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0.3	01/05/2018	Draft	Konstantinos Deltouzos (UoP)	Refined deliverable sections
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1.0	07/05/2018	Final	Vasilis Megalooikonomou, Konstantinos Deltouzos (UoP)	Final version of the preliminary deliverable

EXECUTIVE SUMMARY

The overall objective of work package **WP6** is to implement the FrailSafe Applications and Services, the Virtual community and finally to orchestrate the system development tasks of WP2 – WP5 in order to produce the FrailSafe integrated system, explicitly taking into account security and privacy issues.
The main focus of the deliverable **D6.1** is to describe the specifications and technical details of the developed Virtual Community Platform (FVC) which is a Health 2.0 social media patient support community for caregivers, older people, and their families.

DOCUMENT INFORMATION

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Keywords	Virtual community platform, forum, social network, health 2.0			

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Table of contents

Table of contents **5**

List of figures **6**

List of Tables **6**

LIST OF ABBREVIATIONS AND ACRONYMS **6**

1 Introduction **7**

2 Health 2.0 ..... **8**

2.1 Technologies and Tools 9

2.2 Drawbacks 11

3 FrailSafe Virtual Community Platform **13**

3.1 Specifications 13

3.2 Technical details 14

4 Conclusion **17**

References **18**

List of figures

FIGURE 1 EXAMPLES OF HEALTH 2.0 TOOLS 10
FIGURE 2 FRAILSAFE VCP PRELIMINARY VERSION 15
FIGURE 3 FRAILSAFE VCP PROFILE PAGE 16

List of Tables

No table of figures entries found.

LIST OF ABBREVIATIONS AND ACRONYMS

(*in alphabetic order*)

ALS	Amyotrophic Lateral Sclerosis
CMS	Content Management System
OSN	Online Social Network
SaaS	Software as a Service
SM	Social Media
VCP	Virtual Community Platform
VHC	Virtual Health Community

1 Introduction

The recent growth of online technology and mobile innovations has affected significantly the health technologies and tools, leading to a new era called the “Health 2.0”. This new term describes the integration of SaaS and cloud-based technologies into much of general clinical and administrative workflow in health care.

In this deliverable we present the recent advances in Health 2.0 and the benefits and drawbacks they have. Towards this direction we describe the specifications of a Health 2.0 tool developed for our project called the FrailSafe Virtual Community Platform (VCP). We present the technical details of the preliminary version of the VCP as well which was developed till M28. In the next period we will focus our work on the refinement of the design and technical issues of the VCP in order to prepare an alpha version. We will work also on engaging users to use it and collect valuable feedback from them in order to prepare the final version.

2 Health 2.0

With the growth of online technology and mobile innovations, health information has never been more accessible. Given the constraints of working in a tightly regulated environment, life sciences companies (pharma, biotech and medical device) have moved slowly to adopt Health 2.0, treating it as a minor component of their commercial strategies and marketing plans.

The term "Health 2.0" was introduced in the mid-2000s, as the subset of health care technologies mirroring the wider Web 2.0 movement. It has been defined variously as including social media, user-generated content, and cloud-based and mobile technologies. These technologies can empower patients to have greater control over their own health care and thus diminish medical paternalism [1].

It was built on the possibilities for changing health care, which started with the introduction of eHealth in the mid-1990s following the emergence of the World Wide Web. In the mid-2000s, following the widespread adoption of the Internet and the tools used for communication, social networking, and self-publishing, there was spate of media attention to and increasing interest from patients, clinicians, and medical librarians in using these tools for health care and medical purposes [2,3].

While the "2.0" moniker was originally associated with concepts like collaboration, openness, participation, and social networking, in recent years the term "Health 2.0" has evolved to mean the role of SaaS and cloud-based technologies, and their associated applications on multiple devices. Health 2.0 describes the integration of these into much of general clinical and administrative workflow in health care. As of 2014, approximately 3,000 companies were offering products and services matching this definition, with venture capital funding in the sector exceeding $2.3 billion in 2013 [4].

