



# social media

journalist workshop  
on organ donation and transplantation

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# Background

Campaigns, Organ shortage & Social Media

1

The major problem in transplantation medicine is the shortage of organs

2

Most countries (& national transplant organizations) focus on public campaigns to cope with this problem!

3

Social media offers a new approach in shaping public opinion and in mobilizing people's participation!

# Background

Campaigns, Organ shortage & Social Media

Social media include collaborative projects (e.g. Wikipedia), blogs and microblogs (e.g. Twitter), content communities (e.g. YouTube), social networking sites (e.g. Facebook), virtual game worlds (e.g. World of Warcraft), and virtual social worlds (e.g. Second Life)

Kaplan, Haenlein (2010)

# Social media

CDC-Toolkit: <http://www.cdc.gov/socialmedia>



The Health Communicator's Social Media Toolkit  
Table of Contents

- Social Media Introduction
  - Social Media Overview 1
  - Getting Your Feet Wet With Social Media 2
  - CDC's Top Lessons Learned from Using Social Media 4
  - Developing a Social Media Strategy 5
  - Social Media Monitoring and Evaluation 6
  - Governing Social Media Efforts 6
- Social Media Tools
  - Buttons and Badges 8
  - Image Sharing 9
  - Content S... 10
  - 11
  - 13
  - 15
  - 18
  - 19
  - 21
  - 27
  - 32
  - 36
  - 40
  - 46
  - 47
  - 50
  - 53

health messages, increase audiences and advance efforts.

## Getting Your Feet Wet With Social Media

There are a variety of social media tools that can be utilized as part of an integrated health communications program. Tools range from easily downloadable products, such as buttons and badges, that can be implemented with minimal resources, to engagement tools that foster two-way communication and ongoing interaction, such as social network sites. Generally, as you progress from dissemination to engagement, more resources are needed for set-up and maintenance and the potential exists for greater participation, learning and sharing. We recommend giving careful consideration to the amount of resources and expertise required before deciding on the tools you may want to use. It is often beneficial to start with social media projects that may be considered low risk or use fewer resources at the outset, and then adopt more engaging tools that may require additional resources, expertise and leadership support. The table below documents specific social media tools, showing the continuum from dissemination to engagement, as well as the resources generally needed to implement health communications activities in many popular channels. The Social Media Tools section of this toolkit provides an overview of the tools and how they may help you meet your health communication objectives.

	Tools	Resources					
		Time/Staff		Cost			
		Low	Moderate	High	Low	Moderate	High
Dissemination ↓ Engagement	Buttons/Badges	✓					
	Content		✓		✓		
	Streamlining						
	RSS Feeds	✓					
	Image Sharing	✓			✓		
	Podcast Posting	✓			✓		
	Online Video Sharing	✓			✓		
	Widgets 1, 2	✓			✓		
	eCards <sup>3</sup>				✓		
	Micro-blogs		✓		✓		
	Podcast Creation		✓			✓	
	Online Video Production					✓	
	Blogs		✓			✓	
	Mobile Technologies <sup>1</sup>						✓
	Feeling		✓				✓
Virtual Worlds				✓		✓	
Social Networks				✓		✓	

<sup>1</sup> Indicates the posting of a widget, not production.  
<sup>2</sup> Although the majority of widgets feature embedded content, some may contain an interactive component such as a quiz or a calculator.  
<sup>3</sup> Indicates the sending of an eCard, not production.

# Social media

In organ donation

Facebook and Twitter are the most frequent used instruments for social media communication

**Justin Bieber boosts organ donations with Twitter plea**



## 25,000 New Dutch Organ Donors Recruited Through Social Media

Megan O'Neill on October 19, 2010 2:30 PM



# Social media

## Facebook

- Facebook is the largest social network with > 900 million users world wide (2013)
- Every user is linked to many “friends“



[Get Started](#)[Add a Profile Picture & Cover Photo](#)[Add Things You Care About](#)[Update Your Basic Info](#)[Share, Star & Hide Stories](#)[Explore Your Activity Log](#)[Share Your Organ Donor Status](#)[Timeline Privacy](#)

### Facebook Organ Donor Tool: Mark Zuckerberg Talks Social Network's Initiative To Save Lives (VIDEO)

The Huffington Post · By Courtney Pitt · Posted on 10/21/12 10:40 am (updated on 10/21/12 12:21 pm)

Like 1,544 people like this.



## Share Your Organ Donor Status

### Make it Official

You can officially register as an organ donor with the appropriate registry online. [Learn more.](#)

- ▶ [How do I share that I'm an organ donor on Facebook?](#)
- ▶ [How do I register as an organ donor?](#)
- ▶ [Why did Facebook add "organ donor" to the Life Events section of timeline?](#)

### ▼ [Why did Facebook add "organ donor" to the Life Events section of timeline?](#)

More than 114,000 people in the United States, and millions more around the globe, are waiting for the heart, kidney or liver transplant that will save their lives. Many of those people – an average of 18 people per day – will die waiting, because there simply aren't enough organ donors to meet the need. Medical experts believe that broader awareness about organ donation could go a long way toward solving this crisis.

