



European Translational Information and Knowledge Management Services

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Outreach and Engagement plan 1st draft

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Overview

A detailed plan and procedures for engagement including tools to be used, processes, responsibilities, and strategies.

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Outreach

Executive summary

This outreach plan is developed to provide a goal oriented and structured approach that is flexible and allows for adaptation and iterative improvement.

The focus is on the goal of convincing stakeholders of the value of eTRIKS which can be summarized in 4 **value propositions**:

- 1) Ensuring the legacy of project data/results
- 2) Facilitating dataset integration
- 3) Increasing operational efficiency
- 4) Establishing a common set of standards

These value propositions form the framework around which outreach will be formed with outreach being organized as a series of **campaigns**, targeted on a set of customer segments defined by **avatars**. Each campaign will employ a combination of **channels** and be undertaken with a clear goal in mind. Effectiveness of channels will be measured and analyzed.

Approach

The purpose of the outreach effort by the eTRIKS project is to enable the sustainability of the eTRIKS platform through the building of a community of users and developers.

The outreach effort has the following objectives:

- Convince IMI projects of the value of the eTRIKS platform
- Build a relationship with users and developers that enables them to provide feedback to the eTRIKS consortium
- Gain recognition of eTRIKS in the wider translation research and bioinformatics community
- Disseminate the progress and successes of the eTRIKS project
- Build a community of developers
- Market the eTRIKS platform as a valuable solution for translational research knowledge management and analytics needs. €

Value propositions

In order to frame the approach to stakeholders and potential users of the eTRIKS platform we formulated a set of value propositions. The concept is that these will reflect the benefits of the eTRIKS platform to the user/user consortium, not a list of features. While there are a number of benefits to using the eTRIKS platform we focus on four main value propositions:

- 1) Ensuring the legacy of project data/results
- 2) Facilitating dataset integration
- 3) Increasing operational efficiency
- 4) Establishing a common set of standards

These value propositions are to be used as a framework for any dissemination efforts. Content for websites, brochures, social media should fit in to one of these value propositions with the exception of project progress updates.

All content will be registered against these value propositions.

The outreach effort will be organized into a series of campaigns. For each campaign the following will be identified

- Concept
- Goal
- Duration
- Targeted avatars
- Channels to be used

Targeted Avatars

The Clinician

I am concerned about patients. How can I treat my patients? How can I best advise my patients? I look into the relevant journals and keep in touch with peers in my field. I'm interested in developments in medicine, technology relevant to the field and the perspectives of patients. I don't necessarily want to concern myself with technological details. I want to know that a technology is reliable, validated, safe and easy to use. I want cost effective tools and services. I am always busy, I don't want to go back to the same thing again and again, which means I'm not always interested in facebook, linkedin, and twitter. I don't want to monitor, I want to be updated. I am strong willed, focused, protective, compassionate and disciplined. If a website can

provide up to date information relevant to my patients, and my interests, I might keep using the site for articles, contacts and state of the art news.

The IT Specialist

What's the latest app? Who has joined my social media sites? What is the least amount of time I can spend away from my computer? If I'm away from my computer, can I use my phone to stay connected and updated. What would make my life more convenient. What would make other people's lives more convenient? What is Apple and Google doing now? I want to see working networks. I like to use all the social media that is significant on the day. As an IT specialist, how do I provide my customers with the data they need at the moment they need it?

The Patient

How long until I am well again? How will my illness affect my family? Will I get well? How can I find Information regarding my treatment or diagnosis? Who can help me? Are there people researching my condition? How can I help improve the lives of others with the same condition? Are there clinical trials? Is there hope? I need to know where the cutting edge of medicine is. I need to know who and how. The information needs to be clear, understandable, honest and hopeful. I want to see links to relevant websites, groups and new centre's that are dedicated to improving the live's of patients sharing my condition. I will connect where I need to connect. My motivation for success is high.