The "traditional" definition of "Health 2.0", as described in [5], focused on technology as an enabler for care collaboration: *"The use of social software t-weight tools to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health".* However, Indu Subaiya [6] redefined Health 2.0 as the use in health care of new cloud, SaaS, mobile, and device technologies that are:

1. Adaptable and interoperable, allowing other tools and applications to link and integrate with them, primarily through use of accessible APIs
2. Focused on the user experience, bringing in the principles of user-centered design
3. Data driven, in that they both create data and present data to the user in order to help improve decision making

This wider definition allows recognition of what is or what isn't a Health 2.0 technology. Typically, many enterprise-based customized client-server systems do not fit this definition and cannot be considered as Health 2.0 technologies, while other more open cloud based systems might do. However, this line was blurring by 2011-2 as more enterprise vendors started to introduce cloud-based systems and native

applications for new devices like smartphones and tablets. In addition, Health 2.0 has several competing terms, each with its own followers including Connected Health, Digital Health, Medicine 2.0, and mHealth 2.0 (next generation mobile technology to support patient care). All of these, support a goal of wider change to the health care system, using technology-enabled system reform, and are designed to help patients, medical professionals, caregivers and researchers work together to promote a higher standard of care. The five major aspects emerging from this new healthcare innovation include:

1. Social Networking: Serves as a platform to facilitate conversation, allowing users to see what their peers are doing.
2. Participation: Allows patients to play an active role in their healthcare by controlling their own health information.
3. Apomediation: Offers patients a third option to receive high-quality healthcare information – in addition to healthcare professionals and conducting online research – from experts, tools and services.
4. Collaboration: Provides the opportunity for researchers, healthcare professionals, patients and the community to come together and work to improve healthcare initiatives.
5. Openness: Permitting the public to have access to information that was previously limited, such as health records, research and data.

Healthcare organizations traditionally operated as a closed system, but Medicine 2.0 / Health 2.0 strives to change that by promoting the above five themes to allow everyone to be involved.

2.1 Technologies and Tools

Early examples of Health 2.0 were the use of a specific set of Web tools (blogs, mailing lists, online communities, podcasts, search, tagging, Twitter, videos, wikis, and more) by actors in health care including doctors, patients, and scientists, using principles of open source and user-generated content, and the power of networks and social networks in order to personalize health care, to collaborate, and to promote health education. The more recent Health 2.0 solutions are based on forums and social networks, interoperable health records, and mobile technologies. An overview of different tool types and typical examples are presented in Figure 1.

We will focus here mostly on the social media tools for Health 2.0, which can be classified into two generic categories: general-purpose online social networks (OSNs) and virtual health communities (VHCs) [7]. General-purpose OSNs are Facebook, Twitter, Instagram, and YouTube. They are the most used social media (SM) platforms for health information. VHCs are SM platforms that are designed for individuals to facilitate online interaction around specific health topics. VHCs are mostly used by online community groups, like Inspire.com and ask-a-doctor websites, such as MDTalks.com.

