CLINICAL INVESTIGATION

Is social media suitable for patient recruitment?

The use of social media is tremendously increasing since years and will continue its growth. Recent examples show that social media can also be used to attract patients to clinical trials and improve recruitment rates. In addition, retention of the patient is increased. Social media help in designing clinical trials by obtaining early feedback from possible patients, informing patients about clinical trials and facilitating their participation by providing tools to guide them through the trial. To achieve this, social media use three different channels, listen – inform – engage. For listening and feedback, blogs can best be used, for information purposes social networking sites. To engage patients, apps are very useful.

Keywords: digital strategies • patient recruitment • patient retention • social media

Wolfgang Eglmeier
Centre for Clinical Trials,
Witten/Herdecke University,
Alfred-Herrhausen-Str. 50,
58448 Witten, Germany
Tel.: +49 230 292 6708
Fax: +49 2302 9264 4786
wolfgang.eglmeier@uni-wh.de

A perpetual problem: the recruitment & retention of patients

The scientific, most reliable and rigorous method in clinical trial design is the randomized controlled trial (RCT), which provides the highest standard in evaluating treatment efficacy [1]. The success of such RCTs depends very much on proper recruitment and retention of sufficient trial subjects. Andrews [2] reports that still up to 86% of the trials performed in the USA do not meet recruitment goals. Recruitment goals are not met when either the number of needed patients is not reached or too many drop-out patients occur or if the end of recruitment is delayed compared with the plan. In the USA, every year more than 2.3 million women and men participate in about 80,000 US FDA registered clinical trials. In total, 75% of US Americans believe in the great value of clinical research. Despite these two facts, low participation in clinical trials is still an obstacle in creating results and translating those into clinical practice [3]. Substantial resources need to be allocated by sponsors, investigators and other partners to different initiatives to achieve sufficient patient recruitment and retention rates in clinical trials [4]. In 2010, the sponsors and investigators spent $1 billion in the USA for initiatives on patient recruitment and retention, like advertising and support activities, with an annual growth rate of 15% [3]. More than half of the possible participants for clinical trials are discouraged to enroll in trials by their treating physician or by their relatives [5]. This shows clearly that proper information flow is essential for the success [6].

The rise of the problem: the principles of recruitment & retention

The stakeholders in clinical trials: their influence on recruitment & retention

In general, four different groups of stakeholders collaborate in clinical trials. These stakeholders with partially conflicting interests influence the success of the clinical trial [7]:

- Health authorities and ethical committees (IECs) or institutional review boards (IRBs);
- Sponsors (either commercial companies or academic sponsors for investigator initiated trials) in cooperation with CROs and third-party providers; the sponsor is

FUTURE SCIENCE part of fsg

either a person or an organization being responsible for the initiation, management or assuring financing of a clinical trial;

- Investigators with their study team members;
- Study participants (either volunteers in Phase I trials or patients in Phase II–IV trials).

The health authorities with IECs/IRBs provide guidance to the sponsors and also to the investigators. The health authorities and IECs/IRBs focus on GCP compliance and protection of patient rights and data protection rules. The sponsors with CROs try to achieve optimal trial performance by high recruitment rates, low screening failure and drop-out rates. This is necessary to collect high-quality data, which can be submitted to the health authorities. The investigators focus more on scientific issues and are partly interested in research. But they also want to get access to new treatment options for their patients. Finally, the patients would like to get immediate access to a physician, who provides the best medical care and therapy regarding efficacy and safety to them. This causes sometimes a 'clash-of-intentions' [8]: the health authorities with IECs/IRBs in cooperation with the sponsors focus more on standardized, simplified, multicenter RCTs; the investigators and patients on the other hand focus more on single cases, who need individual and personalized help. Social media is an approach to provide individualized information to single patients.

The sometimes ignored stakeholder: the patients & their intentions

Patients have different intentions to participate in a clinical trial (see Table 1: types of patients and their intentions to participate in a clinical trial). For successful recruitment, the intentions of the patients to participate in a clinical trial have to be taken into consideration [9]. Patients have often more than one of these intentions and show a varying mixture of different intentions. Younger patients are more innovative, desperate or impatient. Elderly patients are more health conscious, economic or altruistic. The use of social media can support well innovative, desperate, health conscious and impatient patients in their need for new information or access to new therapy options.

