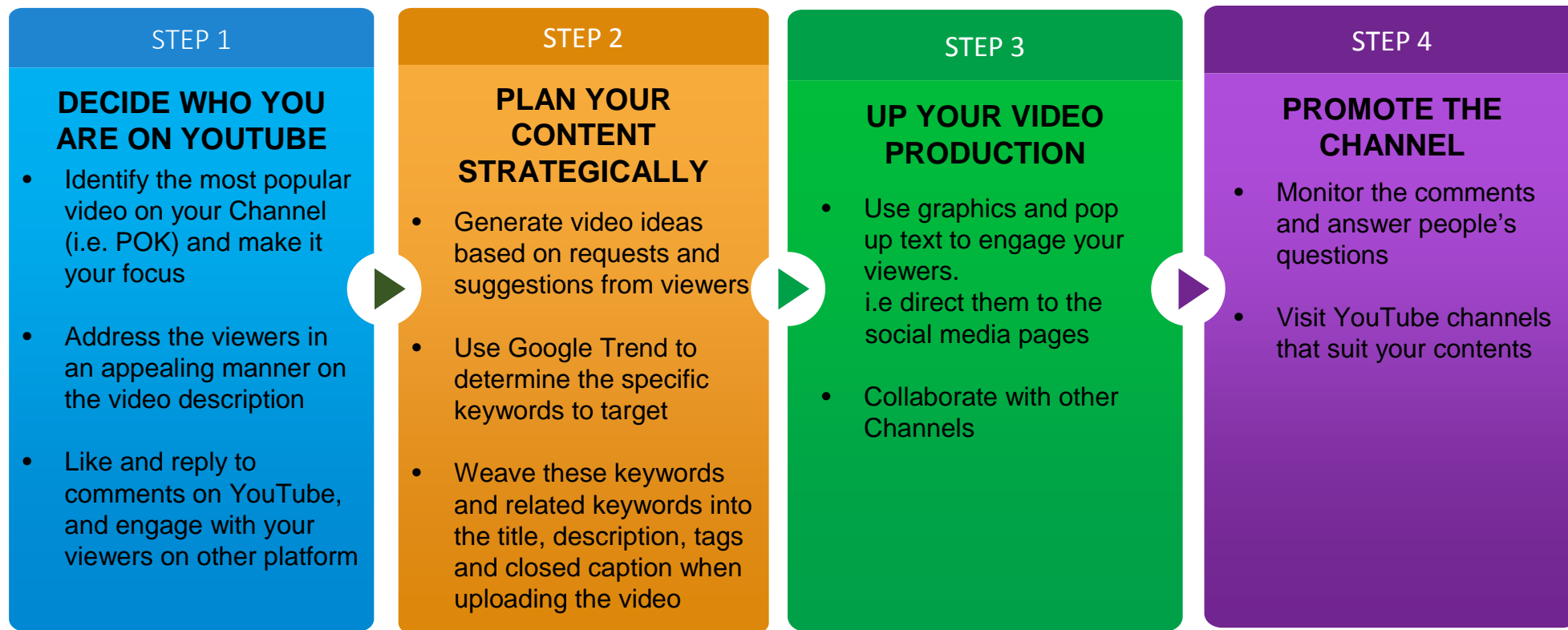
# Conferences on YouTube: VASCERN vs other ERNs



ERN	N subscribers	N videos	N playlists	Most views video	Overall viewers	Channel creation
Endo-ERN	0	2	0	49	nd	nd
ERN EpiCARE	5	13	3	47	212	18 Dec,2017
ERN EYE	11	35	6	90	335	27 June, 2017
ERN ITHACA	0	2	0	41	41	26 July,2018
ERN RARE-LIVER	7	2	0	152	nd	nd
ERN ReCONNET	38	5	1	63	219	23 March,2018
ERN-RND	3	1	0	39	39	24 March, 2018
MetabERN	1	25	0	74	136	23 Dec,2017
<b>VASCERN</b>	<b>49</b>	<b>73</b>	<b>8</b>	<b>1335</b>	<b>3746</b>	<b>30 Oct, 2017</b>