The Patient`s Mum

I need information about my child's condition that is relevant and understandable. When I type something into google, that information needs to be there. What is the current state of the art? Who are the people to know? Who are the experts in the field? Who comprise support groups?. What does the future hold? I don't know what groups to join. If I find a web page, can it direct me to the right people and location? These people need to be serious. I want some hope.

The Funder

People's lives are at stake. Where and how will the money be most effectively used? What are the priorities? What diseases and initiatives need the most attention? How can I best improve the success of research? Who do I need to know? What's the most up to date information. Lots of people are hounding me. I need to make the right decisions. I have no time to think. Info, now! Not too technical, but reliable information, from a reliable source. I need to be certain. Who can I trust to be successful.

The Student

I need information, and then some more information. Relevant, up to date, field specific, not too wordy. I want to leave a website feeling that I have learnt something. The website's presentation and relevance will steer my opinion about the project and the field. Do I want to have anything to do with this line of work? The website needs to be serious, and I want to feel I have found something worth referencing in my essay, and worth telling a colleague.

Software Developer

It's going to take a little more than a webpage to garner my interest. As far as I'm concerned, if a basic webpage is not serious, then the people behind it are not serious. A poorly presented webpage disturbs me, like undercooked food disturbs a chef. No one goes back for more undercooked food. The content needs to provide relevant technical detail to provoke interest. I need a portal to enable access to the developmental framework. I also need to see the requirements of customers to make sure that development reflects the needs of the supported projects. I need to be able to add to the development and I need to see that key questions are being addressed at any one time. I need to know where I fit in, and I need to know who is doing what at any one time so that I can target my tasks.

Project Manager

Organization, simplicity, point of reference. There are a number of fields at play here, and I need to keep abreast of them all. I like things to be tidy, intuitive and in place. I don't want to go hunting around for things to get jobs done. I like to solve as many problems as well as I can, in as little time possible. Technical details are important, but dealing with project problems are my concern, and so communication is more important to me. I need to have access to many aspects of the project, including; staff registries, issue trackers, plans and progress and meeting reports. I want to see what people are talking about, i.e. the hot topics. I also want to keep in touch with the cutting edge and see what else is out there.

Ethicist

The law of individual countries must be observed, as well as the legislation of the European Union. But primarily, patients must be protected. Observing the ethical obligations associated with patient data are vital. I need to know the chain of custody

of the data in use. With these, I can identify the international and governmental colleagues I need to consult to determine what can and cannot be done with the patient data that has been made available. It is important that I and the general public see evidence of due process. When I am convinced, the public should be convinced, that the work I'm overseeing is reliable, safe, lawful and truthful. I want transparency, and I want to see that transparency reflected in the projects to which I'm associated. I'm not too concerned with technical details of projects. I want to see evidence of accountability and good clinical practice.

Laboratory Researcher

Data, data, data. The acquisition of data, the analysis of data and the presentation of data. Is there anything else? Maybe, if there is I don't see it! If I get good data, I want to show it off to as many people as I can. For this, I need to know the best places to go and the best people to know. I need to attend the best conferences and publish in the most relevant journals. I also need to know the latest developments in the field I'm working in. Who is doing what? What new technology has become available? I need to be at the cutting edge!

Coordinator of a project

People need to know about the project I run. They need to know it is being run well and I need to know that the project is moving forward. I want to see updates, good practice and good progress. I need access to everything.

Bioinformatics WP lead

As an experienced Bioinformatician I have preferred software platforms for managing, integrating and analyzing data. I am concerned that the amount of work that needs to be done in my project cannot be achieved with the 0.3 FTE and 20.000 euros allocated to do it. I am skeptical of any knowledge management system. I will explore the details of any system that I work with and identify features that are not supported that 'should be'.

The Animal Rights Activist/Hacker

No animals in research. If I can't stop animal testing, at the very least I want to know such testing is being conducted humanely. If I see any sign of animal testing on a website, I'm going to follow up. If I don't get what I want, I might push for action against the researchers. Action might come in the form of protest, or even computer hacking. If I hack their websites, then I can slow their communications and perhaps their operations.