As a consequence of the 'clash-of-intentions,' clinical trials are often designed for 'ideal patients' instead of for 'real patients' [9]. To cope with these problems, the trial design should be adapted to 'real patients' (see Table 2: overview of characteristics of 'ideal patients' vs 'real patients' and possible adaptions in trial design to facilitate patient participation in clinical trials).

The traditional ways of patient recruitment

There is an evolution of recruitment strategies in the past decades. It started with the direct approach of a patient to participate in a clinical trial by the physician (aka 'the investigator'). The investigator was supported by the site staff (aka 'the study nurse'). Printed advertisements were used at the beginning mainly for Phase I trials only. Later, radio and TV spot came in, supported by a system of referrals and the appearance of site management organization. These site management organizations are professional clinical trial sites focusing on trial performance only. The last decade brought us a wide variety of third-party providers supporting the sponsors and also the investigators. These providers offer a very professional way with sophisticated systems for patient recruitment and retention [10]. But all these traditional ways have their limitations. Printed materials have a limited reach out; or TV spots might be bypassed by new technologies. Such technologies are, for example, sophisticated recording systems (e.g., TiVo®), which allow fast forward to avoid commercial advertising. In addition, all these conventional methods work only one way. They do not allow interactions between the investigator and the patients [2]. Therefore, the next step is needed which allows also bidirectional communication with the patient – the use of social media might help in coping with these problems.

A search for solutions: improvement of recruitment & retention

The reasons for patients not to participate in a clinical trial

There are several reasons why patients do not participate in clinical trials [10].

The possible patients are not informed which clinical trial takes place or do not have sufficient information about the clinical trials

To avoid this reason, the news about a trial has to be spread widely. Especially clear information where and how patients could enroll must be provided. It should be enabled for possible patients to precheck easily, whether they would be eligible for enrollment (by providing a 'guided tour' through the pertinent inclusion and exclusion criteria). The use of social media might support such an approach.

The patients are not motivated to participate in a clinical trial and see no benefit to devote their time

Patients are more motivated to participate in a clinical trial and to stay there, if they are properly informed. If they get easy access to information and see the

Table 1. Types of patients and their intentions to participate in a clinical trial.

Patient type	Intention to participate
Innovative patients	They look for new treatment options and also for new technology
Desperate patients	They look for any treatment option
Health conscious patients	They look for high attention by their physicians
Economic patients	They look for free treatment, free examinations and free support
Impatient patients	They look for fast access to physicians and to new information
Altruistic patients	They look for an opportunity to do something good for the society
Bored patients	They would like to do something unusual

benefits their motivation increases. Such information needs by the patients can be covered by the use of social media.

The participation in a clinical trial is cumbersome for the patients and not facilitated

If patients have to face too many burdens in a clinical trial (high number of time-consuming visits at site, with cumbersome procedures), they are often scared off to participate. The use of social media might guide these patients better through the trial and improve their retention.

The wrong investigational sites are selected or wrong assumptions of their capabilities to enroll patients had been made

Social media might also help here by assisting in protocol design regarding selecting appropriate inclusion and exclusion criteria. These criteria should reflect the real world and should not only be based on best guessing. Social media can also help in the feasibility process to identify where a specific type of patient might be found and treated. The use of social media can help clarify at which type of investigator the patients are treated (e.g., at general practitioners, in outpatient clinics, general hospitals or university clinics) – and this might differ from country to country.

The traditional solutions: their use for recruitment & retention

According to Lamberti [4], pharmaceutical companies use a wide variety of tactics to boost enrollment. The most tried tactic is to establish physician referrals. Then pharmaceutical companies used different methods of advertisements (newspaper, radio), followed by meetings with patient groups. Electronic record screening and direct mailings are also used. TV spots and other local media, like advertisements in public mass transport were less used. The least use for recruitment was made of patient education sessions.

Regarding patient retention, the maximum use is made of reminders, especially phone calls, and of travel reimbursement. Additionally, trainings and patient education are used [4].

The use of tactics which interact directly with the patients, like reminding or providing information and training, gave the best results. But the use of social media was so far mainly limited to the Americas [4], despite the fact that social media might fit in well in all these tactics as they allow a bidirectional and also tailored communication with the patients.