+ 10 POK during Paris Days  
+1 VASCERN Presentation

# Conferences on YouTube: Strategy





# Conferences on YouTube



The screenshot shows the YouTube channel page for VASCERN ERN Rare Vascular Diseases. The channel name is 'VASCERN ERN Rare Vascular Diseases' with 49 subscribers. The page features a navigation menu with 'HOME PAGE', 'VIDEO', 'PLAYLIST', 'CANALI', 'DISCUSSIONE', and 'INFORMAZIONI'. The main content area displays a video titled 'An Overview of Pediatric and Primary Lymphedema' as the first video in the 'HOME PAGE' section. Below it, there are two playlists: 'Pediatric and Primary Lymph...' and 'Heritable Thoracic Aortic Di...'. The right sidebar shows popular channels like 'Fanpage.it', 'La7 Attualità', 'FlashTV@', 'Breaking Italy', 'Luca Mastrangelo', and 'M5sParlamento'. Red boxes and arrows highlight specific elements: '1) Personalized logo' points to the channel logo; '2) Insert image' and '3) Add link to other Media' point to the channel banner; '4) VASCERN Trailer at first' points to the first video; and '5) Organization's of videos and playlists' points to the playlist section.

# Conferences on YouTube: Component for a succes



1. Regular uploading and publishing (schedule)
2. Compelling programming (evergreen topics such as health)
3. Optimization such as:
  - Metadata (title <50 characters in order not to be cut off, description, tags)
  - Annotations (links within your Channel)
  - Channel art
  - Publishing best practices (respond to any comments)

**Look at the analytics to find out how long viewers are watching each video (viewers retention rate) and how many viewers are converting to subscribers**

# Conferences on YouTube: Channel Tips



- 5-10 min max
- Different playlists
- Multilanguage
- Link to other videos
- Be part of the YouTube community
- Video embedding (website, Fb, ...)
- Add subscribe end screen



# Conferences on YouTube



**YouTube and Google** can't watch or listen to your video, that is why **title tag info, keywords in description and tags** are important for SEO (Search Engine Optimization), the more YouTube knows about our video, the higher the possibilities for the video to be ranked on the first search results.

**If you search "European Reference Network" in the YouTube search bar VASCERN is the 26° results**

## TEXT IS AS MUCH IMPORTANT AS THE VIDEO

- **Video description** is at least 200 words
- Use **keywords** that will be always present in the presentation of your videos.
- Use at least 10 **tags**. Optimal tags are choose using the search bar of YouTube or Google to see trending topics



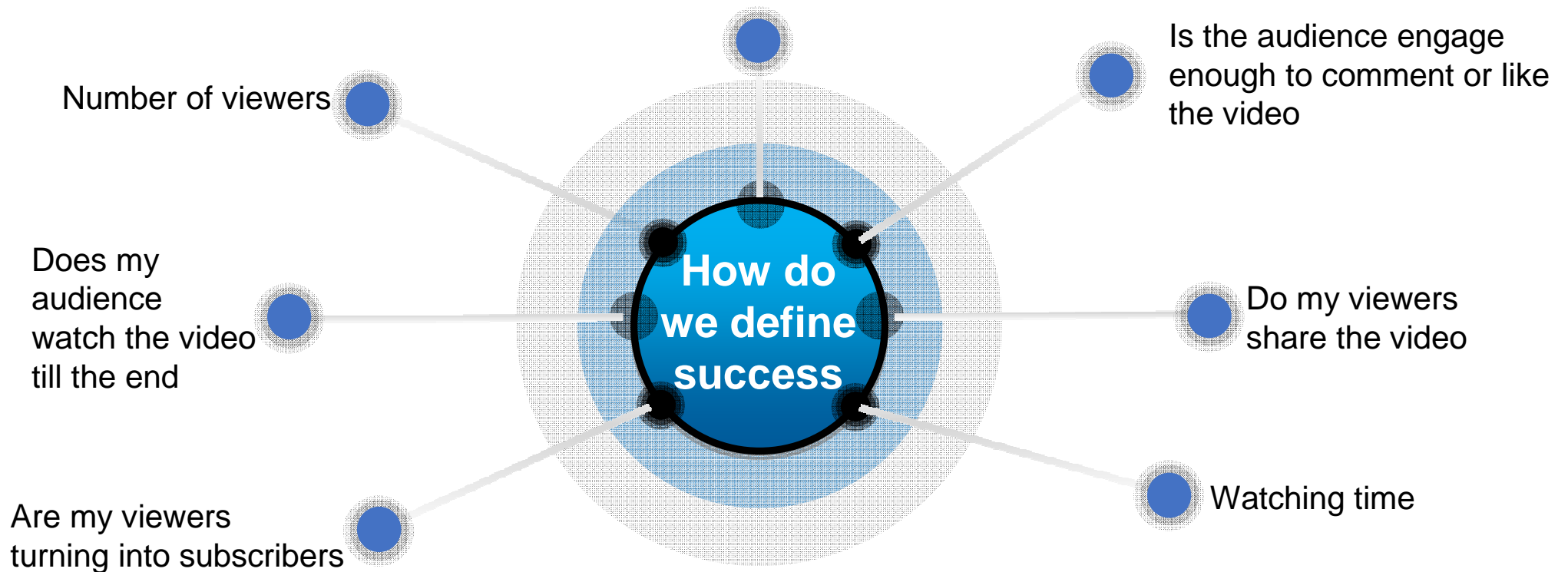
*"the most important criteria that a search engine examines are your keywords."*

