

## IMI2 821520 - ConcePTION

### ConcePTION

#### WP8 – Scientific coordination, project management & sustainability

## D8.6 Public website and social media plan

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### Document History

Version	Date	Description
V1.0	25 May 2021	Submission to project management office for quality assurance.
V1.1	27 May 2021	Final version

## Abstract

To support impact, the ConcePTION project communicates through a number of channels. This report outlines an overall strategy for three types of audiences: lay, well-informed and experts, with corresponding communication objectives. The strategy outlines a set of communication tactics for each audience, and corresponding channels. This document includes an action plan for how this strategy is operationalised in WP8 (Scientific coordination, project management and sustainability) and will serve as a framework for communication activities in WP5 (Dissemination and education for health care professionals, pregnant and breastfeeding women and the general public). A high level summary of this strategy is outlined in the table below.

<b>Lay audiences</b>  Raise awareness  Call to action	Pregnant & breastfeeding	<b>Channels:</b> Twitter, YouTube (video)  <i>(third party channels through task 5.3)</i> <ul style="list-style-type: none"> <li>• Plain language/national language</li> <li>• Short form &amp; editorial content</li> <li>• Framing and explaining</li> </ul>
	Women of childbearing age	
	Partners	
	General public	
<b>Well informed</b>  Raise awareness  Disseminate results	Patients	<b>Channels:</b> Twitter, website, newsletter  <i>(third party channels through task 5.3)</i> <ul style="list-style-type: none"> <li>• Building on short form, linking to long form</li> <li>• Linking to source (publication/report)</li> </ul>
	Patient organisations	
	Health care professionals (broadly)	
<b>Expert</b>  Raise awareness  Disseminate results  Develop buy-in & readiness to implement	Prescribers	<b>Channels:</b> Twitter, website, newsletter & LinkedIn <ul style="list-style-type: none"> <li>• Cross-disciplinary/cross-professional</li> <li>• Focus on results</li> </ul>
	Pharmacists	
	Pharma industry	
	Scientists/Academics	

**Table 1:** Summary of audiences, objectives, channels and communication tactics

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## Introduction

Communications is one of the building blocks for an overall strategy to achieve impact. To support impact, we communicate through a number of channels to raise awareness of the objectives of the project and the challenges addressed, and to share the results of the project with a wider audience. Communication activities help frame questions and challenges the project is here to solve, and prime stakeholder audiences for results, with the aim to raise expectations. This in turn can support the development of buy-in and readiness to implement the infrastructures, ecosystem, and knowledge bank. Communication activities and channels also support the consortium's interactions with various stakeholders, and this report describes how project channels can support this work, all in a timely fashion.

## Scope and purpose of this report

In the ConcePTION project, responsibilities for communications are divided between WP8 and WP5. As a part of the overall project management tasks, WP8 is responsible for communicating about the project as a whole, its parts, and results. WP5 is responsible for dissemination and education for health care professionals, women, and the general public (outlined in [D5.2: Report describing communication plan and governance for Work Package 5, Subtask 5.3](#)). These activities are intertwined as all communications from the project should use uniform messaging.

This report outlines communication objectives, audiences, key messages, tools, and tactics in relation to all stakeholders and audiences that the project will address. The current report describes how ConcePTION channels can be used in relation to WP5 communication activities, and provides a framework within which WP5 can operate. In this document we show how an effective communications and dissemination strategy will:

- enable the IMI ConcePTION consortium members to communicate effectively to support overall objectives;
- engage with and tailor communication and dissemination to various audiences and ensure they understand the value of the ConcePTION project and its results;
- support effective and timely publicity for results;
- enhance ConcePTION's visibility and reputation with the aim to support impact in the EU and internationally;
- change stakeholder behaviour and perceptions where necessary;
- demonstrate the success of ConcePTION;
- set measurable goals for communication and dissemination;
- ensure ConcePTION adheres to IMI communication guidelines.

This document includes an action plan in annex. The action plan is a living document that outlines how different activities will facilitate timely and consistent communication. In the plan and this document we define with whom (the audience), why, when, what (the type of activity), where (the channel) communication is expected. We also identify who is responsible for implementation of the activities.

**Note:** The resources committed to communications in WP8 are very limited, which restricts the number of activities and outputs that can be achieved in the operationalisation of this strategy into activities and actions.

## Guiding principles

ConcePTION communications should be accurate, timely and relevant to the project and the target audiences defined in this plan. Communications should be accessible and inclusive, acknowledging that

our audiences include members of all publics with various backgrounds and abilities: from young mothers and members of immigrant communities to experts in the fields covered by the project. Furthermore, communications should be factual (accurate and adapted to the target audiences), transparent (in relation to contributions, authorship, data management, and any conflicts of interest), consistent (using templates and agreed on messaging), and respectful towards our audiences and the partners and members of the consortium.

## Aligning impact and communication objectives

All communications from ConcePTION have a dual purpose:

1. First, to raise awareness about the problem (lack of safety evidence and information), and explain how the ConcePTION project can fix it.
2. Second, send a message and/or call the audience to action. For example by explaining what is happening in the project, by encouraging audiences to take part in project activities (responding to a survey, donating milk and blood samples), or by presenting highlights from results (reports or journal publications) in a digestible format, and encouraging readers to explore the source. This requires messaging, a set of tools and tactics to reach audiences and channel access. Both to project channels and those owned by third parties (e.g. IMI, partners, and other organisations with access to our intended audience).

Communications is one part of the impact strategy. To ensure that there is alignment, the communications manager will work closely with the sustainability workstream, with the aim to build relevant audiences and use communications activities to prime them for messages about the way the infrastructures and ecosystem will be sustained after the project ends. This means that the tools and tactics described here are part of an iterative approach to communications strategy: As the project and its impact objectives develop, the communication objectives and strategy needs to develop along with it.

## Communication objectives

To support impact objectives in relation to these activities, we have formulated a set of over-arching communication objectives. These objectives should be coupled with objectives related to specific activities, and when appropriate also calls to action. Overall objectives include:

- Raising awareness of the fact that there is a knowledge gap regarding medicine use in pregnancy and breastfeeding
- Explaining how ConcePTION will fill this knowledge gap through its outcomes of the project and what it will deliver
- Increasing the likelihood that all audiences will choose to engage with the project (by answering a survey, donating milk and blood, or sharing a social media post)
- Increase reporting of exposure to medicines during pregnancy
- Raising awareness that the use of medicines in pregnancy is something that both women and health care professionals should be aware of and prioritise (for example by asking questions, using and providing reliable information)
- Raising awareness about how ConcePTION can help patient organisations to build a stronger connection with their pregnant and breastfeeding members by being able to offer safety information about their medicines

- Raising awareness about the infrastructures we are building and how they can support women, but also how they can help health care professionals in their daily work
- Increasing awareness of the fact there are other ways to generate safety information that are more effective than the current methods used (e.g. pregnancy registries are resource-intensive and often don't deliver data for the label)
- Explaining how using ConcePTION outputs would simplify work already carried out by different stakeholders (e.g. pharmaceutical companies, regulatory authorities, research infrastructures, and individual researchers)
- Changing perceptions among various stakeholder audiences, creating a readiness to implement and use tools and infrastructures developed in the project

To support these objectives, communication activities and messaging need to cover a wide range of topics, aimed at a very wide range of audiences. This is best achieved when communications can combine project branding, awareness-raising, and information about what the project will deliver with sharing specific results or calling audiences to action. Elements that should be considered include:

- The project (branding)
- The problem (lack of knowledge)
- The importance of pharmacovigilance reporting
- The infrastructures (the model for drug transfer & the biobank & analysis platform)
- Individual results (everything coming out of the project)
- The ecosystem
- The knowledge bank

## Stakeholders and audiences

Our audiences are diverse, ranging from academics and experts in different fields (which requires an approach for cross-disciplinary communications); health care professionals (ranging from specialist's and general practitioners who prescribe medicines, pharmacists who fill prescriptions, midwives who meet pregnant women, to nursing staff in aftercare, lactation specialists and physiotherapists); the women, trans men and non-binary individuals who might become pregnant, want to become pregnant, are pregnant, want to breastfeed and those who are breastfeeding; and other publics (which includes partners).

Women of childbearing age make up a large proportion of all these audiences, which puts them at the core of all our communications efforts. This group includes trans men and non-binary. We strive to be inclusive. However, to ensure we are able to use an active voice when addressing the collective, we will henceforth use the term 'women' interchanged with 'pregnant', 'breastfeeding' in instances where this allows an active voice, and when appropriate also address the audience in the first person (e.g. 'you', 'your medicines', 'your health'). These women are scientists, they work in pharma, they are health care professionals, and they are members of all other publics. As a consequence, all communications directed at all audiences need to include messaging for women and their partners.

We divide our audiences into three segments: 1) lay audiences, 2) audiences who are well informed about medicine use in general, and 3) expert audiences. This allows us to use a three-tiered approach to content in our communications.

1. The first tier consists of plain language short-form content in social media (for example short plain language videos about the project, tweets, and images). This is complemented by editorial

content on web, and publicity activities. This content is meant to frame, explain, generate interest, and call audiences to action.

2. The second tier builds on the short-form content, but this time aiming to engage with well-informed audiences, linking to the source (publications, reports), and calling to action.
3. The third tier is aimed at cross-disciplinary and cross-professional communications, supporting understanding of data and results by scientists and experts in different fields.

Each tier corresponds to an audience segment, and each segment consists of a number of groups, with a set of general tactics identified per each group.