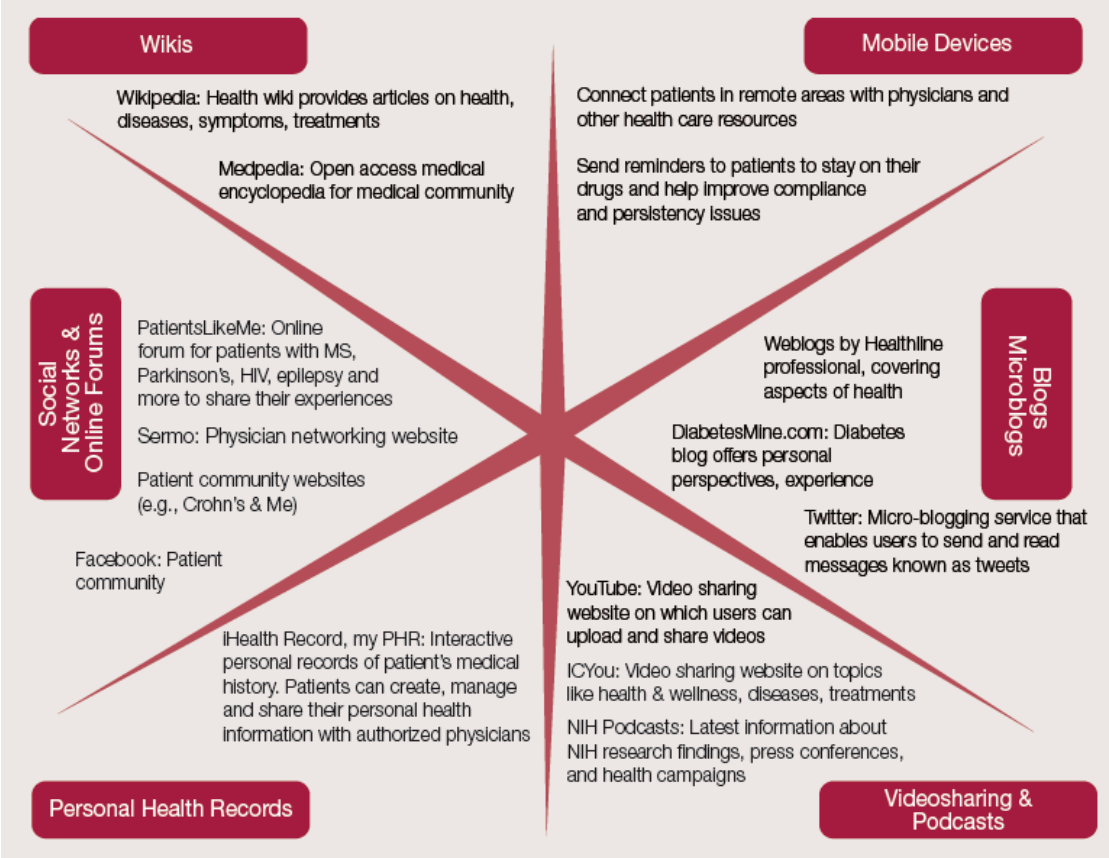

Figure 1 Examples of Health 2.0 Tools

OSNs are mostly used in the communication between physician and consumer. Through these sites, physicians and health-care organizations can communicate with individuals helping them to learn more about their health-related problem and make better future decision on their health and health care. OSNs can also be used to enhance the communication among patients around a specific medical topic. Thus, patients can share their opinions and experiences in order to empower themselves and play an active role in their health care processes and education [8].

VHCs are mostly used in the communication between patients. These SM platforms are typically built upon mass collaboration on health-related topics, favoring social interactions and social support among patients. Health discussion boards and forums are the most used platform in the patient collaboration. The discussion boards and forum are typically topic-oriented platforms to discuss about a specific disease or health-related topic [9]. Usually, patients can initiate discussion threads on a topic, asking a question or seeking support from others on the platform, and in response to the thread initiator, other patients can post their comments and provide their experience, information, sympathy, and thoughts about the thread topic. Another form of collaboration among patients is the user review. Patients can rate medicines, physicians, and health-care organizations expressing their personal experiences in order to help other patients who potentially need them in the future. Physician rating platforms are among the fastest growing user reviews in the context of health-related SM [10, 11]. Physician-rating websites represent a different type of communication

where patients can post their reviews for the advantage of other patients. Health care organization can learn from patients' opinions about the physicians with the scope of improving the quality of care that they provide for the patients [7]. Currently, the most commonly visited physician-rating websites include Healthgrades.com, vitals.com, ratemds.com, zocdoc.com, and GoogleReviews. Patients who use these websites to determine the quality of a physician should do so with some caution as there is no verification process to substantiate the reviews listed for each physician. The benefit of these websites is that they do provide immediate feedback to other patients and the physician on the quality of care received.

Bonesmart.org is a comprehensive virtual health community focusing on patients undergoing hip and knee replacement surgery. The online forum is divided into the preoperative area and the postoperative recovery. This online forum provides a comprehensive resource for people who share hip or knee pain and are interested in potential treatments, what to expect prior, during, and after surgery. These online patient forums provide an invaluable source of online information for patients.

PatientsLikeMe.com is a patient network and real-time research platform. Through the network, patients connect with others who have the same disease or condition and track and share their own experiences with the goal to improve outcomes. In the process, they generate data about the real-world nature of disease. With over 600,000 members, PatientsLikeMe is a source for real-world disease information and its patient-generated data form the basis of more than 100 peer-reviewed scientific studies. PatientsLikeMe was inspired by the life experiences of Stephen Heywood, diagnosed in 1998 at the age of 29 with amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease.