**WHO?**

# Conferences on YouTube: Analytics



Number of subscribers



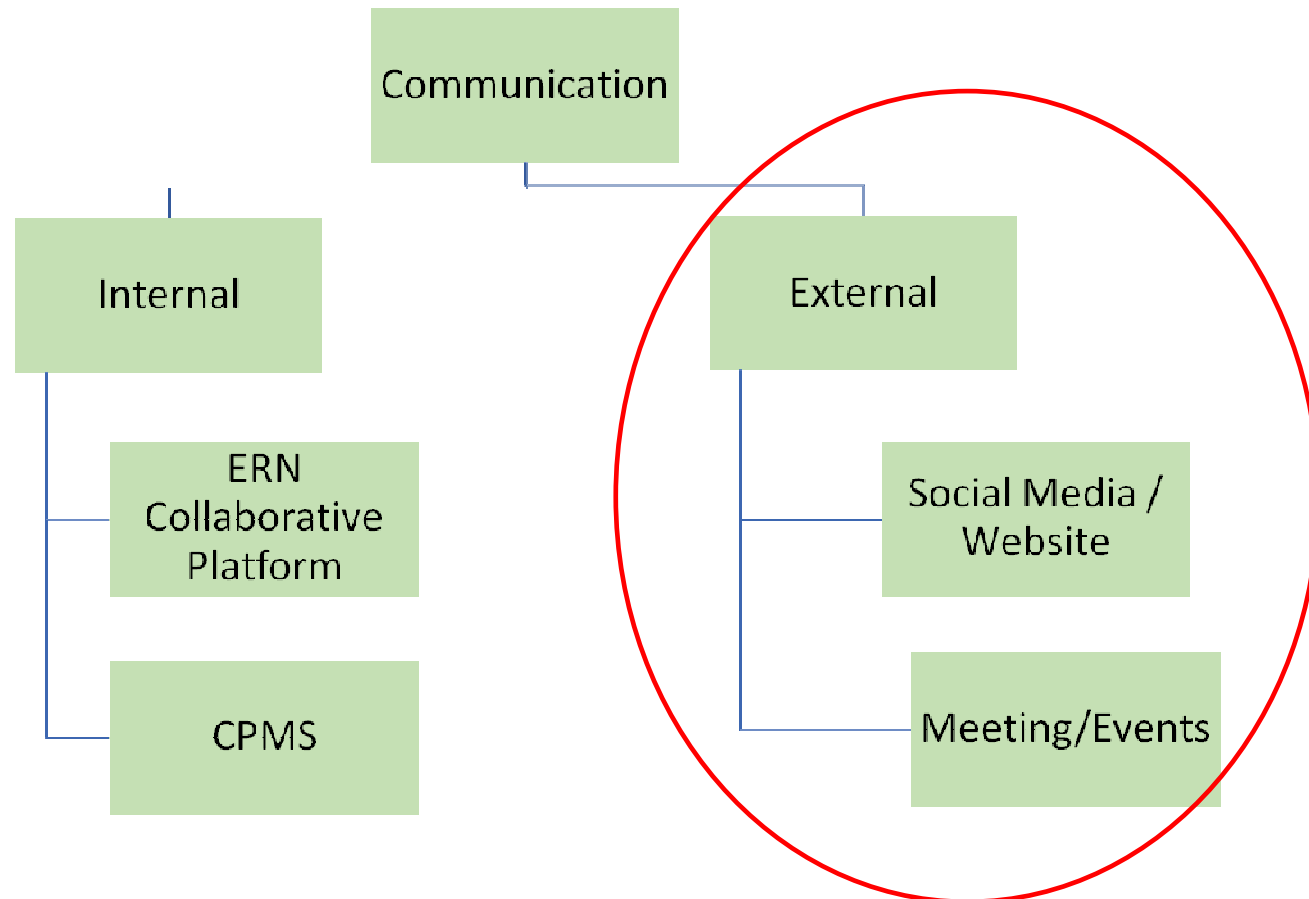


# Communication advisory task-force





# Communication advisory task-force





# Communication advisory task-force

**“The Communication advisory task-force  
aims to follow the progress and results  
regarding communication and dissemination  
of VASCERN's outputs”**