	Audience	Definition	General tactics	Approach
LAY AUDIENCES	<b>Pregnant &amp; breastfeeding</b>	Anyone who is pregnant or breastfeeding, planning a pregnancy or considering breastfeeding.	<p>Always use an active voice.</p> <p>Use plain language and when possible also national language.</p>	PLAIN LANGUAGE/NATIONAL LANGUAGE, SHORT FORM AND EDITORIAL CONTENT, GENERATING INTEREST, FRAMING & EXPLAINING
	<b>Women of childbearing age</b>	Pregnancy and breastfeeding are temporary conditions over the course of many reproductive years. They are sometimes planned, sometimes not. We, therefore, extend our audience to all who have a uterus and are of childbearing age.	<p>Inclusive communications (including visual representations).</p> <p>Portray women as active subjects, e.g. in visual communications by avoiding 'male gaze' images.</p> <p>Addressing the audience as women to allow us to use an active voice (acknowledging the fact that not all who are pregnant consider themselves women).</p> <p>Using 'women' interchanged with 'pregnant', 'breastfeeding' without gendering in instances where this allows an active voice.</p> <p>Address the audience in the first person (e.g. 'you', 'your medicines', 'your health').</p> <p>Informing about the need for more knowledge and how reporting can support the development of safety evidence.</p> <p>Short video for social media.</p>	

			<p>Calling women to action to report exposure during pregnancy.</p> <p>Calling (specific groups of) breastfeeding women to action to donate samples.</p>	
	<b>Partners</b>	Anyone who is the partner of a woman of childbearing age	Indirectly addressed through general awareness-raising.	
	<b>General public</b>	All members of all public(s)	<i>(Note: biological fathers who use medicines are out of scope in this project).</i>	
<b>WELL INFORMED</b>	<b>Patients</b>	Female patients with chronic or temporary conditions.	Framing communications with specific conditions, sharing results related to specific medicines.	<b>BUILDING ON SHORT FORM, LINKING TO LONG-FORM CONTENT + LINKING TO SOURCE</b>
	<b>Patient organisations</b>	National and international organisations for patients with specific conditions or umbrella organisations covering a specific disease area or who work as umbrellas for patients in general. This audience includes organisations aimed at supporting breastfeeding	<p>Informing about the need for more knowledge and how reporting can support the development of safety evidence.</p> <p>Informing about how to report exposure and that both women and their doctors can report.</p> <p>Informing about results and outputs from the project (including the upcoming knowledge bank)</p>	
	<b>Health care professionals</b>	All health care professionals, including students (prescribers, professionals who have medication-related conversations or treat those who are pregnant or breastfeeding).	<p>Framing communications with specific conditions, sharing results related to specific medicines.</p> <p>Informing about the need for more knowledge and how reporting can support the development of safety evidence.</p>	
	<b>Professionals who tend not to have medicines related conversations (but meet patients):</b>	Sonographers, physiotherapists. This group could get questions, and then direct patients to online knowledge databases, Teratology Information Services, or other health care professionals for advice.	<p>Informing about how to report exposure and that both women and their doctors can report.</p> <p>Informing about results and outputs from the project (including the upcoming knowledge bank)</p>	
	<b>Professionals who</b>	Midwives, nurses,		

	<b>have medication-related conversations</b>	pharmacists. Note: in some countries, this group can also prescribe medicines.		
<b>EXPERT AUDIENCES</b>	<b>Prescribers</b>	Medical doctors (includes all: specialists for specific disease management, OBGYN for pregnancy-related issues, GP's to treat temporary or chronic conditions, or (as in the UK) manage pregnancy-related issues). Note: in some countries, this group includes pharmacists, nurses, and midwives who can prescribe for example birth control.	<p>Framing communications with specific conditions, sharing results related to specific medicines.</p> <p>Informing about the need for more knowledge and how reporting can support the development of safety evidence.</p> <p>Calling doctors to action to report exposure to medicines during pregnancy.</p> <p>Calling doctors to action to use the knowledge bank and read our published results.</p>	<b>CROSS-DISCIPLINARY/CROSS-PROFESSIONAL COMMUNICATIONS</b>
	<b>Pharmacists</b>	Pharmacists who fill prescriptions.	<p>Calling pharmacists to action to encourage women to report exposure to medicines during pregnancy.</p> <p>Calling pharmacists to action to use the knowledge bank and read our published results.</p>	
	<b>Pharma industry</b>	Pharma companies, business associations (e.g EFPIA), regulatory authorities (e.g. EMA, FDA) & senior individuals working in these organisations.	<p>Framing communications with the fact that pharmacovigilance data is scattered and inconsistent.</p> <p>Call pharma to action to use the infrastructures &amp; ecosystem developed in the project.</p>	
	<b>Regulators, HTA &amp; health authorities</b>	All European and national authorities that develop policy, recommendations or take decisions on medicine use in pregnancy, particularly regulatory authorities, health technology assessment bodies and payers	<p>Framing communications with the fact that pharmacovigilance data is scattered and inconsistent.</p> <p>Calling authorities to action to read (and use) our published results.</p>	
	<b>Scientists/Academics</b>	Senior and junior staff	Framing communications with	

		<p>in public and private research organisations active in all fields that are relevant to the project.</p> <p>Technical and administrative staff working for research infrastructures and biobanks (e.g. BBMRI)</p>	<p>the fact that pharmacovigilance data related to prebanncy and breastfeeding is scattered and inconsistent.</p> <p>Calling scientists to action to read (and use) our published results.</p> <p>Call to action to use the infrastructures &amp; ecosystem developed in the project.</p>	
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**Table 2:** Audiences, tactics & general approach

## Consistent and agreed messaging

The ConcePTION project uses a messaging strategy coupled with calls to action, results, or other content. In the autumn of 2019, the need for clear and consistent messaging became clear in relation to the online survey recruitment in task 5.3.1 and donor recruitment in WP4. This initiated a process to develop high-level key messages about the project (for all audiences) and more specific messaging to engage women in different project activities. These were agreed in the Managing Board and serve as guidance for all public-facing communications:

### Talking about the ConcePTION project (for all stakeholders & publics)

- Pregnant and breastfeeding women should be provided with up-to-date high-quality safety information about the medications they use, built on strong science.

### Talking to & engaging women (e.g. WP's 2, 4, 5 & 6)

- Pregnant, breastfeeding, or want children? - Please help us to generate good information on the safety of medicines you use

These are high-level key messages that will be used as building blocks for narratives and social media campaigns, such as the Twitter campaign to recruit survey respondents in an annex to this document, and the video about the project developed for ConcePTION channels (published on YouTube: <https://youtu.be/o3DXHxTNZ4o>). Additional messaging was developed in a process in spring 2020, facilitated by the Synergist. These key messages are listed in the table below. Input from this process was later refined and used to describe key messages for women and health care professionals in the WP5 communication plan ([D5.2: Report describing communication plan and governance for Work Package 5, Subtask 5.3](#)). This messaging will be revised as the project develops, adding messaging related to the infrastructures, knowledge bank, and ecosystem. We also require (and use) output- and activity-related messaging, or “take-home” messages and calls to action, for example the highlights from a publication or report. How we use messaging in communications is outlined below.

## Using key messages

A key message is just that: a message, that serves as a building block for news and other communications. Messaging should always be adapted to the media where it will be used. Both in terms of wording and order. In communications, this messaging will always be accompanied by supporting

statements, for example facts that support the claim that there is in fact a knowledge gap and why there is a need for safety evidence. For example:

*Almost 90% of pregnant women take at least one medicine, but we don't always know how safe the medicines are. Women who are pregnant or breastfeeding, deserve to know if their medicines are safe. Based on strong science.*

This kind of messaging should be accompanied by a take-home message, and when possible a call to action. They should also be adapted to the channel and audience: using plain language when addressing all lay audiences, and a tone that fits the channel (e.g. informal for social media). Examples of this are offered in social media toolkits that have been made available to the consortium (less formal, plain language, active voice).



**Figure 1:** adapting messaging for social media

## Using take-home messages and calls to action

As a rule, the key message serves as the headline for a communication and will help us develop a relationship with the audience. But we also need to offer something concrete: Key messages are only effective when they are supported by take-home messages and calls to action: stating that women should have access to up-to-date high-quality safety information states a problem but does not provide a solution. Adding a take-home message, for example stating that ConcePTION is developing an analysis platform for breast milk, an app where women can report exposure to medicines during pregnancy, or developing a knowledge bank is what will support our communication objectives. Similarly, a call to action (for example encouraging women or health care professionals to report medicine use, donating samples to the biobank, responding to a survey, reading a report or a publication in a journal, watch a video, or register to join a webinar) will engage our audiences.

When we have defined an audience, an objective, and key messages, what remains is to fit that to a tactic that can be used in our channels to support the objective. A blueprint for how we intend to operationalise this strategy is outlined in an implementation table below. This is a living document that will evolve as the project evolves.

## Audiences, objectives, key messages, and tactics

This table groups audiences in less detail than the table where the audiences are defined. Instead, audiences are grouped on the basis of channel tactics. This way we provide an overview of how we can use the project's channels and implement different communication tools and tactics in an effective way.

	Audience	Objectives	Key messages	Tactics for ConcePTION channels
Lay audiences	Women	<p>Raise awareness among women about the knowledge gap that ConcePTION will fill</p> <p>Increase the likelihood that women choose to engage with the project (by answering a survey, donating milk and blood, or sharing a social media post)</p>	<p>Pregnant and breastfeeding women should be provided with up-to-date high-quality safety information about the medications they use, built on strong science.</p> <p>It is important to report exposure during pregnancy</p> <p>ConcePTION will develop a knowledge bank with trusted information</p> <p>ConcePTION will develop an ecosystem for medicine safety</p> <p><b>Take-home messages</b> Results coming out of ConcePTION related to specific medicines</p>	<p><b>Main channels:</b> Twitter, video, editorial content <b>Main focus:</b> awareness-raising</p> <p>Plain language video translated to other European languages</p> <p>Editorial content for ConcePTION website (linking to the source) explaining results in language that is as plain as possible (e.g. using everyday language to describe pregnancy outcomes)</p> <p>General publicity activities &amp; editorial content on ConcePTION web</p> <p><i>Note: Communications to this audiences in external channels is the responsibility of T5.3</i></p>
	Partners & the public	Raise awareness of the need to close the knowledge gap	<p><b>Calls to action</b> Report exposure during pregnancy</p> <p>Donate samples (study-specific)</p>	<p><b>Main channels:</b> editorial content <b>Main focus:</b> awareness-raising</p> <p>General publicity activities &amp; editorial content in third party channels</p>

				<i>Note: Communications to this audiences in external channels is the responsibility of T5.3</i>
Informed to expert audiences	Patients	<p>Raise awareness of the need to close the knowledge gap</p> <p>Increase reporting of exposure to medicines during pregnancy</p>		<p><b>Main channels:</b> Twitter, video, editorial content, patient organisation channels  <b>Main focus:</b> awareness raising</p> <p>Engaging with patient organisations encouraging them to multiply our messages</p> <p>Use the momentum of disease/disease area awareness-raising activities in social media</p> <p><i>Note: The division of responsibilities between WP8 and T5.3 is unclear in relation to this audience.</i></p>
	Patient organisations	<p>Raise awareness about medicine safety in pregnancy and breastfeeding &amp; encourage patient organisations to support awareness and vigilance among both women and health care professionals</p> <p>Raise awareness about how ConcePTION can help patient organisations build a stronger connection with their pregnant and breastfeeding members by being able to offer safety information about their</p>	<p>ConcePTION is building an ecosystem to provide evidence on the safety of medicines in pregnancy and breastfeeding</p> <p>ConcePTION will help close the knowledge gap and develop evidence on medicine safety for pregnant and breastfeeding women with chronic (and temporary) conditions</p>	<p><b>Main channels:</b> Twitter, E-mail newsletters, conferences  <b>Main focus:</b> awareness raising, publicity for published results</p> <p>Engage with umbrella organisations</p> <p>Engage with champions/influencers - the ones already raising the maternal health/pregnancy and medicine agenda in wider groups</p> <p>Identify conferences where many patient organisations participate and ask to put this topic on the agenda</p> <p>Produce materials &amp; toolkits for patient organisations to support them in</p>

		medicines		communicating with their members and advocating for the topic ( <i>scope of T5.3</i> )
	Health care professionals	Raise awareness about the knowledge we are building and how this can support health care professionals in their daily work	<p>ConcePTION is building infrastructures and developing knowledge that will help health care professionals support women's reproductive autonomy, improve the health of women and babies, and reduce disease burden</p> <p>It is important to report exposure during pregnancy</p> <p>We publish our results in peer-reviewed publications.</p> <p><b>Take-home messages</b> Results coming out of ConcePTION related to specific medicines</p> <p><b>Calls to action</b> Report exposure during pregnancy</p>	<p><b>Main channels:</b> Twitter, editorial content, E-mail newsletters <b>Main communication focus:</b> publicity for published results, awareness-raising, developing readiness to implement</p> <p>Engage with professional organisations, encouraging them to multiply messages in social media</p> <p>Editorial content in professional organization channels/media</p> <p>Engage through scientific dissemination by publishing in peer review journals, present and discuss results at conferences health care professionals attend</p> <p><i>Communications to this audiences in external channels is the responsibility of T5.3</i></p>
Expert audiences	<b>Scientists/Academics</b>	<p>Calling scientists to action to read (and use) our published results.</p> <p>Call to action to use the infrastructures &amp; ecosystem developed in the project.</p>	<p>ConcePTION is building and ecosystem for medicine safety. This includes different research infrastructures and methods that will become available to you.</p> <p>We publish our results in peer-reviewed publications.</p>	<p><b>Main channels:</b> Twitter, e-mail newsletters <b>Main communication focus:</b> publicity for published results, awareness-raising, developing readiness to implement</p> <p>Engage through scientific dissemination by publishing in peer review journals, present and discuss results at conferences health care professionals attend</p>