Bioinformatician

I Work in bioinformatics within a company. I`m concerned about the cost of databases and try to avoid 'database' lockin with proprietary systems. I believe Big Data is the future of biomedical research and have a hobby of learning about Big Data and the systems used to analyze it. I feel that I work in an unusual position within the company and feel I always have to justify my existence.

Statistician

Overworked and in high demand. Skeptical of automated statistics but yet appreciative of speedy summaries. Sees tranSMART as a hypothesis generating tool with real statistics necessary for the true analysis. Wants to know the processes under any automated analyses.

Database Manager

Has worked a few years for a CRO. Sees a lot of effort in cleaning any database. "There will always be manual work". Sees a lot of value in standards as they will limit the amount of data that is not comparable and minimize the transformational work. Spends most of his time querying people on incorrect data.

Curator

Librarian for data. Concerned about semantics and naming conventions. Spends lots of time in front of a computer preparing data for entry into databases. Concerned about interfaces for entering data and tools that enable automated loading.

Channels to be used

- 1) Website:
 - a. Overview content,
 - b. slideshare,
 - c. value proposition case studies,
 - d. video interviews, news items,
 - e. blog posts
 - f. twitter updates
 - g. links are partners sites
 - h. engaged project newsletter
- 2) Linked In:
 - a. Discussion topics
- 3) Journal Publications:
 - a. Attribution toward eTRIKS

- b. press releases on publications
 - c. blog posts on publications
 - d. twitter
 - e. internal circulation
 - f. engaged project newsletter
- 4) Abstracts at meetings:
 - a. Attributions
 - b. internal circulations
 - 5) IMI:
 - a. direct communications about news
 - 6) Word of mouth:
 - a. Pitch
 - b. standard slide set
 - 7) Conference talks:
 - a. Standard slide set
 - 8) Our own conference:
 - a. newsletter,
 - b. IMI notification,
 - c. ads
 - 9) Guest Blogging:
 - a. Building relationships with thought leaders
 - b. Targeted blogs in topics – refer back to our website
 - 10) Commenting on blogs:
 - a. Target relevant online blogs articles & write mini-blog post comments
 - 11) News articles:
 - a. updates on progress
 - b. relevant news items
 - 12) Printed material:
 - a. brochure
 - 13) Presentations at engaged consortium meetings:
 - a. standard slide set
 - 14) Newsletter:
 - a. Aweber email form auto responder
 - 15) Public eTRIKS:
 - a. Membership forms, newsletter, website links
 - 16) Educational outreach
 - a. Materials for educators – slide set
 - b. eTRIKS outreach evangelists lecturing
 - 17) Patient organizations
 - a. Materials to patient organizations
 - b. Feedback from patient involvement in projects
 - c. Guest posts on patient forums etc.
 - d. Links to relevant articles posts etc.

Campaigns

Each campaign will have a specific name – i.e. Rising Star for the initial campaign etc. This facilitates identification of the campaign within the project.

Within Trello each of the Channels will get a card that contains basic information, updates, tips and knowledge on each channel type as well as supporting document files etc.

When a campaign starts a new list or column will be created for that campaign. Cards will be moved into the relevant campaigns. Whenever there are parallel campaigns a duplicate card will be made for a channel.

At the end of a campaign cards will be moved back into the channel's list. When there are duplicate cards these will be merged into one card.

Each campaign will be analyzed for results at the channel level. These results will be summarized and added to the channel description. Thereby building up knowledge base of the effectiveness of each channel.