# Communication advisory task-force

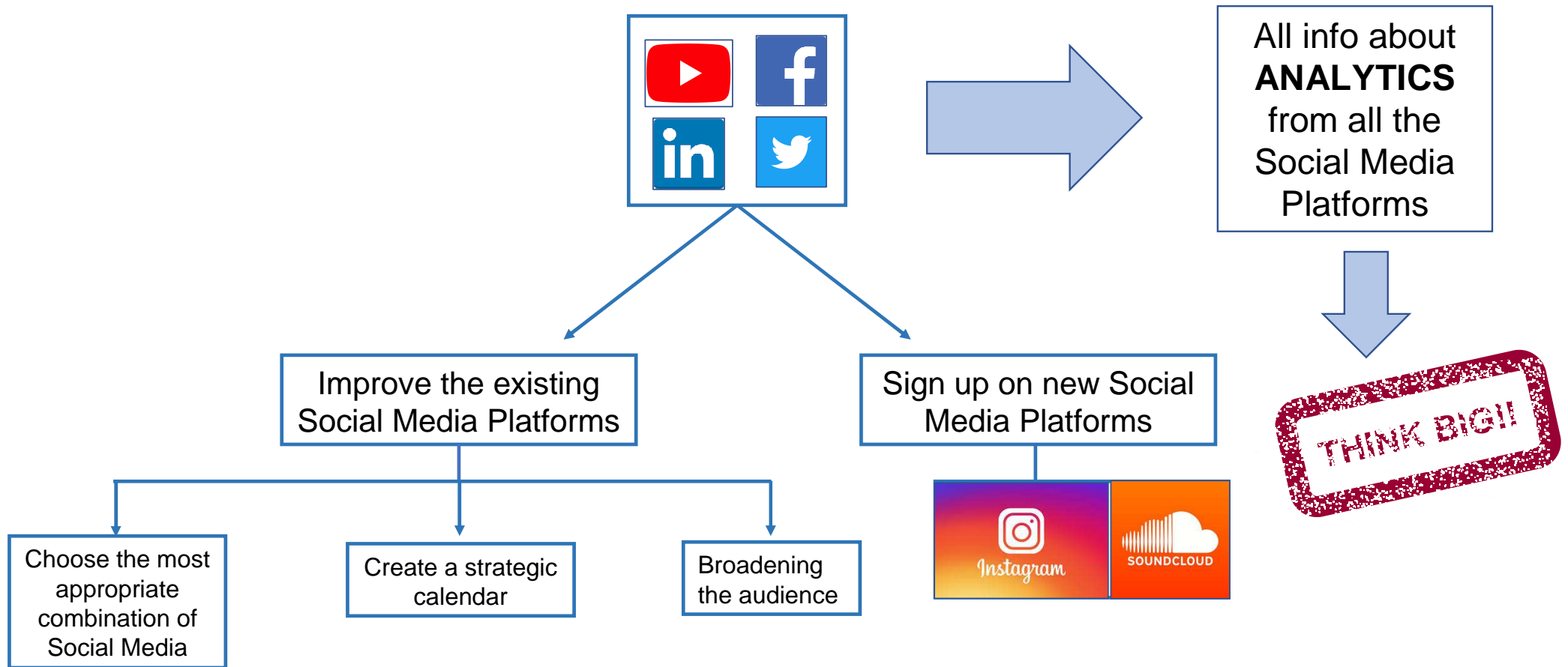
By now, the group is composed by **7 members**:

- Ange vdV
- Caroline vdB
- Claudia C
- Marine H
- Raffaella R
- Eulalia B
- Hans-Jurgen M
- Alessandro P
- Raffaella G