Table 2. Overview of characteristics of 'ideal patients' versus 'real patients' and possible adaptions in trial design to facilitate patient participation in clinical trials.

Ideal patient: the assumption	Real patient: the experience	Adaptation in trial design
Has always time	Has a job	Limit the number of visits
Lives close to site	Lives far away	Provide remuneration
Trusts the physician	Looks for a new physician	Use advertisements and referrals
Is interested in research	Has critical opinion to change	Prepare proper informed consent
Understands the trial	Shows lack of cooperation	Provide excellent supporting materials
Shows compliance	Is interested in own advantage only	Offer 'fast track' examinations and treatment
Has only a few comedications and codiseases	Is multimorbid with numerous comedications, especially for geriatric patients	Do not 'copy-and-paste' inclusion/exclusion criteria from other trails, but adapt and streamline for current trial

A new & promising opportunity: social media

In May 2012, Facebook started a campaign, to create awareness for organ donation, through which the number of possible organ donors should be increased. Facebook just gave their users the opportunity to identify themselves as donors on their profiles. This approach spread the awareness for organ donation in the USA. Within 6 days the number of online registrations of donors increased by 1000% across the USA [11].

Such an example is only possible as the internet changed in the past decade from web 1.0 to web 2.0. Web 2.0 provides now interactive web pages, which allows bidirectional communication [2]. But is such use of social media also transferable to clinical trials now?

Social media: a possible add-on to the traditional solutions

Social media: a clear definition is still missing

There is no clear definition what social media is. The meaning is different for different people [12]. The minimum consensus is that 'it is something digital,' either technology or media provided by that technology. In general, the understanding is that social media includes different portals to a wide variety of web pages. In addition, social media allows online interactions between individuals who share the same interests or activities. The focus of social media might be on the pure content or also on the communication aspects. If the communication aspects are the main focus, the term social networking sites (SNS) is often used [2]. There is a tremendous growth in use of social media in the past decade. In North America alone, the use grew from 5% of the population in 2005 to over 50% in 2011 [13].

Social media: the six different types

According to Kaplan and Haenlein [14], six different types of social media exist. Most promising types for clinical trial used to attract patients are SNS and blogs. To provide supportive information about trials, collective projects and content communities are most useful (see Table 3: overview of the different types of social media and their usability for clinical trials).

Collective projects like Wikipedia are mainly content-driven media. They offer a wide variety of information about clinical trials, drug development and related topics in several languages. As these media are normally controlled by a large community, the amount of false, biased or even too commercial information is reduced. But such information channels should always be complemented by other sources.

Content communities like YouTube could also be used as additional sources for information about clinical trials. But this medium is less interactive and not suitable for bidirectional communication. The information provided here might be more biased or more commercial.

Blogs, microblogs, E-fora like Twitter focus mainly on the rapid, but very brief communication. These media could be used for bidirectional communication about clinical trials with (possible) patients. The information can be provided specifically for a single trial to a much targeted even 'geo-targeted' audience.

SNS like Facebook, LinkedIn or XING focus on communication and content. A more specific targeting to a selected audience is possible, as more information is available about the recipient.

Social media: the three channels to interact with patients

There are three different channels how patients can be involved by social media in clinical trials [15]. Each channel has different purposes. For each channel, other types of social media work best (see Table 4: channels of social media to address patients).

Social media can provide more information than every other media. By use of social media, a sponsor of a clinical trial can obtain information where potential trial patients meet. In addition, sponsors can get information what patients talk about and what they are interested in. Sponsors can also receive feedback via this channel, which they use to design the trial and adapt it better to the 'real world.' Social media provide the sponsors with the ability to place their studies in the online interactions among patients. The trial will be a part of the discussions between patients.

Social media: the technical solutions – bringing types & channels together

Patients can be provided with three different technical solutions to use social media [12].