Expert audiences	Pharma industry	<p>Increase awareness that there are other ways to generate safety information that are more effective than the current methods used (preg registries are resource-intensive and often don't deliver data for the label)</p> <p>Change perception among scientists and lab technicians and get them to use our tools (such as those being developed in WP3)</p> <p>The main need is to raise awareness of the project, outcomes of the project and what it would deliver, how it would simplify the work each company is doing</p>	<p>ConcePTION will build the tools needed to increase the probability of getting reliable data into labels and out to women and their healthcare providers</p> <p>We offer a much better solution than pregnancy registries which don't work: we bring a PV system to have more info (WP2), ways of doing pharmacoepidemiology studies by going to one place, not different studies (WP1,7). Biobank - able to use/collect real, human data, measure drug concentrations in milk, and the knowledge bank will provide consistent information</p>	<p><b>Main channels:</b> LinkedIn, E-mail newsletters  <b>Main communication focus:</b> publicity for published results, awareness-raising, developing readiness to implement</p> <p>Engage through scientific dissemination by publishing in peer review journals, present and discuss results at conferences health care professionals attend</p> <p>Share editorial content through E-mail newsletters</p> <p>Engage with senior individuals on LinkedIn</p>
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**Table 3:** Implementation table (audiences, messages, and tactics for ConcePTION channels)

## Mitigating communications risks

The ConcePTION project is developing safety evidence for those who are pregnant and breastfeeding. Inherent to that is a focus on women's bodies and reproductive functions, at a time when there is a lot of discussion on how we can use inclusive language in relation to those functions, not to exclude those who do not identify as women. At the same time, we need to use an active voice and ensure most of our target audience feels included and that our communications are directed at them. In addition, we are a public-private partnership involving participation from pharmaceutical companies at a time of unprecedented pressure to focus efforts on developing vaccines for the global pandemic. There is also a potential conflict between the systems for reporting exposure during pregnancy between public and private partners. Finally, the project is using animal data, which requires added external monitoring.

We are taking a proactive stance in relation to industry involvement, putting the focus on the fact that ConcePTION is a public-private partnership. We are also taking a proactive stance to communication on animal data, educating the consortium, and developing strategy for how to present the WP3 infrastructures and explain how we work to reduce, refine and replace. Potential conflicts of interest in relation to different (and competing) systems for how to report exposure will be managed by presenting the different systems next to each other, ensuring communication through official WP8 channels is balanced and that no systems are favoured.

Risks have been identified through interviews with WP leaders (led by the Synergist) in spring 2020 and developed further in a workshop session at the project's general assembly meeting in spring 2021.

Risk	Mitigation strategy
<b>Industry involvement</b>	Transparency about how the IMI programme works and how industry contributions are funded. Focus on public-private <b>partnership</b> in external communications and how we work together to solve a complicated puzzle: turning data to evidence.
<b>Reactions from animal rights activists/movement</b>	<p>Strategy and plan under development in WP3, explaining the model for drug transfer as a whole and animal data as part of that. An action plan for what to do in case of negative publicity has been developed and a webinar to educate the consortium on the role of animal data in ConcePTION is planned for 28 May 2021. We are also monitoring the external environment and doing sentiment monitoring of reactions to communications relating to WP3. Decisions on the timing of any communications related to these topics are taken on a case-by-case basis.</p> <p>The IMI does not have guidelines for communicating animal data. Therefore, we have decided to follow the recommendations outlined in <a href="#">A note from the League of European Research Universities on Good Practice in Communicating Animal Research in Universities</a>, emphasizing the need for transparency. Communicating all parts of WP3 allows us to emphasise the 3R's (replacement, reduction, and refinement), and framing communications with a fourth R: responsibility.</p>
<b>How to report exposure</b>	A website landing page describes the different systems, without favouring one over the other. This link is shared in all general awareness-raising and calls to action.

<b>Objectification of women</b>	We are using an active voice in editorial content, ensuring women are portrayed as active <i>subjects</i> , instead of passive <i>objects</i> . Strategic decisions are taken in our visual communications to ensure images of women and women's bodies are as representative as possible of European women's ethnicities, abilities, and body shapes. We also monitor the sentiment of reactions and take care to ensure that images of breastfeeding are focused on the baby, not the bosoms.
<b>Non-inclusive language</b>	We use the term "partners" instead of fathers (note: biological fathers using medicines that can affect a foetus is out of scope for this project), but use the term women and mothers to ensure we are able to communicate using an active voice when we address our main audience. This choice can spark controversy, as could a decision to use a more inclusive vocabulary.
<b>Vaccine skepticism</b>	Working with medicine safety for vulnerable populations during a global pandemic with several companies producing vaccines as partners requires monitoring the discussion on vaccine safety in relation to pregnancy, breastfeeding, and fertility, taking decisions on a case-by-case basis on the timing of any communications related to these topics. We are also monitoring the sentiment in reactions to social media postings.
<b>Consortium not informed</b>	In a large consortium, it is difficult to have an overview. WP leads have a responsibility to educate the consortium. The communications team can support this by developing communication materials, such as infographics (explaining the infrastructures developed in the project), and by considering consortium members as part of all other audiences, ensuring external-facing communications are also shared in internal newsletters.
<b>Negative publicity</b>	Routines for negative publicity have been developed for the consortium in general, along with an action plan for animal data. The consortium has been offered media training. This training was recorded, but the live session will be repeated in 2022 as a refresher.
<b>Interpretation of data</b>	When communicating about the knowledge bank, we need to be transparent about how content is assessed and by whom in our messaging.
<b>Communicating risk</b>	We cannot talk about medicine safety without acknowledging that there can be risks. Risk communications should take into consideration that there can also be risks to mother and baby if conditions are not adequately treated. To communicate responsibly, we also need to provide some general information about what risk means. Researchers in ConcePTION need to understand that our audiences do not always have the health literacy and health numeracy required to understand the results, and unable to differentiate between absolute and relative risk. The communications team will need support to be able to

	communicate this. We should consider organising webinars for women, patients, health care professionals. We should also explore whether any training developed in the project can be exploitable for communications purposes. We also need to be transparent about uncertainties and what we do not know.
<b>Becoming visible in the flood of information for pregnant and breastfeeding women</b>	Pregnant and breastfeeding women are flooded with information and targeted by a multitude of actors online and offline. There is a risk of pregnancy information exhaustion, some of which is tapping into women's fears. This needs to be taken into consideration in any communication targeting this group, ensuring we are not exploiting vulnerabilities and fears. In addition, we should make sure that information we provide is a consensus opinion that generally aligns with national guidelines.
<b>Missing data sources</b>	ConcePTION website analytics data from April 2019-May 2021 was not recorded properly due to an error in the process of setting up the tracking ID. As a result, data recorded and subsequently reported in the first reporting period belong to a different website. This means that there is no historic website data from the ConcePTION website to report. To be able to offer an estimate of the number of visits, we have turned to other sources, using data from Google Search Console (providing data on search results and link clicks from January 2020). We have also looked at the number of times people clicked the links shared in ConcePTION tweets. Together, these numbers will serve as a proxy, allowing us to estimate the number of visitors. Since the discovery of this error on 18 May 2021, the UMC Utrecht has fitted a tracking ID to the project website, to ensure we are recording data from now on.

**Table 4:** Risks and mitigation strategies

## Tools and tactics to reach lay audiences (including women)

In spring 2020, a strategy for how to communicate with women was developed to guide communications campaigns. This includes a set of tools and tactics for communications with all lay audiences and serves as a guiding principle for all conception channels. These tactics should also be implemented in any public-facing communications coming out from WP5.

First, we acknowledge that 'women' are a diverse audience and members of all publics. Women represent half the world's population. They are of different ages, come from different cultures, have different levels of education, different interests, and speak different languages. Many of them are patients. They also constitute a large proportion of all other audiences.

### Inclusive communication

All communications should be inclusive. Women (who are or can become pregnant) should be able to recognise themselves in ConcePTION communications and understand what is being said. In practice, this means using a combination of plain language and inclusive images in any campaign aimed at women, and inclusive visual representations of pregnant and breastfeeding women in all communications.

When we want women (or any other lay audience) to engage with the project, we aim to develop flexible communication materials that can be translated to national & minority languages. We will also use images of several women in the same campaign. Images should depict “real” women (as opposed to standard stock images). This can be achieved by sourcing images from pixabay, unsplash, or pexels, (in the public domain and free to use).

Communication materials should be flexible, translatable, and adaptable, which means products should be developed with the possibility to develop a range of complementary tools in mind:

- **Graphics** that fit Twitter, Facebook AND works in print
- **Video** to support the campaign
- **Print leaflets** (for distribution in clinics)
- **Engaging with patient organisations**

## Cheap and adaptable tools

Because of budget restrictions, should also develop materials that can be shared on (close to) zero budget, which requires:

- Graphics that are **easy to adapt** (for example using a PowerPoint template) including taglines + logo + alternating images.
- Materials that are designed to reach **ALL kinds of** women, which means it should be possible to make cultural adaptations of both images (which should be inclusive) and translate to other languages.

## General publicity

As a complement to digital communication materials and social media campaigns, we should also seek publicity through **blog posts and editorial text**. This is a strategy that allows us to be **where the women are** (e.g. social media, online discussion forums) and use already established **third party channels** (that have a wide reach), for example:

- Patient organisations (national + international)
- Companies that sell products to women
- Pregnancy bloggers/influencers
- Prenatal care providers

Tools for this will vary, from editorial text (written by us), encouraging others to talk about ConcePTION, and using print materials (e.g. posters or leaflets for distribution in prenatal care providing clinics/waiting rooms, depending on the purpose of the campaign/outreach activity).

## Publicity for results

We aim to do timely publicity for publications in ConcePTION channels using two parallel strategies: Sharing DOI-links in social media to boost Altmetric scores and drive discovery of publications; and developing editorial content to support understanding of the results and their implications for our audiences.