# Communication advisory task-force





# Communication advisory task-force



Follower **338**  
Created on **Feb 2017**

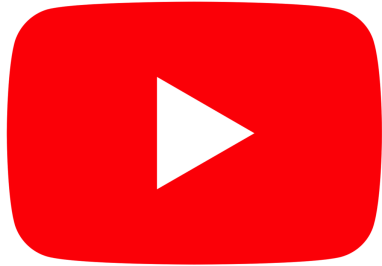
- This platform is an **opinion sharing** Social Media, therefore useful for VASCERN to share the content presented on other Social Media platforms



Follower **279**  
Created on **Oct 2017**

- **Should be our main focus for circulating content** as it can spread information quickly and for create dialogue with patients and POs
- **Facebook Watch**, is FB video on demand service. It offers a place on Facebook to discover shows and video.  
***We could share the video on our YouTube Channel also on Facebook / Fb watch***

# Communication advisory task-force



Subscribers **49**  
Created on **Oct 2017**

## YouTube Instant tips:

- All VASCERN Members **should follow** the page and **invite** their Patients to subscribe
- More functional way to organize the video
- Importance of using tags/keywords



Followers **43**  
Created on **2016**

## LinkedIn Instant tips:

- All VASCERN Members with a **LinkedIn account** (HCP/POs/patients) should be kindly asked to follow the page and add a link on their own profile
- The Coordination team may regularly add posts and updated regarding POK in particular and VASCERN outcomes in general in order to share them among the network



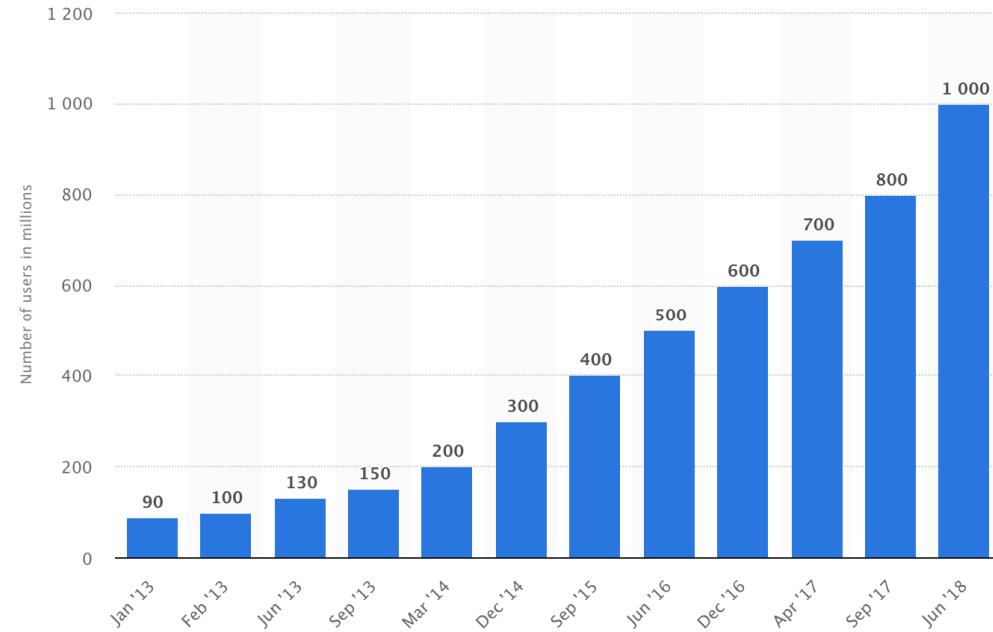
*Instagram*



# By Numbers



Some Numbers (updated on Sept 2018):	
Total N. of Monthly Active Instagram Users	<b>1 billion</b>
Total N. of Daily Active Instagram Users	<b>500 million</b>
Instagram Stories Daily Active Users	<b>400 million</b>
N. of Photos Shared to Date	<b>50 billion</b>
N. of Instagram Likes per day	<b>4.2 billion</b>
N. of Photos/Videos uploaded per day	<b>100 million+</b>