Online patient communities

These tools are mainly formed around the websites of (nonprofit) patient advocacy groups. These websites offer also background information about clinical trials and fora for discussions. Examples are 'PatientsLikeMe' [16], a general portal dealing with a lot of indications, or 'Inspire' [17]. 'Inspire' directs you easily to patient advocacy groups. Unfortunately, 'Inspire' is difficult to locate on the web. If you search the web for it, you will receive first referrals to 'INSPIRE: Infrastructure for Spatial Information in the European Community' or to 'INSPIRE: High Energy Physics Literature Database,' to 'Inspire-Technologies' or 'Inspire – the Online magazine of al-Qaeda.' Other websites like 'WeAre.US' or 'NexCura' do no longer exist or had been sold. A downside for these websites is also, that they mainly

Table 3. Overview of the different types of social media and their usability for clinical trials.

Type	Examples	Characteristics	Possible use in trials
Collective projects	Wikipedia	Content driven	Provide generic Information
Content communities	YouTube	Content driven	Provide generic (and trial specific) information
Blogs, microblogs, E-fora	Twitter	Communication driven	Bidirectional communication and discussion
Social network sites	Facebook, LinkedIn, XING	Communication and content driven	Communication and trial advertisements
Massively multiplayer online role-playing game)	World of Warcraft	Content driven with communication	No
Virtual game worlds	Second Life	Content driven with communication	No

use English language (and sometimes Spanish in addition to this). They often exclude people with other languages. Therefore, such initiatives are only suitable for local strategies mainly in the America, but not globally.

A more global approach is provided by online communities run by commercial providers specialized in offering support services for patient recruitment and retention. These services can be tailored to specific clinical trials of different sponsors. These services are very helpful due to their link with patient advocacy groups. This supports the design of study protocols, especially for orphan drugs.

Social networking sites

Due to their sheer size with billions of users worldwide, the SNS seem to be the most promising approach to support recruitment and retention activities of patients into clinical trials. Facebook, Myspace or Twitter allow targeted advertising regarding age, gender, other characteristics or 'geo-targeting' of specific regions of the world or even cities.

It is still a huge step to be made from the 'buckshot principle' of addressing many possible patients finally to their engagement of showing up at an investigational site and enrolling into a clinical trial. 'The Facebook example' (increase of possible organ donors by 1000% within 6 days) is misleading. To announce to be an organ donor does not request an immediate action or further obligation. But to enroll in a clinical trial needs immediate action by the patients. They have to accept additional responsibilities. In addition, it is more enticing to announce, that oneself is an organ donor and does something good for the society (in a far remote future), than instead of showing all people, that oneself is suffering from a disease and needs help. This behavior of these possible donors making their willingness public appears more to create self fulfillment only. The donors seem to be more interested in collecting 'likes' as for posted 'selfies' or food at a dinner, instead of doing something good.

Software applications

These applications should fulfill two purposes, either enhance the search capabilities to find appropriate information about clinical trials or improve the access

Table 4. Channels of social media to address patients.

Channel	Purpose	Type of social media to be used
Listen	Collect information from possible patients to: – Locate them – Adapt inclusion and exclusion criteria	Blogs, microblogs, E-fora
Inform	Spread the news and advertise the trial, especially to targeted recipients	Social networking sites, blogs, microblogs, E-fora (and partly collective projects, content communities)
Engage	Motivate patients to: – Participate – To motivate others to participate	Social networking sites, blogs, microblogs, E-fora

Table 5. Examples for free available 'apps' for clinical trials.

App	Purpose	Nonprofit
Cleveland Clinic Cancer Trial	Oncology trial listing for patients at Cleveland Clinic in Ohio, USA	Yes
Clin Trial Refer	Five apps for hematology or melanoma trial listings for patients in Australia and New Zealand	Yes
ECRAB Lab	Information material prepared by the EU on clinical trials	Yes
KCI Trials	Oncology trial listing for patients at the Barbara Ann Karmanos Cancer Institute in Detroit, USA	Yes
Lilly Oncology Clinical Trial Resource	Oncology trial information for healthcare professionals	No
Markey Cancer Center Clinical Trials	Oncology trial listing for patients and researchers in Kentucky, USA	Yes
My Clinical Study Buddy	Clinical trials information for patients, including tools to manage own trial participation (by BBK)	No
Ongoing Trials	Worldwide Novartis clinical trial listings	No
SCI Clinical Trials	Oncology trial listing for patients and researchers at Stanford, California, USA	Yes
Shire	Training tool for trial participant, including documentation of informed consent procedure by Shire	No
UH Seidman Clinical Trials	Oncology trial listings and information for patients in Ohio, USA	Yes
UK Clinical Trial Gateway	Clinical trial listing for patients and healthcare professionals in the UK	Yes

to clinical trial information. Websites listing clinical trials and trying to match patients with suitable trials and investigational sites had been developed. An example is 'Clinical Connection' [18], which also provides additional information about clinical trials. This website allows searching for trials, mainly in the USA, also in your neighborhood. Other initiatives like 'Medpedia,' a medical Wikipedia, disappeared again.