All audiences will be served by editorial content published in the website news feed. This content is developed using key messages to frame the communication and take-home messages from the publication provided by the first author. Links to publications will be posted on the website, supporting discovery by expert audiences who visit the website to find results. The editorial content will also be posted to Twitter and shared on LinkedIn and in an e-mail newsletter.

## Publications

Dudman DC, Tauqueer F, Kaur M, Ritchey ME, Li J  
in migraine treated patients: a contribution from

Ventrella D, Ashkenazi N, Elmi A *et al.* *Animal Model  
Clinical Species: A Contribution from the ConceP*

Nauwelaerts N, Deferm N, Smits A *et al.* *A comprehensive review  
contribution from the ConcePTION project.* Biomedicine & Pharma

Lopez-Leon S, Geissbühler Y, Sabido M *et al.* *A systematic review  
sclerosis: a contribution from the IMI2 ConcePTION project.* Journal of



### Predicting how medicines transfer to breast milk

Breastfeeding offers health and wellbeing benefits for both mother and child. Half of new mothers need medicines. Many medicines are likely to be safe, but human lactation studies are challenging to conduct. As a result, women often have to choose between continuing their medical treatment and breastfeeding their infant. In a recent Biomedicine & Pharmacotherapy publication, ConcePTION researchers provide an extensive overview of non-clinical and computational methods that can be used



### Multiple Sclerosis and pregnancy: First systematic review and meta-analysis!

The ConcePTION project is committed to building safety evidence for women and their doctors. One of our first contributions is a systematic review and meta-analysis of pregnancy and fetal outcomes in women with Multiple sclerosis (also known as MS). The results add to the existing evidence for women



### Generating evidence on medicine safety in pregnancy: Elements to consider

To be able to say that it is safe for a pregnant woman to take a particular medicine, we need to know that the safety data is robust. The ConcePTION project is piecing European data together, building a system to generate evidence on medicine safety for pregnant and breastfeeding women. A recent report provides an inventory of the core elements that are needed to generate the evidence that is required. The report guides researchers in performing high quality and meaningful population-based studies: allowing women and their doctors to make informed decisions and weigh the benefits against the risks of treatments. [| READ MORE >>](#)



**Figure 2:** Publicity for publications (static web content, editorial web content, and Twitter)

## Search engine and hashtag optimisation

We should also strive to be found. This means adapting language for the audience: it could be assumed that women search for breastfeeding or nursing rather than lactation. This means we use interchangeable language/synonyms for search engine optimisation (SEO) on web (e.g. medicines should be interchanged with drugs, nursing with breastfeeding), and pick hashtags on Twitter (& Instagram) depending on who we want to find us.

## Toolkits for social media campaigning

To support and facilitate communication in ConcePTION channels, we have developed hands-on toolkits for Twitter and Facebook/Instagram. These toolkits include examples of what to do, and what not to do, and why.

- Ready-to-use design templates that can be adapted to local country/language
- It is easy: we use PowerPoint!
- Explains how to export and save images
- Tells you where good and free photos can be found
- Explains how to craft a message with a call for action

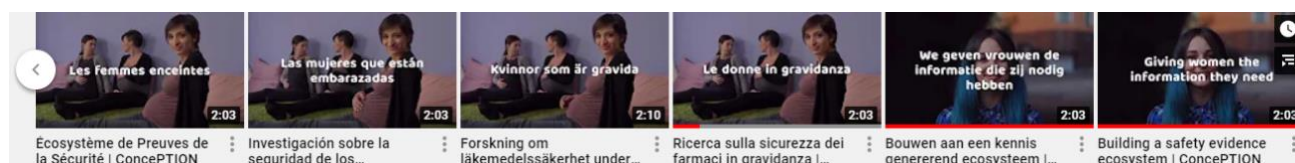
## Using video

### Short videos with key messages from the project

Short, succinct text-based videos are developed to deliver key messages in plain language with the aim to support engagement in social media, raise awareness, and call to action. Videos use a horizontal format to support embedding on websites (from YouTube) and video length is adapted to ensure they can be uploaded in-stream on Twitter (maximum 2.20 minutes). With the help of ConcePTION partners, videos are also translated to support communication with women in different European countries.

This format is used to deliver general messages about and from the project (e.g. [video presenting the project](#) published 6 March 2020, and [video explaining the public-private partnership](#) published on 8

March 2021). The format will also be used for recruiting milk donors in WP4 studies, with a first example being the Norwegian antihistamine study.



**Figure 3:** Video in different languages

## Recorded presentations

Presentations from webinars and other events will be recorded, and (in cases where they can support a communication objective) be made available on YouTube. For example, a series of presentations explaining how different systems for reporting exposure to medicines during pregnancy were recorded to support the objectives of task 5.3, to explain and encourage women and health care professionals to report exposure. These videos are around 10 minutes. They use expert language and support the second and third tiers in our communication approach, allowing all audience segments to access information on a level that suits them on a general web landing page that includes plain language content for women, their partners, and the public.



**Figure 4:** Video presenting pharmacovigilance reporting systems

## Other video formats

In cases where work packages are resourced to produce video content explaining the project, its infrastructures, and results, these will be included in ConcePTION communications and WP8 will offer advice to ensure the content fits our channels (web, YouTube, Twitter).

## ConcePTION channels

Currently, the ConcePTION project owns three channels: the website which serves as the main point-of-contact, a Twitter handle, and a YouTube channel. After an audience analysis of existing channels, it became clear that we need additions to our channel portfolio: LinkedIn, and an external-facing e-mail newsletter.

Channel	Purpose	Access
Website	Main point of contact	<a href="https://www.imi-conception.eu">https://www.imi-conception.eu</a>
Twitter	Disseminating results & engaging with audiences, including IMI, other projects	<a href="https://twitter.com/IMIConcePTION">https://twitter.com/IMIConcePTION</a>

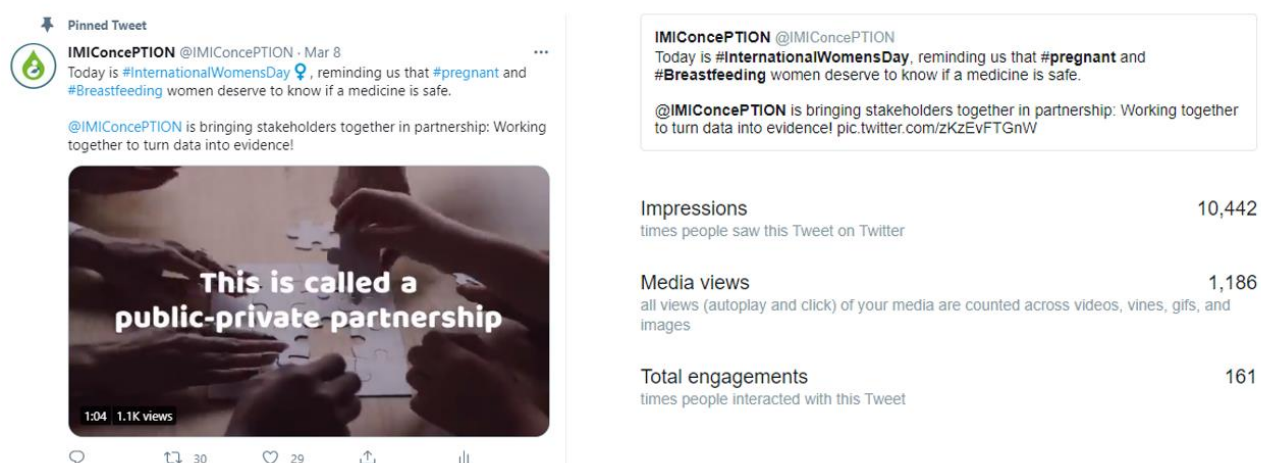
	and initiatives, individual academics, patient organisations, civil society organisations, policymakers, health care professionals, and women of childbearing age (see audience analysis below).	
YouTube	Repository for video that is embedded on web and shared through social media and newsletters.	<a href="https://www.youtube.com/channel/UC-K76tkUSDoFMqaU-LhgZAg">https://www.youtube.com/channel/UC-K76tkUSDoFMqaU-LhgZAg</a> .
Newsletter	An external newsletter would support engagement with key stakeholders and organic reach through forwards.	Sign up for external audiences to existing Mailchimp account planned.
LinkedIn	Disseminating results and engaging with senior professionals in the pharmaceutical industry, IMI, and women of childbearing age in all professions.	Planned
Publications	Disseminating results	Peer review journals
Presentations	Disseminating results	Submitting abstracts to conferences
Media	Raising awareness and communicating results to all audiences, including patients and women of childbearing age.	Press releases (from author's press officers), expert interviews
Editorial text	Raising awareness and communicating results to all audiences through journals, newspapers and blogs (e.g. <a href="http://www.ethicsblog.crb.uu.se">www.ethicsblog.crb.uu.se</a> )	Individuals in the project writing and submitting text
Third-party channels	Reaching beyond the project's own audiences through third-party channels (e.g. web. newsletters, social media)	Access through individual project members and organisations that are either partners or collaborators

**Table 5:** ConcePTION channels

## Twitter

Twitter strategy is an iterative process, where monitoring and learning play a central role in deciding how to proceed, based on evaluation of the effectiveness of a campaign, with the aim to adjust and fine-tune tactics depending on how the audience grows and the objective of any campaigning.

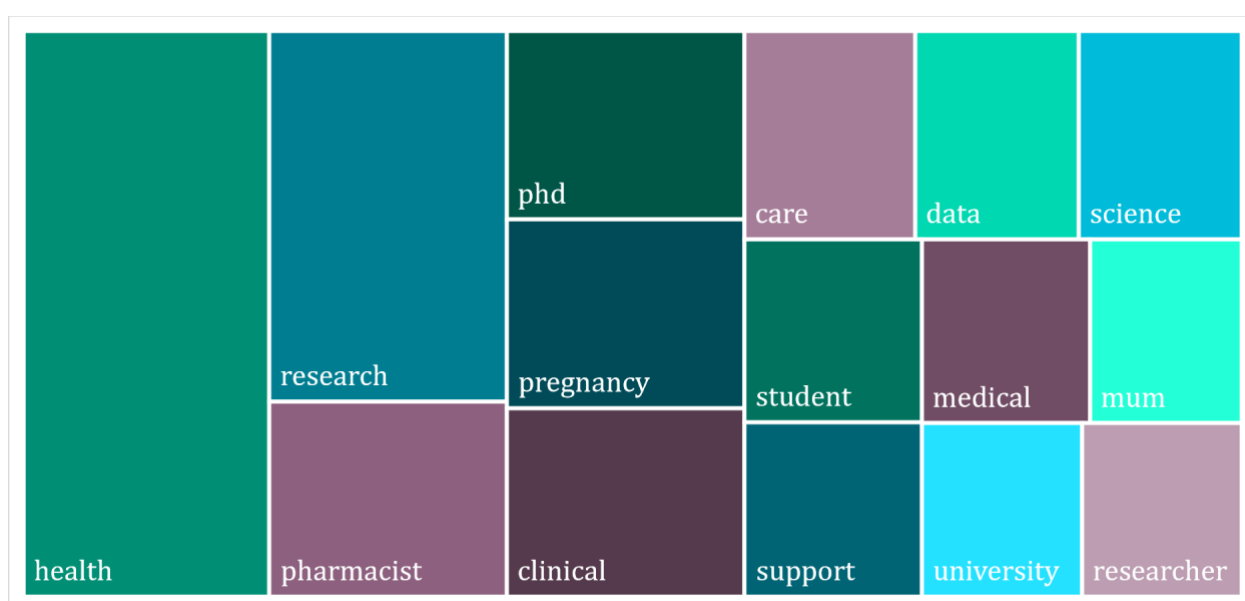
The ConcePTION Twitter handle has a small following (310 followers at the time of writing), but a large organic reach. On 8 March 2021, we used the momentum of international women's day to mobilise consortium partners in the launch of a video that was shared natively on Twitter. In the first 24 hours, the video was viewed 2,186 times: 1,186 times in our own tweet, 169 times on YouTube, 104 views in an IMI native tweet, 44 times in an Uppsala University native tweet, and 683 in one of the consortium members native tweet (Sandra Lopez-Leon). Campaigns where we share content have been successful, and the 30 January-6 April 2020 campaign to recruit survey respondents for WP5 doubled our Twitter following.