Planned Campaigns

Rising Star

Concept: Establishment of content and plans for dynamic content

Goal: Establish and initial dissemination architecture and messaging set

Duration: Jan 2013 – Mar 2013

Targeted avatars: Coordinator of a project

Channels:

- Website
- Linked In
- Printed Materials
- Conference presentations

Conference

Goal: Convening of a first outreach conference – establish the process and identify possible concepts for future conferences

Concept: Should involve affiliated projects, stakeholders

Duration: Jan 2013 – July 2014

Targeted avatars: Coordinator of a project, Ethicist, Bio-informatician,

Channels:

- IMI
- Linked In
- Word of mouth
- Newsletter

- Our own conference

Public Server

Goal: Demonstrating tranSMART and build an email list of people interested in eTRIKS

Concept: Promote the public server and have individuals provide a simple email signup for access to the public server.

Duration: June 2013 – Sep 2013

Targeted avatars: Coordinator of a project, Bio-informatician, Clinician, Laboratory researcher

Channels:

- IMI
- Linked In
- Guest posts – affiliated sites
- Newsletter
- Press release
- Twitter
- Blog

Pitch

Building a new knowledge management system for each translational research project is highly inefficient and creates the risk that the data will be lost or inaccessible once a project ends.

eTRIKS is working to extend the open source knowledge management system tranSMART into a platform that will.

- Ensure the legacy of project data/results
- Facilitate dataset integration
- Increase operational efficiency
- Establish a common set of standards

This will be achieved through the provision of:

- Curation and tranSMART installation expertise and services.
- An open source platform that enables comparison of different types of data i.e. clinical (observational) and molecular data.
- Development of a common set of data handling and ethics standards and services.
- An “Apps” environment that includes analytical tools and the ability for open source development.

At the outset eTRIKS will support Innovative Medicines Initiative (IMI) projects and then extend to the wider translational research community as well as the open source development community.

eTRIKS is funded by the IMI from October 2012 to End of September 2017. The goal is to make the eTRIKS platform self sustainable through revenue generation or other funding mechanism.

Managing website content

The goal is to have dynamic website content to build strong relationships with stakeholders.

The best manner to get engagement via a website is content. The eTRIKS consortium has a potential wealth of content that can be generated. The challenge will be in presenting that content that is most pertinent to the various avatars.

The approach will be to generate content that is somewhere between highly readable, yet entertaining and informative content as seen on sites such as this one: <http://www.boostblogtraffic.com> and the typical detail oriented research project website.

Management Structure

A typical website or magazine structure will be adopted

Chief Editor: Scott Wagers

Associate Chief Editor: Trevor Garrett

Section Editors

- Improving operational efficiency with eTRIKS:
- Integration of datasets:
- Assuring legacy of TR research projects:
- Standards:
- News on progress:

Chief Editors will be responsible for driving most of the content. Section editors will be charged with reviewing the content and working to get more content generated.

Over time the plan will be to move from content that is generated by project partners to content being generated by a broader eTRIKS community. This can be fostered at the outset by asking projects we are engaging with to produce blog posts, infographics etc for the website.

Website stats January 30th– March 27th 2013

With 1213 visitors the website has had a reasonable start. At the outset of monitoring the Alexa site rank was 19.000.000 it is now down to 8.000.000 which puts it ahead of the transMART project website. For comparison the Sage Bionetworks site had an Alexa rank of approximately 4.000.000

Website statistics demonstrate that Linked In is the highest referral site followed by Twitter. The referral of twitter is a surprise.

The top post was one of 30 quotes on knowledge management relevant to translational research was the most viewed post with 183 followed by a post on the eTRIKS/transMART Developer's Workshop with 170 view. The quotes blog post is serving to attract a wider audience to the website as people come to find quotes. The post on the developer's workshop is delivering visitors who are highly relevant.

Visitors are from a wide array of countries. The UK and the US dominate with the UK in the lead. This is an indication that the audience reached is Europe centric. Often the US dominates site traffic stats mostly on the basis that there are more people on the internet in the US.

Engagement

Collaborating on data

eTRIKS address a problem faced by all translational researchers: How to maximize the impact of the collected data while minimizing costs.

Moral imperative

Maximizing the value of collected data is a moral imperative. Data comes at the expense of those who volunteer as well as those doing the research.