2.2 Drawbacks

While using the Health 2.0 technologies can have significant benefits both to the patients and the medical professionals, there are some drawbacks as well. Hughes et al. [12] argue there are four major tensions represented in the literature on Health/Medicine 2.0. These concern:

- the lack of clear definitions
- issues around the loss of control over information that doctors perceive
- safety and the dangers of inaccurate information
- issues of ownership and privacy

Several criticisms have been raised about the use of Web 2.0 in health care. Firstly, Google has limitations as a diagnostic tool for Medical Doctors (MDs), as it may be effective only for conditions with unique symptoms and signs that can easily be used as search term [13]. Studies of its accuracy have returned varying results, and this remains in dispute [16]. Secondly, long-held concerns exist about the effects of patients obtaining information online, such as the idea that patients may delay seeking medical advice [17] or accidentally reveal private medical data [18,19]. Finally, concerns exist about the quality of user-generated content leading to misinformation [20,21], such as perpetuating the discredited claim that the MMR vaccine may cause

autism [22]. On the contrary in [23], a 2004 study of a British epilepsy online support group suggested that only 6% of information was factually wrong. In a 2007 Pew Research Center survey of Americans, only 3% reported that online advice had caused them serious harm, while nearly one-third reported that they or their acquaintances had been helped by online health advice [23].

During the development of a new Health 2.0 tool, one should take into account all the above issues and address them as best as possible, in order to for the tool to be as safe as possible and be adopted by the end users.

3 FrailSafe Virtual Community Platform

The FrailSafe Virtual Community Platform (VCP) is a Health 2.0 tool which will be released together with the FrailSafe's final integrated system. Its main aim is to be a platform which the caregivers, older people, and their families can use in order to communicate and exchange ideas. It will serve as a space for older people to ask and answer questions about diagnoses, etiology, and treatment and to exchange disease and health related information. In the next sections we present the specifications and the technical details of the VCP.

3.1 Specifications

The FrailSafe VCP is intended to be used by a large number of users, who will use the platform for different reasons and should have different access rights. In the following list the identified user categories are presented and their access rights are described:

- **Older people**: the main target group of this platform. These users will be able to browse and update their profile, browse other users' profiles, participate in the forum etc.
- **Clinicians**: certified medical personnel. They will be able to browse older people profiles and interact with other users through the forum. They will be able to give suggestions to the older people.
- **Administrators/moderators:** users with elevated access rights, which will be the ones approving the new members of the platform (especially the clinicians which need to be certified). Also, they will need to approve the messages exchanged in the forum to ensure that they do not contain offensive or dangerous messages.
- **Other users**: mainly family members and caregivers which will be able to browse the older people profiles and use the forum.

The older people which will use the FrailSafe VCP are going to be clustered in communities based on predefined filters (frailty status, location, medical information, etc). Users can be part of multiple communities based on the filters, i.e. an older person can be clustered into in "Frail", "Patras, Greece", and "Stroke" communities. The aim of having these communities is that the older people will feel they are part of a group that users have similar needs and interests and the communication between them will be easier. As part of the VCP there will be tools for the evaluation of the effectiveness of communities and their impact on the health condition and personal factors of users. These tools will include pop-up windows to collect feedback and statistics of forum posts, in order to check the effectiveness of the communities.

The platform will offer the following features to the users:

- **Forum**: All registered users will be able to read and write posts to the VCP forum. The forum however is going to be moderated, so each post will need to be approved by a moderator in order to be visible. This security feature serves

as a mechanism to remove offensive or dangerous messages towards the users of the platform.

- **Older people profiles**: Each older person will have his/her own profile which will contain both personal information (such as demographics) and medical information (parameters that are considered important). These medical parameters will be identified in the final version of the VCP, when the completion of the data analysis will show which parameters are important. The user is responsible to insert his/her own information and keep his/her profile up-to-date. In order to motivate him/her to do so, the VCP can send reminders in case a user shows inactivity.
- **News feed**: This feature will show news and articles that are of interest to the users of the platform (such is articles about frailty, healthy ageing etc). These articles can be written either by the users or collected by other online sources. The aim of having a news feed is to promote positive health-related activities (fitness, daily habits) and engage the users to use the platform.
- **Calendar**: The calendar will be used to show activities or events (online or physical) that a user can attend. These events can be formal (ie. a presentation about frailty), or informal (ie. taking part in a walk with users that live closeby).