**Figure 5:** International women’s day campaign reach on Twitter

### Twitter audience

To learn who follows ConcePTION on Twitter, we utilise a free service called Followerwonk (<https://followerwonk.com/>) that can tell us how our followers describe themselves, when they are more active, and how active they are. Looking at our followers’ bios (short self-authored descriptions), we can learn that most of them are interested in health, they are researchers, pharmacists, and clinicians involved in the care of pregnant women. We also find many mothers in our audience. This confirms that there is often an overlap with other audiences. Many academics, clinical researchers, and medical practitioners who follow us on Twitter are also mothers and women of reproductive age. This is backed up by additional data from Followerwonk that tells us the vast majority of ConcePTION followers are women.



**Figure 6:** Word cloud of keywords in @IMIConcePTION followers’ bios

Looking at how active our followers are on Twitter, in general, can tell us how useful they are to us. Active Twitter users are more likely to retweet and engage with content they appreciate. By looking at how many original tweets they post (as opposed to retweets that share others’ content) and how recently they have tweeted, we can determine whether we have an active audience that is ready to

engage or passive followers who are more likely to observe. For IMI ConcePTION followers, around 50 percent of our followers are active Twitter users, and 50 percent are passive onlookers. Around 35 percent of our followers have over 500 followers. 60 percent of our followers have been on Twitter for over 5 years. This is to be considered a very active audience, which can serve as a tool to build the organic reach (un-paid reach) of ConcePTION's Twitter content.

Our audience analysis tells us that most of our followers are located in Western Europe, primarily the UK and Ireland. This is not surprising seeing as ConcePTION channels use the English language. A significant amount of followers exists also in Eastern Europe and the eastern parts of North America. However, we do not only reach audiences in these geographical areas. We also have followers in Latin and South America, Africa, and Asia. Our followers are most active at 9:00 CEST, 12:00 CEST, and 17:00 CEST, and a lot of activity in the hours in-between. To optimise our reach, we will continue adapting our Twitter schedule to that of our followers.

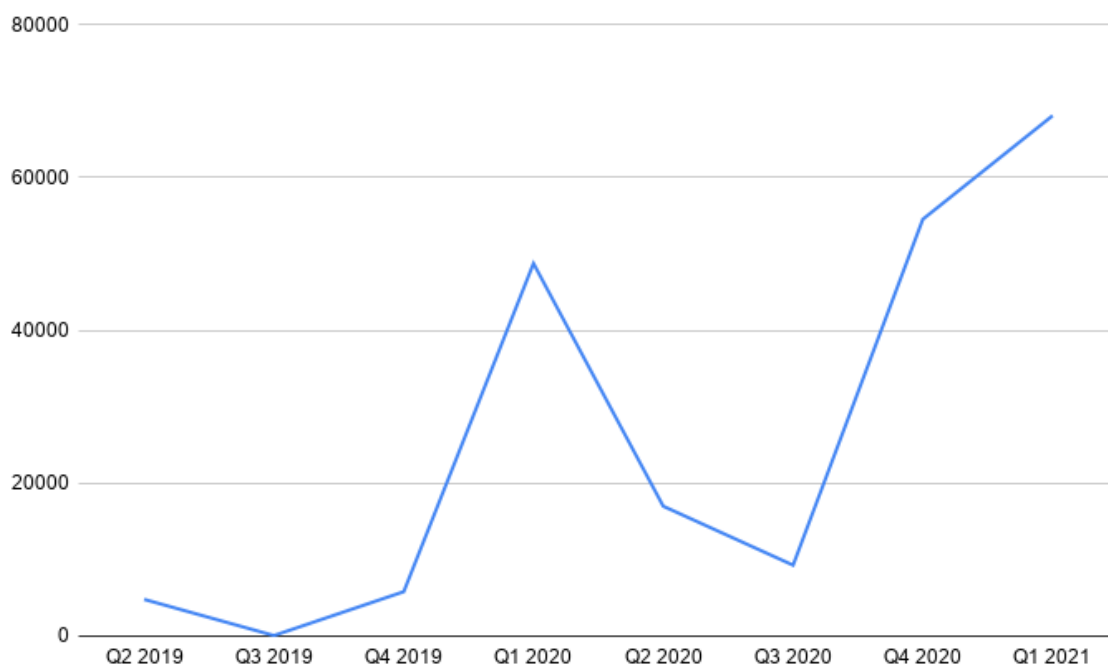
### Evaluating performance

Looking at performance over the lifetime of the Twitter handle, it is (self) evident that activity drives engagement. This is clear when looking at the periods when the handle has been more actively posting (e.g. the survey recruitment campaign described in an annex to this report from Q1 2020 and after adding the role of a communication manager in WP8 in Q4 2020).

Quarter	Number Tweets	Impressions	Engagement	Engagement rate
<b>Q2 2019</b>	2	4739	116	2.448%
<b>Q3 2019</b>	0	0	0	0.000%
<b>Q4 2019</b>	4	5743	119	2.072%
<b>Q1 2020</b>	23	48767	970	1.989%
<b>Q2 2020</b>	8	16946	289	1.705%
<b>Q3 2020</b>	6	9224	223	2.418%
<b>Q4 2020</b>	55	54555	1156	2.119%
<b>Q1 2021</b>	37	68130	1213	1.780%
<b>Q2 2021</b>	18	24338	406	1.668%

**Table 6:** Twitter performance from launch to 12 May 2021 (number of tweets, impressions, engagements & engagement rate). Note that Q2 2021 is only 1,5 months.

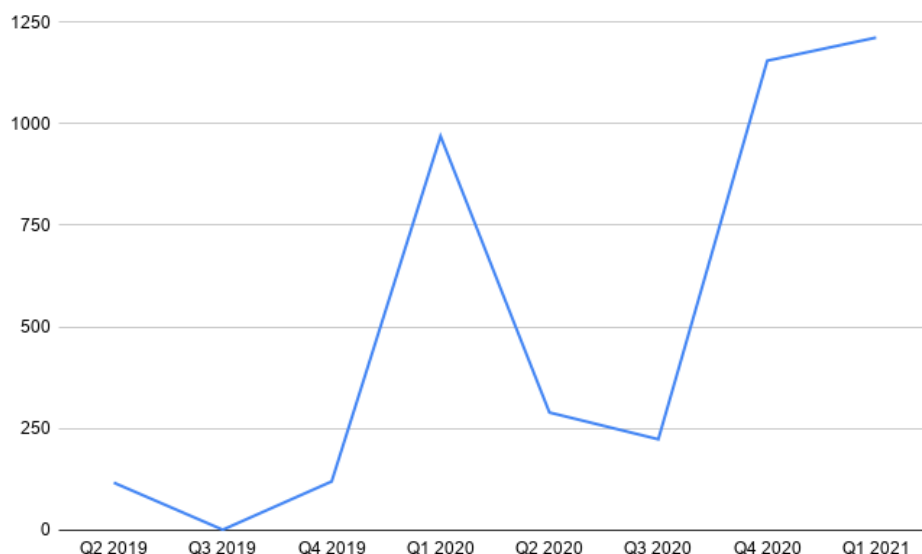
These metrics illustrate different things: Impressions indicate how many times the tweet appeared in someone's feed (as in how many times it was seen). We use this metric to indicate reach, quantifying the potential audience.



**Figure 7:** @IMIConcePTION Twitter reach (impressions) Q2 2019 through Q2 2021

The engagement metric shows the number of interactions with a tweet. Engagements can be retweets, replies, likes, URL clicks, hashtag clicks, or detail expands (clicking on the tweet to see either who liked and retweeted or the image in the tweet). This shows how interested the audience is in the content we post. We can see a steep increase in engagement in Q3 2020. This can be attributed to our participation in two campaigns: The Safe Motherhood Week (mid-October 2020), and the #MedSafetyWeek (beginning of November 2020). The momentum created by these activities was maintained by doing publicity for published results on Twitter, sharing DOI-links and/or links to news items on the ConcePTION website-

Looking at the reach and engagements also provides a very clear picture of what the effect of the pandemic has had on ConcePTION communications. In Q2-Q3 2020, it was nearly impossible to get news out that were not related to the pandemic, and with many consortium members being called to partake in measures against Covid-19 and SARS-CoV-2, we also struggled to produce content during this time. This is evident when looking both at the reach and engagements of the ConcePTION Twitter account during this time.



**Figure 8:** @IMIConcePTION Twitter engagement Q2 2019 through Q2 2021

We can also look at the engagement rate, measured by the number of interactions divided by the total people reached. At the beginning of a project, only those who are already invested follow, which is reflected in a high engagement rate (one follower engaging with the first tweet). As the audience grows, the engagement rate will decrease, unless we share content that users want to engage with. Also in this metric, the two autumn campaigns are reflected, showing the benefit of using the momentum of such big online events. What also becomes clear from looking at the engagement rate is that even though the reach and number of engagements declined in the early stages of the pandemic, those who *were* reached continued to engage. We see only a slight dip in Q2 2020, which we quickly recovered from in Q3, indicating that the following we have built *is interested* in ConcePTION content, even if they do not choose to share it onwards by retweeting our content (which would increase our reach and likely also the number of engagements).



**Figure 9:** @IMIConcePTION Twitter engagement rate Q2 2019 through Q2 2021 (up to April 30, 2021)

## YouTube

The ConcePTION project YouTube channel (<https://www.youtube.com/channel/UC-K76tkUSDofMqaU-LhgZAg>) serves as a repository for video developed for different purposes in the project. The channel was launched to premiere a video presenting the project in March 2020. In the channel's lifetime (6 March 2020—12 May 2021), we have recorded 1,069 views, with a total watch time of 24,39 hours. This represents views and watch-time for videos embedded on the project website or shared through links on social media. These figures do not include views on video content posted “native” on Twitter (uploaded to Twitter).