With the addition of "organ donor" to the Life Events section of timeline, you can state your intention to become an organ donor, and share your story about when, where or why you decided to become a donor. If you are not officially registered as an organ donor, sign up with the appropriate registry.

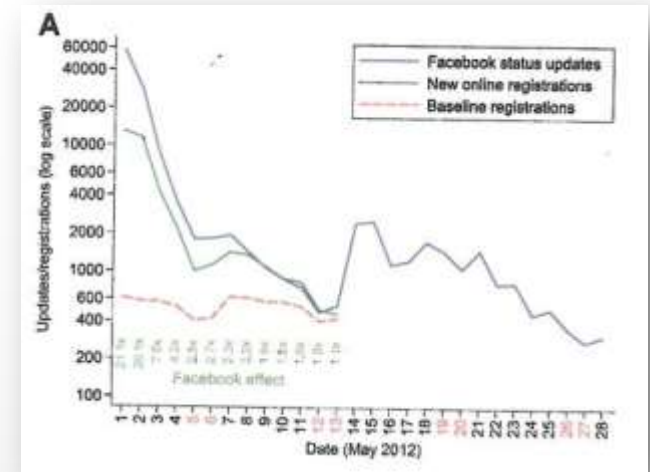
Learn about the organ crisis and the myths and facts about organ donation:

- [Australia](#)
- [Belgium](#)

# Social media

Facebook's organ donation initiative

On the first day of the Facebook organ donor initiative, 57,451 users updated their organ donor profile, leading in 13,054 new online registrations. This is a **21**-fold increase over the baseline average of 616 registrations.”



Cameron et al. (AJT 2013)





# Social media

Facebook's organ donation initiative



## High potential

- Large community (~1 Billion Facebook users)
- Intermittent reminder: update of profile will be visible to all "friends"



Positive influence on people who think similar ("friends")

Fast update of new information



Sustained effect unclear

Data privacy concerns



# Social media in organ donation

## Questions, Problems & Challenges

1

Faster information & higher density of work makes it more difficult to gather information

2

It's getting more difficult to differentiate correct from incorrect information

3

Information on the internet will be stored forever  
→ (mis-) information can be recalled quickly and at any time

# Social media in organ donation

Questions, Problems & Challenges



Anyone can join and become content creators and active media participants

→ excess supply of information and a change in the quantity/quality ratios

# Social media in organ donation

Questions, Problems & Challenges



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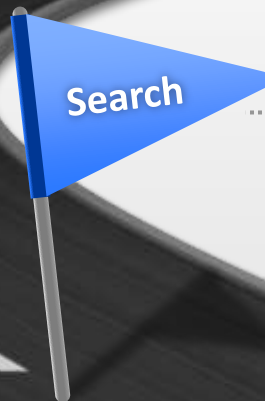
→ the user sometimes loses orientation



# Meet journalists challenges in organ donation

**FOEDUS WP7**

**objective, neutral,  
reliable, transparent  
information**



**guide through the  
jungle of different  
information**



FOEDUS = Facilitating exchange of organs  
donated in EU Member States

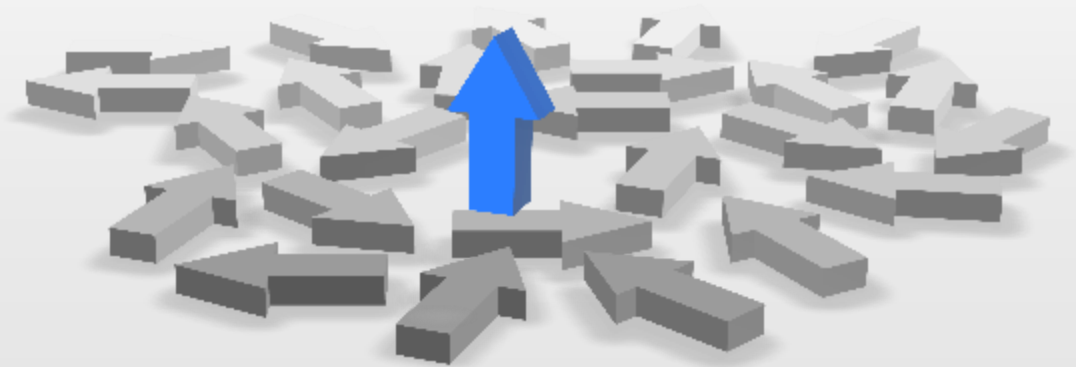
- 3 year project funded by the European Union
- 24 members
- 7 work packages

→ **WP 7 on 'communication' is lead by  
DSO (Germany) & ST (Slovenia)**



## General objectives of WP 7

- developing a manual for CA & OPO's on how to inform and communicate with media about organ donation



# Questions

- What kind of information do you prefer when writing about organ donation ?
- What kind of information and messages should the competent authorities provide?  
(Basic information? Testimonials? Patient Stories?)
- What are your needs in order to find the information you need quickly and clearly?  
(regular workshops, regular press conferences, supply of standard messages, 24/7 hotline for media, ?)
- ???