Video channels on 'YouTube' which are mainly used for information purposes like the 'PfizerClinicalTeamChannel' are no longer used to recruit patients. This channel was last updated in November 2011.

The current trend is that more and more 'apps' are produced for smartphones or tablet computers to support clinical trials [2]. There are many 'apps' available, but this is a very rapidly changing environment. Some examples of free available 'apps' are listed in Table 5 (examples for free available 'apps' for clinical trials). Many of these 'apps' focus on oncology trials only, other indications are hardly covered. In addition many 'apps' are issued by local (cancer) hospitals to attract patients to their trials.

A good example for all these applications is **E**uropean **C**ommunication on **R**esearch **A**wareness **N**eeds. A short internet video tells the story of the first clinical trial (the lemon trial by James Lind performed 1747). The video is available in all languages spoken in the EU and explains comic strip-like how clinical trials are performed [19].

Social media: case studies

There are some successful case studies using social media for patient recruitment and retention. McAnulty [20] evaluated the cost for the 31 randomized patients in a movement disorder trial. The costs per randomized patient attracted to the trial by radio advertisements were $17,222, compared with $3961 per patient randomized by search engine marketing. This shows a clear cost reduction for recruitment by the use of social media.

In a trial on a rare disease, at the MAYO Clinic, social media was used for recruitment support. To find the needed number of patients, survivors of spontaneous coronary artery dissection took only 1 week [21]. The main reason for this success was deemed to be the involvement of the patients via their advocacy groups [22,23]. Additionally, social media are used as a tool to collect adverse events in case of pregnancies [24].

The use of social media: their benefits, their obstacles & pitfalls

From March to December 2013, the Tufts Center for Drug Development collected with a working group of 20 pharmaceutical and biotechnology companies data

on the use of social media in clinical development. The data provide insight into the general policies and principles of the use in clinical development. So far pharmaceutical companies use social media mainly for commercial purposes to distribute information to patients and listen to them. The support of social media for clinical trials is limited. The use of social media for clinical trials started for most pharmaceutical companies in 2010 or later [25].

Social media: their benefits for clinical trials

Social media allow rapid communication with a large audience, even with an immediate global reach. This communication can be targeted and personalized to a specific patient population, in other words, via media like Facebook [2].

Another advantage of the use of social media is that they allow feedback from possible patients. Conventional one-way tools like advertisements in newspaper do not allow this.

Additionally, the use of social media allows the involvement of the relatives and friends of patients [2]. They can join the trial community and provide support and make marketing for the trial.

Social media: the obstacles for the use & pitfalls

Rapid & unlimited communication

Due to the nature of the technology, all these benefits might also have their downsides. The rapid and partly unlimited communication can cause a breach of confidentiality, either violating sponsors' interests or making patients' data public. The inherent nature of social media is not aligned with the data protection rules of traditional recruitment practices [13]. Also, the clear traditional separation between the sponsor of a clinical trial and the patients participating might be broken up. So far, a sponsor cannot get in touch directly with a patient but only via the investigator. This precaution serves on the one hand to obey data protections rules and achieve confidentiality of patients' data. On the other hand this separation prevents coercive actions from the sponsor on the patients (e.g., changing information on adverse events or brushing up efficacy data). Now direct access from the sponsor to the patient might be possible. This would enable direct influence from the sponsor on the patients.

The involvement of friends and relatives might also cause frictions – confidentiality is even more jeopardized. Additionally, these people might influence the patient to quit the trial again and dropout.

Despite the effect of rapid communication, the social media are more useful for chronic diseases than for acute indications. In chronic diseases, patients are on a long-term basis engaged and search for information or need follow-up care. For acute indications instead, where patient need immediate care, social media use is more difficult.