As we noted earlier the evaluation of the FrailSafe VCP is important in order to ensure that the users will use a safe and effective Health 2.0 tool. Therefore, we intend to collect feedback from the users on a regular basis, e.g. short feedback during the login, longer feedback once per month using mail. Moreover, the occasional use of pop-up windows will allow us to collect feedback and evaluate the VCP.

3.2 Technical details

Since the FrailSafe VCP aims to engage a wide audience and not to be restricted to the participants (older people, clinicians etc.) of the FrailSafe platform, it was decided to build the VCP as an extension to the FrailSafe website: http://frailsafe-project.eu/.

The FrailSafe VCP is being built on top of **Joomla 3.7** (https://www.joomla.org/) content management system (CMS). Joomla supports **extensions**, which extend the functionality of Joomla websites. Over 7.900 free and commercial extensions are available from the official Joomla Extension Directory and more are available from other sources. The FrailSafe VCP takes advantage of selected reliable extensions, such as Kunena, JEvents etc., to achieve the functionality presented in the previous sections.

The FrailSafe VCP is also based on the following software systems:

- **Apache HTTP 2.4** (https://httpd.apache.org/), which is the most popular free and open-source web server available today.
- **MySQL 5.7** (http://www.mysql.com/), as the database to store all data.

Finally, and in order to track and report traffic, the FrailSafe VCP is linked to **Google Analytics** a popular service offered by Google (https://analytics.google.com/). Google

Analytics is now the most widely used web analytics service on the Internet. Google Analytics' approach is to show high-level, dashboard-type data for the casual user and more in-depth data further into the report set.

Google Analytics analysis can identify poorly performing pages and features, where visitors came from (referrers), how long they stayed, their geographical position etc., hence assisting decisions to be taken during the development as well as the operational phase of the VCP.

A first preliminary version of the FrailSafe VCP has already been set up, as illustrated in Figure 2, while Figure 3 demonstrates the personal profile setup page of each registered user. Involved partners will continue working on developing and further improving the FrailSafe VCP until it reaches a final version promptly.