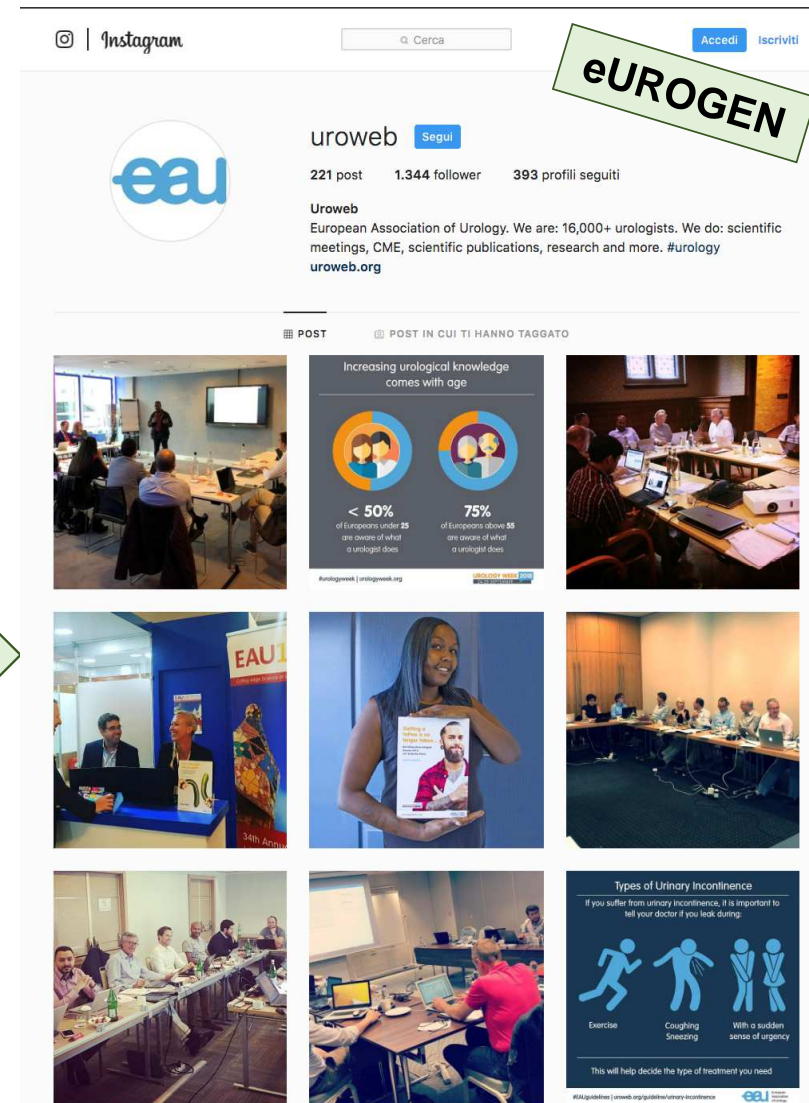
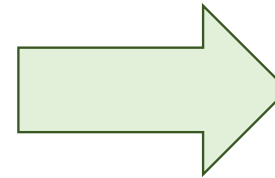


- 80% of Ig users come from outside the U.S.
- 6/10 online adults have Instagram accounts.
- 32% of all Internet users are on Instagram.

**Instagram videos get 2 times the engagement of photos that any other social media platform**



- Possibility to upload photos from events or leaflets
- **IGTV**: create long videos (max 1h) to share with the community (POK or videos from YouTube)
- Videos can be shared, liked and commented





# SoundCloud



- **SoundCloud** is a music and podcast streaming platform
- It is possible to create audio version of our POK general eLearning materials

SOUNDCLLOUD Classifiche Cerca artisti, band, tracce e podcast Accedi Crea account Carica

**EAU Radio**

Tutto Tracce Album Playlist Ripubblicazioni

Stazione Segui Condividi

Follower 8 Seguiti 6 Tracce 2

European Association of Urology. We are: 16,000+ urologists. We do: dozens scientific meetings, CME, scientific publications, research and much more.

uroweb

6 seguiti Visualizza tutto

The Full Release - Sex, Health & R... 41 32 Segui

The Urology Foundation 17 8 Segui

EAU Radio EAU - Highlights Urology Week 2016 - Interviews 2 anni # Science 15:31

EAU Radio EAU - Urology Awareness Podcast 2 anni # Science 7:59

0:00 15:31





# About VASCERN

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million concerned). These include arterial disease (affecting aorta to small arteries), arterio-venous anomalies, venous malformations, and lymphatic diseases.

VASCERN currently consists of 31 highly specialised multidisciplinary Healthcare Providers (HCPs) from 11 EU Member States and of various European Patient Organisations and is coordinated in Paris, France.

Through our 5 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information available at: <https://vascern.eu>

Follow us on [Twitter](#), [Facebook](#), [YouTube](#) and [LinkedIn](#)



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