Amount of information

As the attention span of normal users is very scarce [13] they are often overloaded by the overwhelming amount of information on numerous websites [2]. Therefore, finding the appropriate information on the internet is not facilitated for patients. In addition, users often receive conflicting and confusing information via the internet [26]. As users have the tendency to trust this information without verifying the reliability of the source [20], they follow false information. Often a simplification by the patients exists by focusing rather on alarming news ('bad news is good news') instead on science [24]. Therefore, information is more based on rumors instead of real facts. On one hand, false information might create high hopes for the patients. But on the other hand, correct but not enticing enough information might make the patients 'bored or even scared off' of the trial.

Access to the information

Social media are not yet used worldwide for recruitment. The current use is more limited to the Americas, mainly North America. As European and Asian clinical trial sites are activated easier and more successful than American sites [4], the use of social media might have an additional positive effect there. The limitation to the Americas might be a language barrier, as that entire region can be served by more or less two languages only (English and Spanish, plus Portuguese and some French). The rest of the world demands the preparation of information in numerous other languages.

In addition, the access to the new technology (access to a computer or smartphone) is not given anywhere around the world. Not all people use such media with the same frequency. Especially elderly people are not used to it. Access to such media by use of a public computer (e.g., in a public library) [2] might not be deemed as sufficient. Patients might be informed about a trial via a public computer. But such a computer can hardly serve as a 'permanent' tool to foster retention of patients, where they receive ongoing and immediate information or reminders.

Also recruitment might be biased, as especially 'technology-prone' patients join such trials, but nor the 'normal ones.'

Sponsors' fears

Brescia [27] reports many fears sponsors of clinical trials have. Sponsors anticipate consequences to deal

Table 6. Fears of sponsors and possible consequences they anticipate.

Main fears of sponsors	Consequences for sponsors
Cumbersome adverse event reporting	Searching the web with all blogs, among others, for possible adverse events and increasing their number
Patients share information, risk of unblinding of the treatment allocation	Endangering the statistical validity of the trial
Violation of patients' privacy	Ethical rejection of the trial and additional discussions
Disclosure of confidential company information	Providing an advantage to competitors
Selection bias of patients	Endangering the scientific validity of the trial
Study participants might publish negative comments about sponsor, study or investigators	Endangering the reputation of the sponsor

with these fears and foresee additional burdens (see Table 6: fears of sponsors and possible consequences they anticipate). Especially the fear to make private health information of patients publicly available prevents them from the use of such media. As, for example, HR managers search the web for information of possible applicants, sponsors are afraid of spoiling the career of trial patients. Violation of data protection rules and endangering patients' privacy was also one of the main obstacles for the use of social media reported by participants in the recently performed study by Tufts Center for Drug Development [25]. Finally, sponsors are afraid of ethical issues and discussions with ethical committees/IRBs regarding patients' privacy or selection bias, if they exclude patients having no access to such media.

Limited guidance by health authorities & ethical committees or IRBs

There is still the lack of clearly defined regulations [2,4,12]. This lack of cohesive regulatory guidance presents challenges to the sponsors of clinical trials [28]. The recently drafted FDA guidelines on postmarketing surveillance, social media platforms or recruitment of study subject do not address the use of social media in clinical trials [29–31]. These guidelines demand only an approval of all promotional documents by the ethical committee/IRB. An approval of trial listings on the

Table 7. Best possibilities for use of social media in clinical trials.

Stage of trial	Use for	Purpose	Social media to be used
Planning	Trial design	Shapes inclusion/exclusion criteria	SNS, blogs
Planning	Trial design	Estimates the burden patients are willing to bear (planning for real patients, not for ideal patients)	SNS, blogs
Planning	Feasibility	Optimal target population (where are the patients?)	SNS, apps
Preparing	Information	Creating awareness for investigators and patients	Blogs, apps
Performing	Recruitment	Selecting and directing patients to sites	Apps
Performing	Training	Education of target population	Apps
Performing	Management	Patient reminders and guidance (supports the conversion of real patients into ideal patients)	Apps
Performing	Data collection	Facilitates data collection (PRO)	Apps
Performing	Information	Creates a 'team-spirit'	Apps
Evaluating	Follow-up	Long-term safety	Apps, blogs
Evaluating	Information	Creates a 'team-spirit' – and use this for the next trial	Apps

PRO: Patient-reported outcome.

internet is not deemed necessary as long as only basic trial information is made publicly available [31].