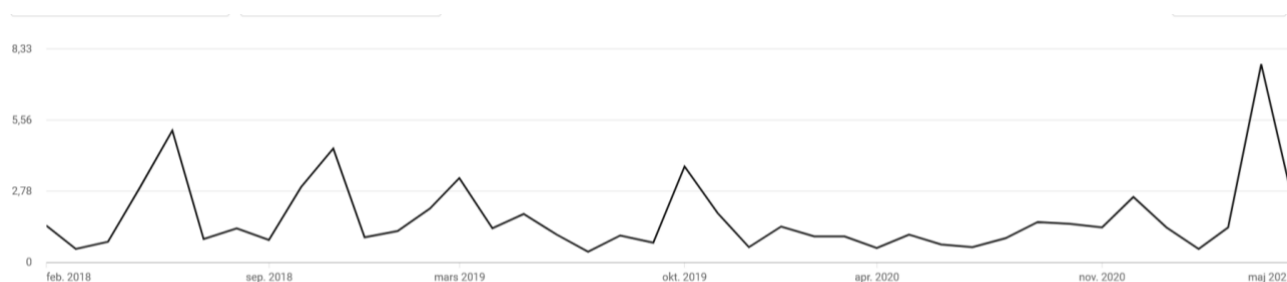
### Evaluating performance

So far, we have published 14 videos on YouTube. With only 15 subscribers, it is clear that YouTube is not offering any “organic” reach and that views depend on publicity in other channels.

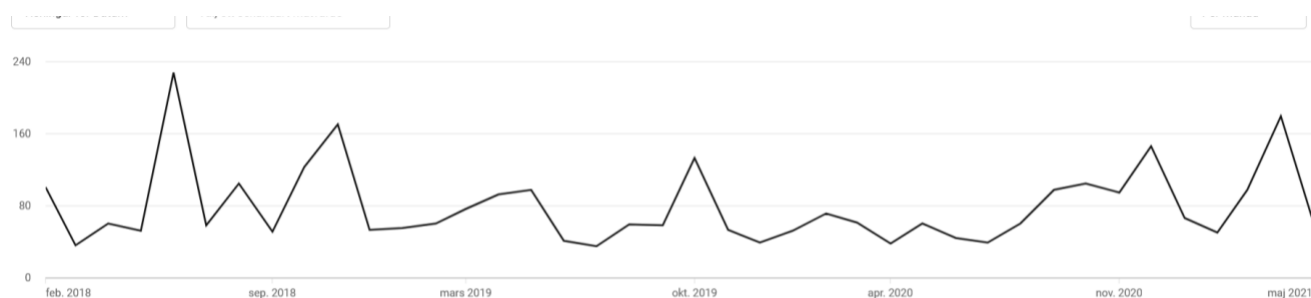
Name of video	Date of publication	No of views	Watch time (hours)
Building a safety evidence ecosystem   ConcePTION	Mar 6, 2020	408	8.0335
ConcePTION: Public-private partnership for medicine use in pregnancy and breastfeeding	Mar 7, 2021	342	5.4787
Bouwen aan een kennis genererend ecosysteem   ConcePTION	Apr 28, 2020	55	0.909
Monitoring the safety of medicines use during pregnancy: Perspective of one MAH - Christine Taeter	Mar 30, 2021	32	1.5904
An overview of how ENTIS monitors medication use in pregnancy - Luke Richardson	Apr 1, 2021	30	0.8182
ConcePTION comms strategy big picture		29	3.0447
Congenital anomaly registries & healthcare databases for med safety monitoring - Helen Dolk	Apr 1, 2021	27	1.1084
Investigación sobre la seguridad de los medicamentos durante el embarazo y la lactancia   ConcePTION	Jan 27, 2021	25	0.3696
Presentation of non-clinical methods to study medication transfer to breast milk used in ConcePTION		22	0.4905
Ricerca sulla sicurezza dei farmaci in gravidanza   ConcePTION	Jul 7, 2020	21	0.3677
Non-clinical methods to study medication transfer to breast milk: Abstract of a comprehensive review		19	0.2822
Écosystème de Preuves de la Sécurité   ConcePTION	Feb 4, 2021	18	0.2595
Media training for ConcePTION		17	1.287
Forskning om läkemedelssäkerhet under graviditet och amning   ConcePTION	Jul 7, 2020	15	0.2563
Construindo um ecossistema de evidências de segurança   ConcePTION	Feb 8, 2021	7	0.0272
<b>Total</b>		<b>1,069</b>	<b>24,39</b>

**Table 7:** YouTube views and view time

The distribution of views and watch time over time supports the conclusion that sharing video links on Twitter drives engagement, which is reflected in link clicks.



**Figure 10:** ConcePTION's YouTube channel, watch time (hours, lifetime)



**Figure 11:** ConcePTION's YouTube channel, number of views (lifetime)

## Newsletter

The ConcePTION project uses Mailchimp to distribute an internal newsletter to the consortium. Mailchimp allows us to segment audiences, using this tool for external audiences. In collaboration with WP6, we plan to build external audiences, adding a possibility to sign up to receive news from the project on the website, and using Twitter and LinkedIn to call people to action by signing up to receive news. The benefit of using an e-mail newsletter is the potential for organic reach, where recipients forward e-mails in their network. E-mail also has the benefit of staying in people's inboxes until they have time to read, as opposed to content posted on Twitter which disappears in feeds in favour of more recent content.

## LinkedIn

To reach senior professionals and decision-makers in the pharmaceutical industry we will add LinkedIn to our social media channel portfolio. LinkedIn will be used to share results (links to reports and publications). LinkedIn moves more slowly than Twitter, where we need to post original tweets around twice a week to stay noticed. LinkedIn posting should happen less often, making more strategic decisions on when and what to post.

All consortium members who are active on LinkedIn will be encouraged to add the ConcePTION project to their profile, and encouraged to like and share posts, to build a following and generate interest in the project.

## Website

The ConcePTION website was set up by UMC Utrecht to serve as a main point-of-contact and repository for information about the project and its results. The structure is complex and includes placeholders for information that we are currently not providing, for example abstracts, protocols, posters and presentations, events and webinars.

### Measuring performance

We will measure website performance using the number of unique page views, users, session time and bounce rates. However, due to an error, we do not have any baseline data to evaluate.

ConcePTION website analytics data from April 2019-May 2021 was not recorded properly due to an error in the process of setting up the tracking ID. As a result, data recorded and subsequently reported in the first reporting period belong to a different website. The means that there is no historic website data from the ConcePTION website to report. To be able to offer an estimate of the number of visits, we have turned to other sources, using data from Google Search Console (providing data on search results and link clicks from January 2020). We have also looked at the number of times people clicked the links shared in ConcePTION tweets. Together, these numbers will serve as a proxy, allowing us to estimate the number of visitors. Since the discovery of this error on 18 May 2021, the UMC Utrecht has fitted a tracking ID to the project website, to ensure we are recording data from now on.

Using the numbers at our disposal described above, combined with experience of working with communications in several Horizon 2020 projects (SIENNA, STARBIOS2 and MINDtheGEPs) and specifically in the IMI PREFER project, we have experience with what the sources of web traffic typically looks like, and their relative proportions. Based on estimations from IMI PREFER, this has allowed us to fill in the blanks.

Based on web traffic from the first and second year web data from the IMI PREFER project, we have estimated that 40 % web traffic is collected through organic search (i.e. someone using a search engine to find the website), another 40 % is generated from direct hits (i.e. someone typing out the URL in their browser), and we expect around 14 % of web traffic to come from other websites talking about ConcePTION, known as referrals. Around 6 % of web visitors have likely come from our social media postings. Using data we already have and this formula for how much traffic can typically be obtained from each source, we were able to outline the following amount of unique visitors for the ConcePTION website.

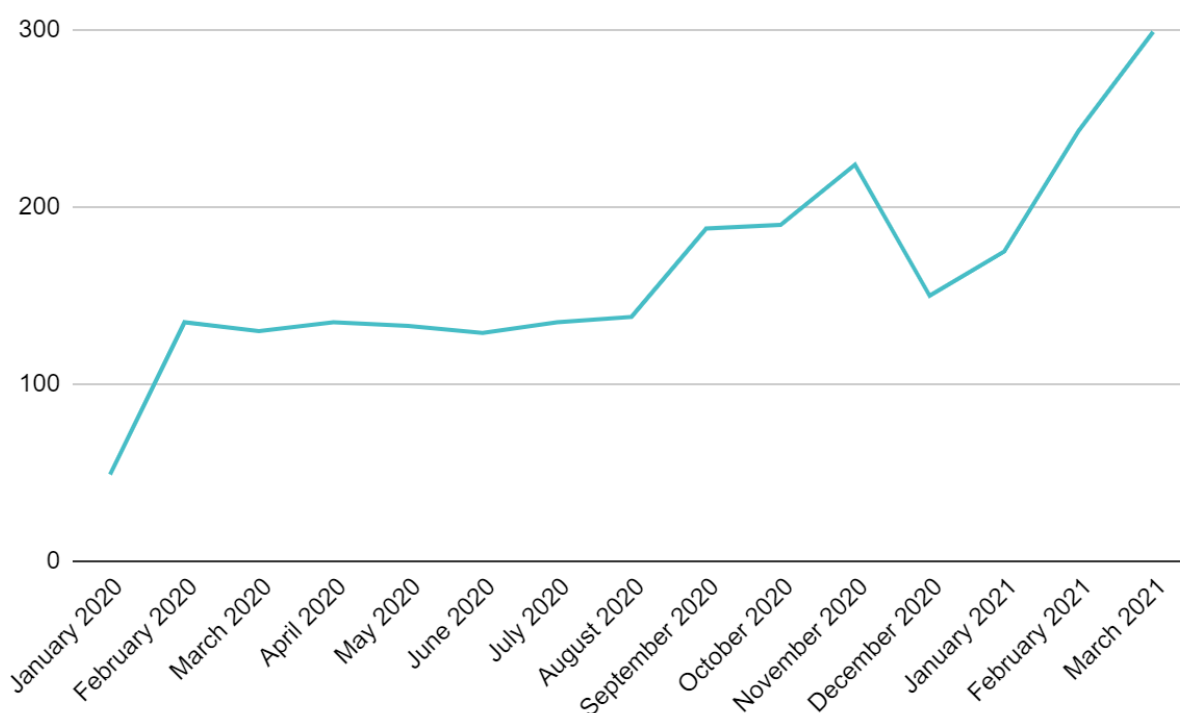
Source	1st period	2nd period
Referral	433*	715*
Social	185**	189**
Direct	1256*	2139*
Organic search	1256***	2139**
<b>Total</b>	<b>3130*</b>	<b>5182*</b>

**Table 8:** Guesstimated figures describing sources of traffic for the ConcePTION website (\*estimation, \*\*known figure, \*\*\* estimation based on known figure)

What we do know about the website is who goes looking for it. For example, we can see that people in the United Kingdom, the Netherlands, Italy, France, the United States and Belgium are Googling ConcePTION, and so are people in Switzerland, Germany and Finland. Further, most people who look for ConcePTION and find our website are using their desktop computers to navigate and find us. This implies that they are looking for us in their professional capacity, rather than as a private person (when not at work using a smartphone or other mobile device is more common). However, the desktop use

could also be an age indicator, based on the use of computers versus mobile devices in different age groups. Either way, the fact that most of our web visitors are using desktop computers does mean that less people than expected might be affected by the non-responsive web design that the website is currently using (measures to take to amend this are outlined in this report). Only around 28% of our website visitors are on their phones or tablets, compared to the other 72% who are on their computers.