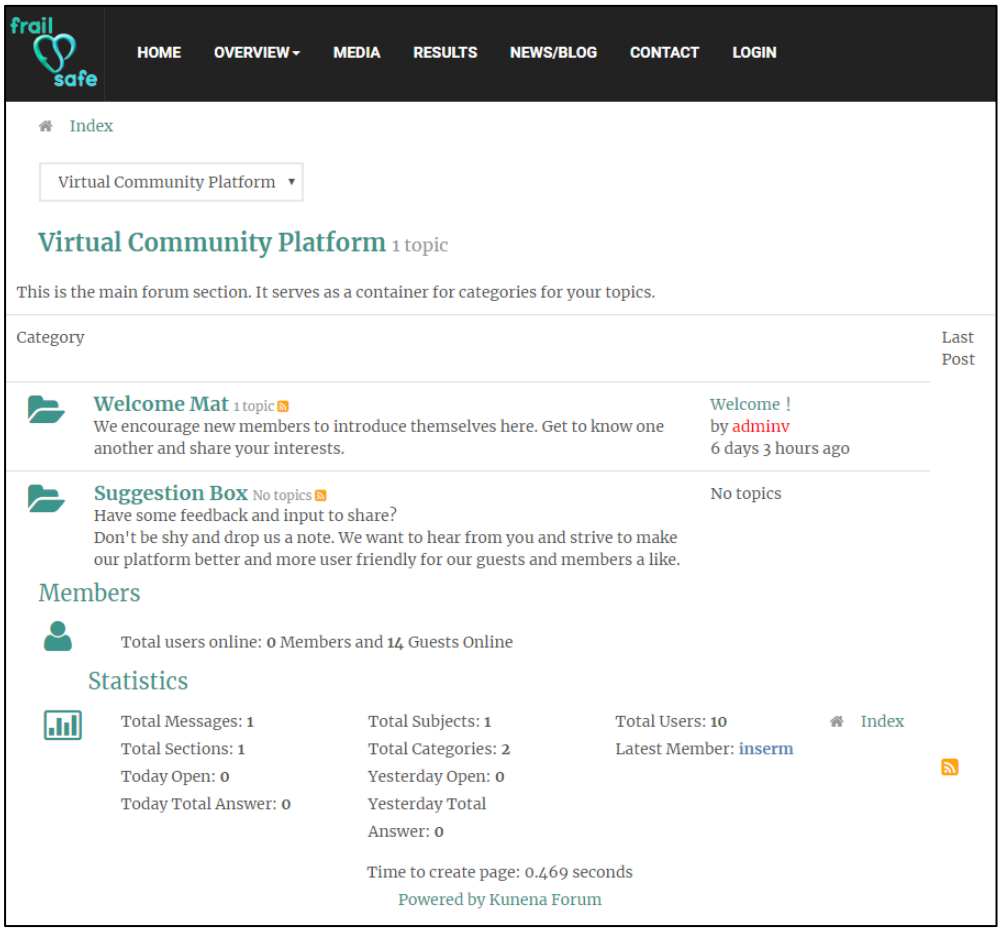

Figure 2 FrailSafe VCP preliminary version

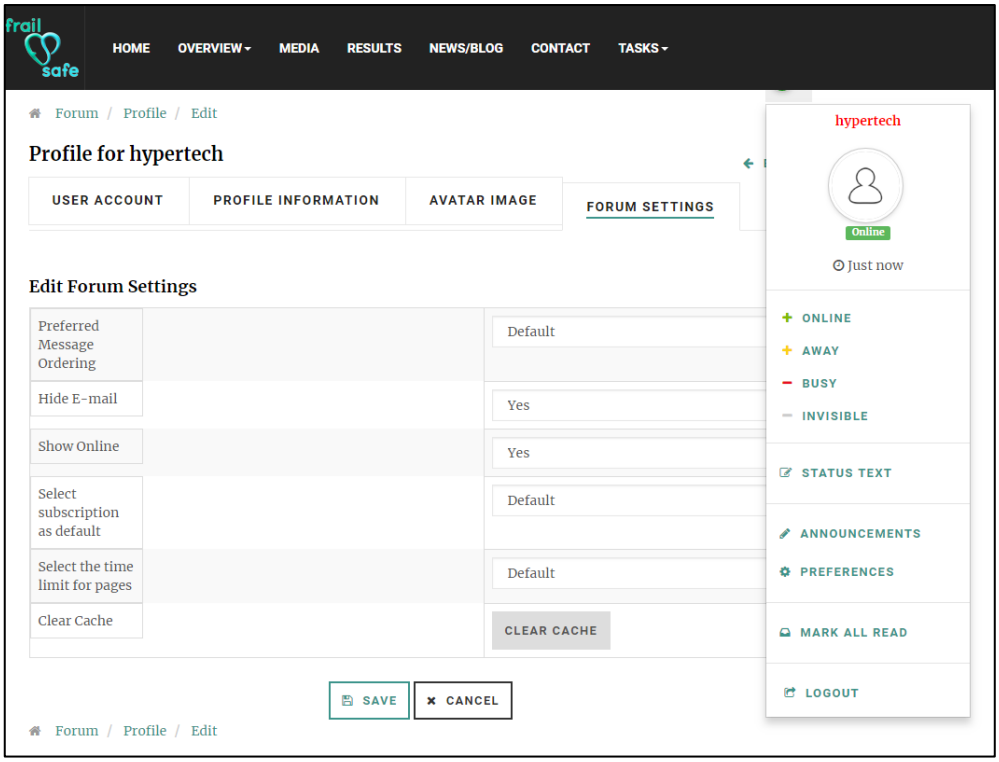

Figure 3 FrailSafe VCP profile page

4 Conclusion

In this deliverable we presented the recent advances in Health 2.0 and the specifications of our FrailSafe Virtual Community Platform. A preliminary version of the VCP was developed and its technical details were presented as well. In the next period we will focus our work on the refinement of the design and technical issues of the VCP in order to prepare an alpha version. We will work also on engaging users to use it and collect valuable feedback from them in order to prepare the final version.

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