Future perspective: the points to consider for the proper use of social media

There is growing evidence that the use of social media helps step by step to improve enrollment of patients in clinical trials [12]. But to obtain substantial gains here, a change in public opinion is a prerequisite – and social media are a powerful tool to change this opinion by providing adequate information.

Points to consider: for which task social media works well

Social media work well for specific tasks in clinical trials. Such tasks are, for example, feasibility, education of trial patients or their follow-up [2]. An overview at what stage of a clinical trial (planning – preparing – performing – evaluating) which social media could be used best is given in Table 7 (best possibilities for use of social media in clinical trials).

Social media: the future perspective

Many different conferences and round-table discussions took place in the past 2 years [32–34]. At the 2013 Annual Meeting of American Society for Experimental NeuroTherapeutics, an FDA representative expressed his expectations for the future that more direct involvement of patients will occur [32]. Patients will provide more data directly like patient-reported outcome or data on adverse events. This can be facilitated by the use of social media. In 2014, a SoCRA Meeting (Society of CRAs) was focusing on the use of social media ('Harnessing social media to advance clinical research') [33]. At this meeting a very optimistic view on the use was given. But this view might be too optimistic, as the focus was only on the use of Facebook and the rapid and widespread communication associated with it. A more realistic view was provided at the Annual Meeting 2014 of the Drug Information Association. The adoption of such media is still deemed slow to achieve an immediate high impact on clinical trials [34]. Only 10% of trials in the USA use such media, but a huge rise is expected in the future [25,34]. There are even some upcoming meetings, where attendees will be trained in the use of social media for clinical trials [35].

The more these media technically evolve, their use is facilitated and the penetration in the population increases, the more value these media will add to performing clinical trials. Up to now the use of social media is an important add-on to recruitment and retention strategies for patients into clinical trials.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

Executive summary

Background

- Slow recruitment of patients into clinical trials and low retention rates are the main reason for delays in performing and finishing clinical trials.
- The use of social media in our society is rapidly increasing and penetrates more and more areas of our daily life.

Increase of recruitment & retention of patients

- By proper and rapid information to the patients.
- By focusing on the patients' needs.
- By providing help and appropriate tools to the patients.

Social media can

- Obtain feedback from possible patients to tailor the clinical trial to the real world.
- Provide rapid information to a targeted group of patients to attract them to a trial.
- Guide patients through a clinical trial.

References

Papers of special note have been highlighted as:
•• of considerable interest

1 Zweben A, Fucito LM, O'Malley SS. Effective strategies for maintaining research participation in clinical trials. *Drug Inf. J.* 43(4), 459–467 (2009).

2 Andrews C. Social media recruitment: the opportunities and challenges social media provides in the realm of subject recruitment. www.appliedclinicaltrialsonline.com

•• **Provides an excellent overview on challenges to the use of social media and also the opportunities they can provide.**

3 Getz KA. Impact of in-pharmacy education on patients' knowledge and attitudes about clinical trials. *Ther. Innov. Regul. Sci.* 47(3), 336–340 (2013).

4 Lamberti MJ, Mathias A, Myles JE, Howe D, Getz KA. Evaluating the impact of patient recruitment and retention practices. *Drug Inf. J.* 46(5), 576–580 (2012).

•• **Provides insights into the basics of patient recruitment and retention with a good overview on the differences in use in various regions of the world.**

5 Thompson MA. Social Media in Clinical Trials. In: *ASCO 2014 Educational Book.* Aurora Health Care, Milwaukee, WI, USA, 101–105 (2014).

6 Smed M, Getz KA. Site characteristics influencing the translation of clinical research into clinical practice. *Ther. Innov. Regul. Sci.* doi:10.1177/2168479014525957 (2014) (Epub ahead of print).

7 Eglmeier W. Site selection: considerations to achieve positive impact on clinical trials. Presented at: *6th Annual Optimizing Clinical Trials Conference.* Vienna, Austria, 13–14 November 2012.