What is evident is that there is still great interest in the project, and that our website visitors continue to return. In the past year, our audience has grown and as time progresses, people discover, and keeps on visiting, the project website. As usual, we see a decrease in activities over the holidays, but otherwise we are seeing a great interest in the website. Given that the below information only reflects part of the website visitors, there is reason to be content with these figures.



**Figure 12:** Number of clicks on imi-conception.eu links in Google Search Results January 2020-March 2021

## Developing the ConcePTION website

The website has an attractive design, where work packages are presented in a drop-down menu, displaying the information when the user clicks on it. The URL of the page remains the same.

**WP1 : Moving beyond pregnancy registries to enhance our understanding of disease-related pregnancy outcomes, medication use and safety of use during pregnancy** ✓

**WP2 : Improving the collection, analysis and interpretation of pregnancy pharmacovigilance data** ✓

### Main objectives

The main objective of WP2 is to optimise pharmacovigilance data collection on reported pregnancies and sharing of data plus analytical methodologies to more rapidly and efficiently quantify and characterise risks associated with use of medications during pregnancy and lactation (to complement data generated through the secondary use of routinely collected EHR (electronic health record) data in WP1).

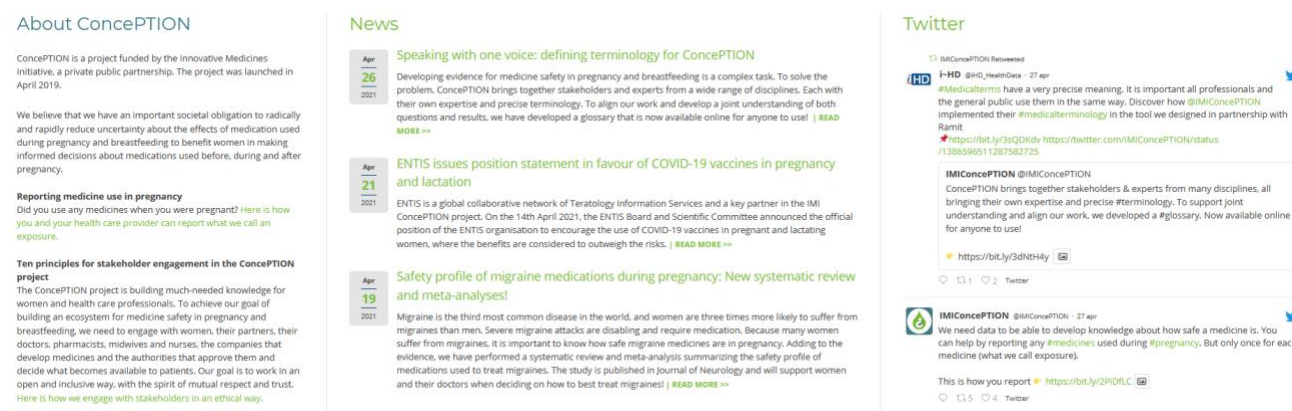
### Sub-objectives

1. To identify and characterise existing data sources that capture reported medication exposed pregnancies;
2. To develop novel methods and analysis of reported pregnancies;
3. To explore and evaluate the role of traditional versus novel data collection systems, methodological approaches and datasets through specific demonstration studies using data from different sources; and
4. To develop best practice guidance to support a more timely and efficient multifaceted approach to data collection, analysis and interpretation of reported pregnancies to inform risk-benefit considerations of medication use in pregnancy for both HCPs and pregnant women.

**WP3 : Determination of drug transfer and infant drug exposure during lactation: generation of quantitative and translatable data** ✓

## Figure 13: Work package presentation

The landing page includes static content, with an about column where we can post shortcuts to information. It also includes feeds with dynamic content, one feed displaying three news items from the website and an RSS feed from Twitter sharing the two latest tweets.

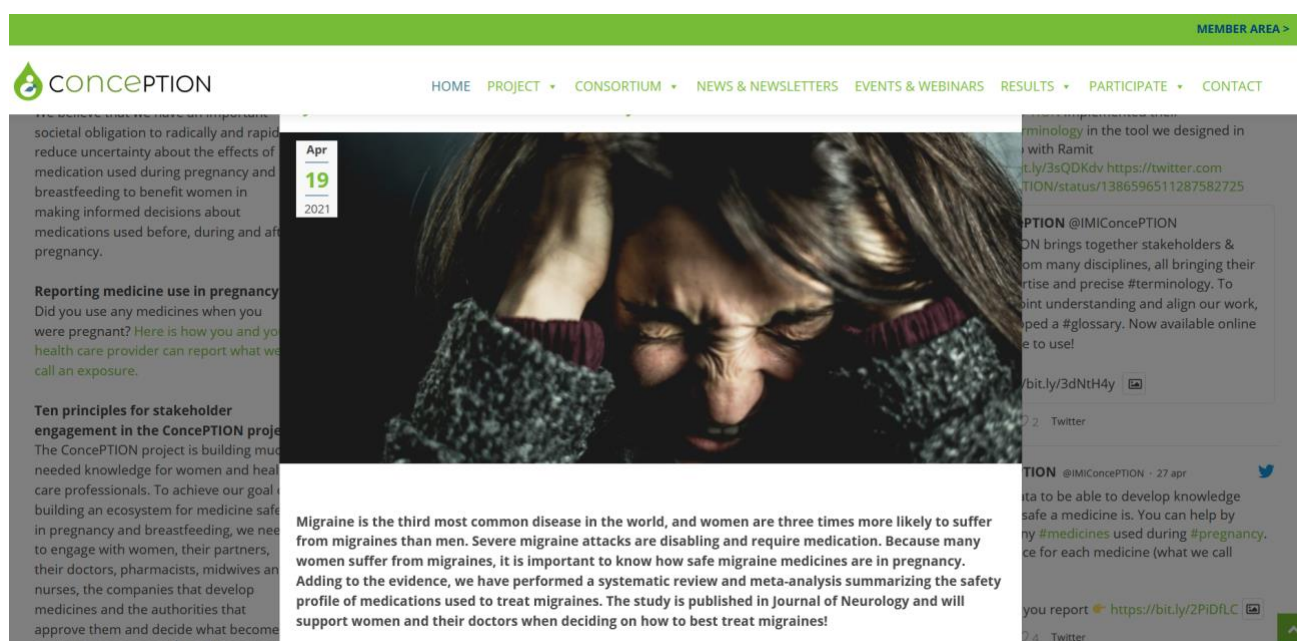


The screenshot displays the ConcePTION website landing page layout. It features three main columns:

- About ConcePTION:** Contains static text about the project's funding by the Innovative Medicines Initiative, its goals to reduce uncertainty and improve decision-making, and a link to 'Reporting medicine use in pregnancy'.
- News:** A dynamic feed showing three news items with dates (Apr 26, Apr 21, Apr 19, 2021) and titles: 'Speaking with one voice: defining terminology for ConcePTION', 'ENTIS issues position statement in favour of COVID-19 vaccines in pregnancy and lactation', and 'Safety profile of migraine medications during pregnancy: New systematic review and meta-analyses!'.
- Twitter:** An RSS feed showing two tweets from @IMConcePTION, discussing the importance of precise terminology and the availability of a glossary.

## Figure 14: Landing page content

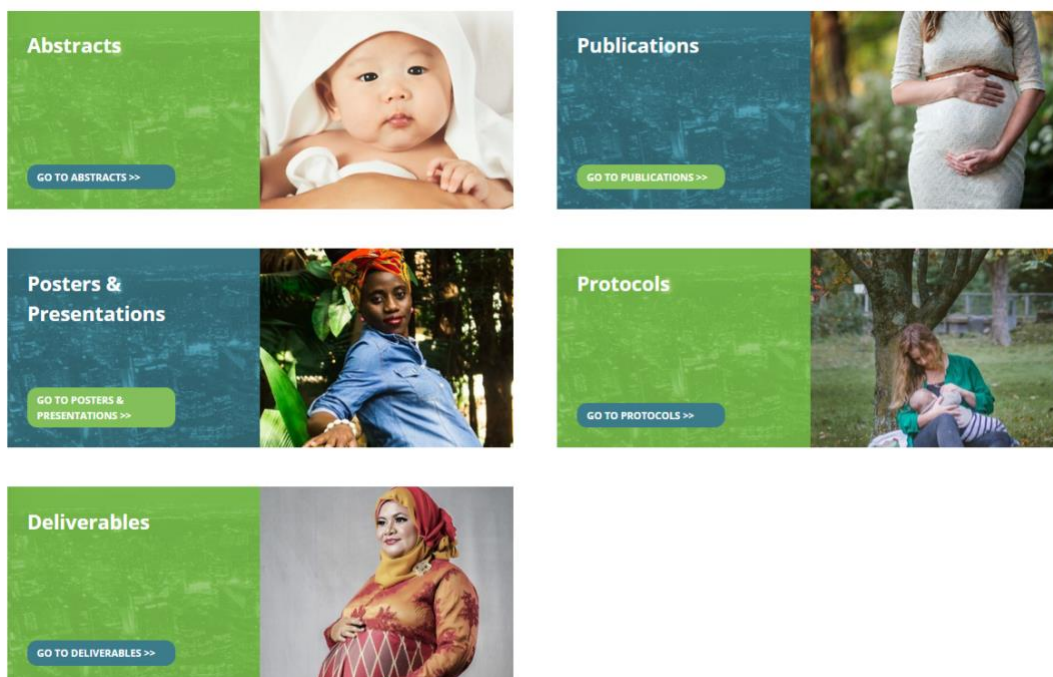
When a news item link is clicked, the news item is displayed in an attractive way, on top of the page. The URL does not change as you remain on the landing page.



**Figure 15:** How news items are displayed on the website

This approach (displaying content without a unique URL) is functional on a website that we use as a repository for information only. However, it does not allow us to share links to content and does not support widespread sharing in social media.