When you consider the opportunity that lies before us the moral imperative becomes even more clear. Advances in technology enable analyses that make use of highly complex datasets. The result: we are coming closer and closer to personalized medicine. What's more the Internet enables collaboration on a scale not even imaginable a decade ago. Isolated data achieves only a fraction of its potential.

Data does not have an expiration date.

When you collect your data today it is likely to still be relevant 20 years from now. The [Framingham study](#) in the US is using data from 64 years ago. Yet research is funded by grants or company projects that have definitive ending dates.

How do you prevent perfectly good data from collecting digital dust in some archival system?

Throw money at it?

Yes you could hire data managers, statisticians, buy some computers and pay for the data to be maintained over decades. However, the cost is prohibitive.

Some good things are free.

Keith Sawyer points in his book [Group Genius](#) tell an interesting story. In 1983 Richard Stallman, a hacker at MIT, began to write and promote a 'free' operating system. He was passionate that it remain free and open. Eight years later it was finalized by Linus Torvalds as what we know today as Linux. This was the beginning of 'open source'.

As Gareth Beavis on [Tech Radar](#) points out another interesting event occurred on November 5th 2007 when Google surprised everyone.

In the latter part of 2007 there was a buzz that Google was about to launch a "Google Phone". They had been working on something in secret and signs were they were heading towards a phone. They even bought an mobile application company known as Android.

The surprise. No phone. Instead they announced the formation of the [Open Handset Alliance](#) which consisted of not only Google but also other big names in technology.

They then proceeded in an open innovation project to build Android into what it is today. Android is free open source operating system that allows developers to build all kinds of applications. It is now being used in much more than mobile devices.

For Google open source and open innovation are their way of innovating. They succeed with this strategy over and over again with projects like Google Apps, Android, and Google Maps.

As Keith Sawyer also points out it is not only Google. IBM in 2005 had 600 engineers working on Linux.

Open source development projects foster formation of 'collaborative webs' that leverage collective genius to reach unanticipated levels of innovation.

It is not free per se.

Successful open source efforts open up new markets. Now there are Apps for sale on the Google Apps site, Linux is the operating system for IBM computers, and a whole new sort of location based advertising has been created with Google Maps.

It's the bottlenecks that matter.

Open source projects eliminate bottlenecks. The bottlenecks being addressed by the Innovative Medicines Initiative are in essence similar to those that inspired the development of Linux and Android.

“The key aim of IMI is to address bottlenecks in pharmaceutical R&D leading to faster discovery and development of better medicines for patients and the enhancement of Europe’s competitiveness.”

[IMI Strategic Research Agenda](#)

Both solve problems that have been hindered by a lack of harmonization and the inability for one company or research group to apply enough resource on their own to solve the problem.

An incremental process

Open source projects do not effect step changes. They provide momentum for the realization of developing ideas.

eTRIKS is the culmination of a long standing effort to pool resources to develop a translational research open source knowledge management system that maximizes both the impact of research projects and operational efficiency.

Like the Open Handset Alliance, eTRIKS is the combined effort of 16 partners working in an Open Innovation project.

However, the collaboration does not stop there.

eTRIKS supports Innovative Medicines initiative projects as well as other projects to:

- 1) Ensure the legacy of project data/results
- 2) Facilitate dataset integration
- 3) Increase operational efficiency
- 4) Establish a common set of standards

Ultimately, eTRIKS looks to be central in the effort to build an open source translational research platform alongside the [transMART consortium](#).

How to take part?

Help build a community. Join the eTRIKS Linked In Discussion Group. It is open to everyone. The discussions are not just updates or promotions or job postings. They are eye opening and informative.

This is the start of the eTRIKS ‘collaborative web’.

So, if you are a translational, researcher, bioinformatician, statistician, systems biologist, clinical researcher, or a developer, join us: [eTRIKS Discussion Group](#).

We aim to also make this website a hub of useful information on Translational Research Knowledge Management. Sign up to receive updates.