8 Eglmeier W. Academic Perspective on investigator initiated trials. Presented at: *Medical Affairs Leadership Forum Europe.* Bratislava, Slovakia, 21–22 October 2014.

9 Eglmeier W. Dealing with challenging patient populations – better focus on patients to improve their recruitment and retention in geriatric settings. Presented at: *DIA 5th Annual Clinical Forum.* Basel, Switzerland, 10–12 October 2011.

10 Eglmeier W. Are non-traditional methods for patient recruitment, such as using social media, suitable to early development? Presented at: *15th Annual Phase I & IIa Clinical Trials.* London, UK, 25–26 February 2014.

11 Danchak C. Can social media change the public perception about clinical trials? In: *The Pulse on Recruitment – Exploring the Use of Social Media and Online Tactics in Patient Recruitment*. A Center Watch Special Report, reprinted from CW Weekly . 16(14) (2012.

•• **Provides good insight, why social media works well in cases of pure communication, but do often not foster the acceptance of responsibility.**

12 Mintz C. Social media's impact on clinical trial enrollment. *Life Science Leader Magazine* (2010). www.clinicalleader.com

13 Gossen R. Study recruitment: social media feasibility model. www.samedanltd.com

•• **A comprehensive status update is provided.**

14 Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of social media. *Business Horizons* 53(1), 59–68 (2010).

15 Mulhall L. 3 social media keys to drive global patient recruitment. http://innovations.bbkworldwide.com

•• **Provides a comprehensive view on the different communication channels.**

16 Patients Like Me. www.patientslikeme.com/

17 Inspire: patients & caregivers. https://corp.inspire.com/patients-caregivers/

18 Clinical Connection. www.clinicalconnection.com/

19 Clinical Research: ECRAN Project. https://vimeo.com/69337236

20 McAnulty JD. Bringing patient recruitment into our digital world. *Drug Inf. J.* 43, 501–508 (2009).

21 Donahue M. Social media patient recruitment success story. www.appliedclinicaltrialsonline.com

22 Gossen R. Social media for patient recruitment: 6 key factors in Mayo Clinic's success. http://rebarinteractive.com

23 Donahue M. Patient recruitment via social media: an uphill battle. www.appliedclinicaltrialsonline.com

24 Clemow DB, Dewulf L, Michaels DL *et al.* A proposed framework to address needs of clinical data for informed medication use in pregnancy. *Ther. Innov. Regul. Sci.* 48, 145–154 (2014). http://dij.sagepub.com/content/48/2/1454

25 Lamberti MJ, Stergiopoulos S, Naik P, Getz K. Industry Usage of Social and Digital Media Communities in Clinical Research. http://csdd.tufts.edu

•• **A good overview on the use of social media based on a recent study performed by Tufts Center for Drug Development.**

26 Clemow DB, Dewulf L, Koren G *et al.* Clinical data for informed medication use in pregnancy: strengths, limitations, gaps, and a need to continue moving forward. *Ther. Innov. Regul. Sci.* 48, 134–144 (2014). http://dij.sagepub.com/content/48/2/134

27 Brescia B. Ethical considerations when engaging with patients online. In: *The Pulse on Recruitment – Exploring the Use of Social Media and Online Tactics in Patient Recruitment.* A Center Watch Special Report reprinted from CW Weekly 16(14) (2012).

•• **Explains the does and do nots for the use of social media.**

28 Metnick CV. Social Media Use for Clinical Trial Recruitment. www.jdsupra.com

29 FDA. Guidance for Industry – Fulfilling regulatory requirements for postmarketing submissions of interactive promotional media for prescription human and animal drugs and biologics draft guidance. www.fda.gov

30 FDA. Guidance for industry – Internet/social media platforms with character space limitations–presenting risk and benefit information for prescription drugs and medical devices draft guidance. www.fda.gov

31 FDA. Recruiting study subjects - information sheet. www.fda.gov

32 O'Brien E. Dr. Katz from FDA Talks social media and clinical trials. www.sireninteractive.com

33 Gossen R. How clinical research sites can engage patients using Facebook. http://rebarinteractive.com

34 Sipes R. Social media's role in clinical research. http://altitudemarketing.com

35 Using Social Media for Patient Recruitment in Clinical Trials. www.lifesciencetraininginstitute.com