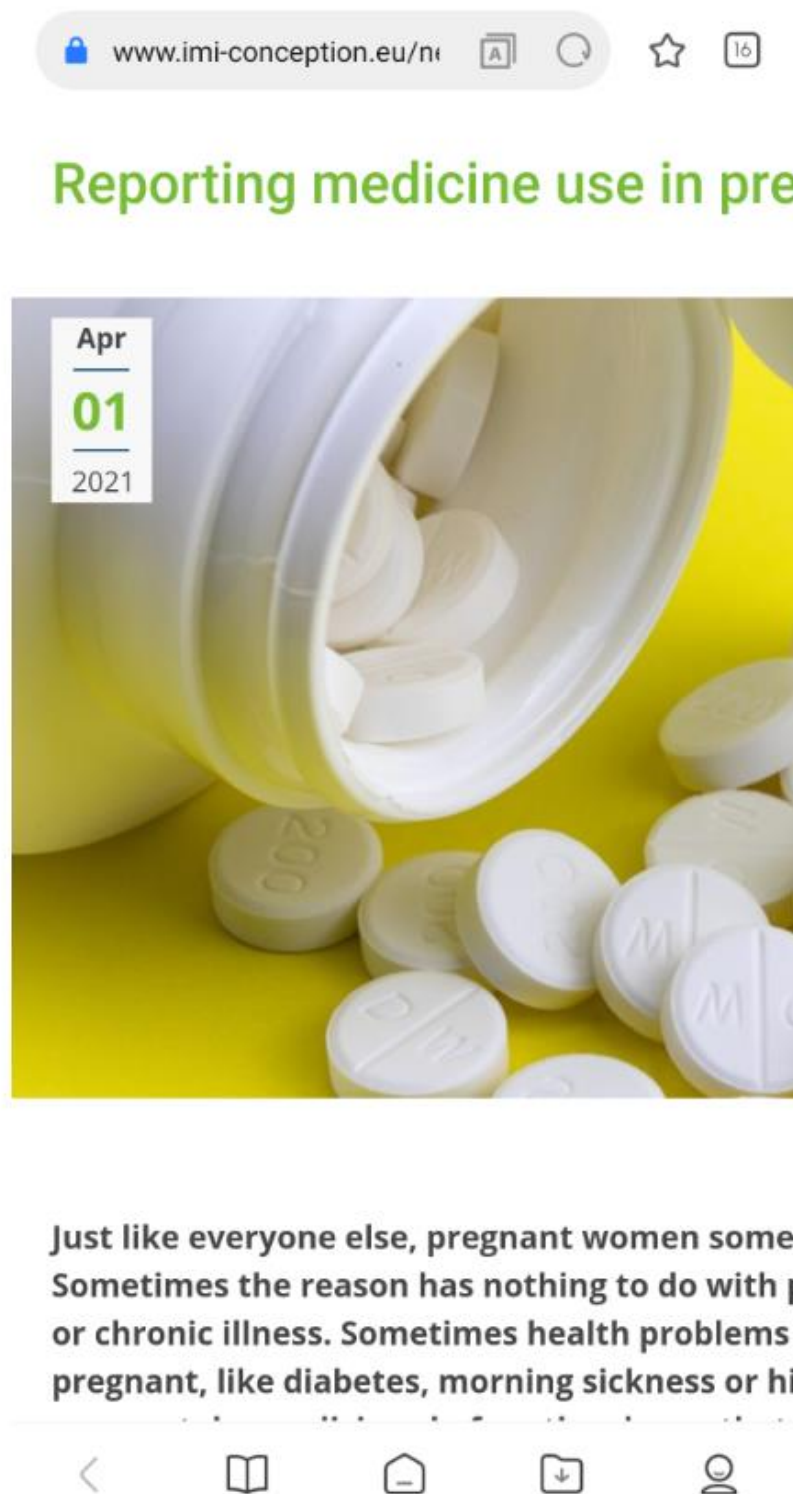
The website also includes placeholders for content that was never developed, for example on the results page, displaying empty pages about abstracts, posters and presentations, and protocols. There is also an empty events page.



**Figure 16:** Placeholders for non-existing content on results landing page

## Responsive web

Accessible and user-friendly web is also responsive, allowing content to be displayed on mobile devices. The current project website does not support sharing links on social media, because news items are not displayed in a responsive way on mobile devices.



**Figure 17:** News item link shared on Twitter displayed on mobile (Android)

## Actions to address immediate concerns

The current website structure includes placeholders for content that does not (yet) exist, which is not helpful for website visitors. Pages that are empty will be deleted, keeping only publications and deliverables. When the need arises, new pages can be added to the navigation. To solve this problem, and allow link sharing in social media, and improving the user experience, the following urgent actions are required:

- Adding unique URL's to the home page news feed when a news item is displayed
- Ensuring the website is responsive, supporting social media use
- Updating top navigation
  - Remove events & webinars landing page
  - Change “participate” to “biobank”
- Removing redundant pages in results structure
  - Abstracts
  - Protocols
  - Posters and presentations

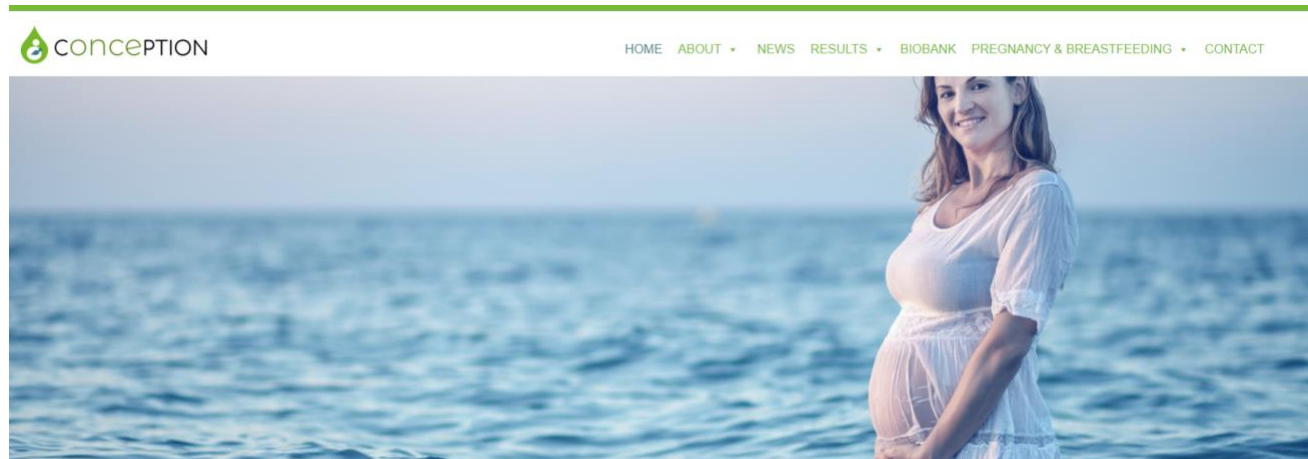
## Developing website structure to fit current needs

The current website includes empty placeholders for content and little space for a much-needed landing page for the end-users: women and health care professionals. It is also difficult to find space for additional landing pages. The navigation also includes empty pages, which were included as placeholders for content that has not been produced, and hence became redundant. We will streamline the navigation, removing redundant content, merging information about the project and its partners, creating space in the top navigation for pages that are needed now, and that will likely be required in the future.

The current “project” and “consortium” landing pages will be merged, supporting website users in finding static and relevant information about the project and its partners in one place. This update will also allow adding and highlighting content that is developed over the course of the project, for example the principles for stakeholder engagement and the glossary developed in WP7.

The updated website structure will include a landing page for women and health care professionals that should include information about how to report exposure to medicines in pregnancy, along with information about ongoing donor recruitment for the biobank. In the future, this page should also include information on how to download the PV reporting app developed in WP2. This landing page will support the needs of task 5.3 and should cover both pregnancy and breastfeeding, support round-trips between different parts of the ConcePTION website, and provide two separate information interfaces: One aimed at women as consumers/users of medicines, avoiding scientific jargon and explaining the project in plain language. One aimed at health care professionals as provides of (and advisors about) medicines, using terminology used in the health care domain.

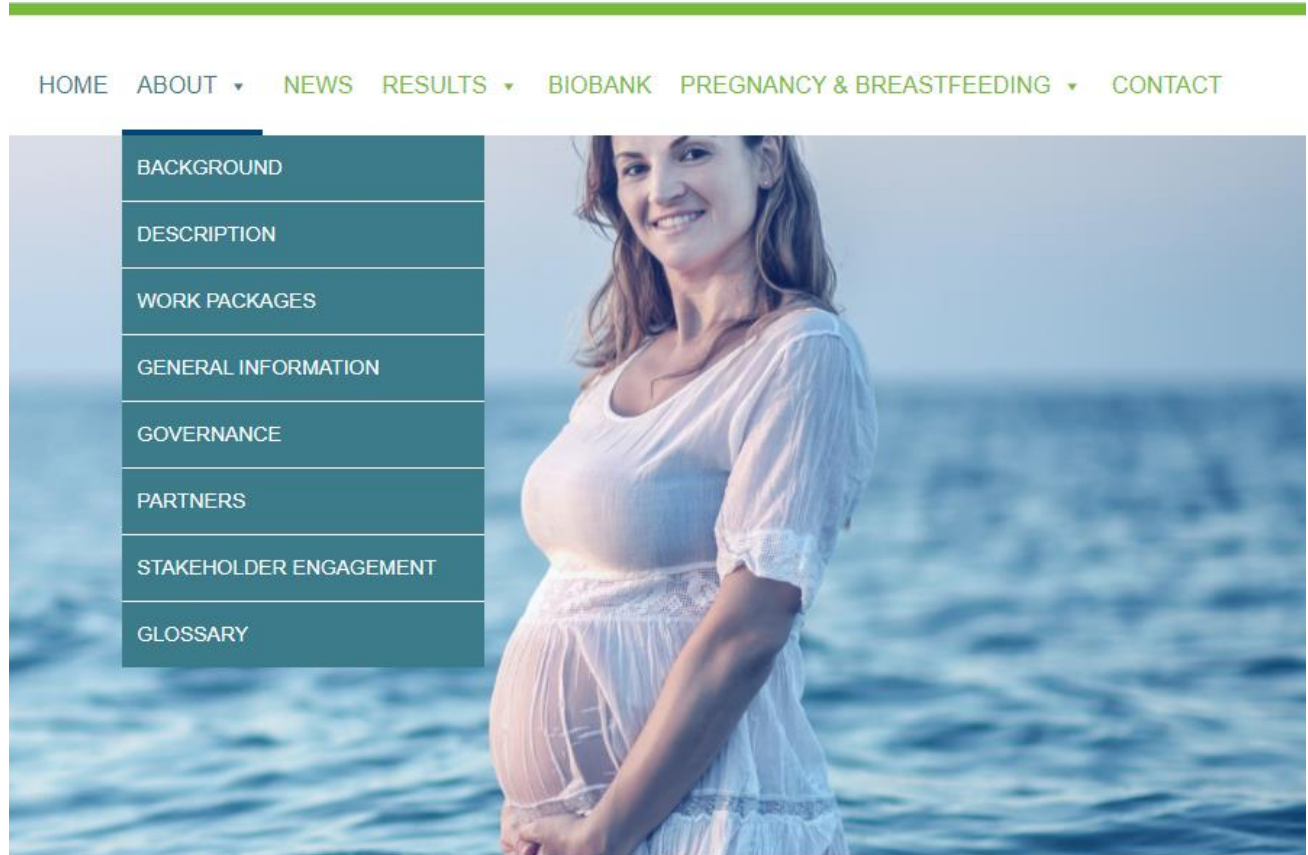
Below wireframes (mock-ups) of what the website structure and navigation will look like after implementing updates.



**Figure 18:** Wireframe for the top navigation

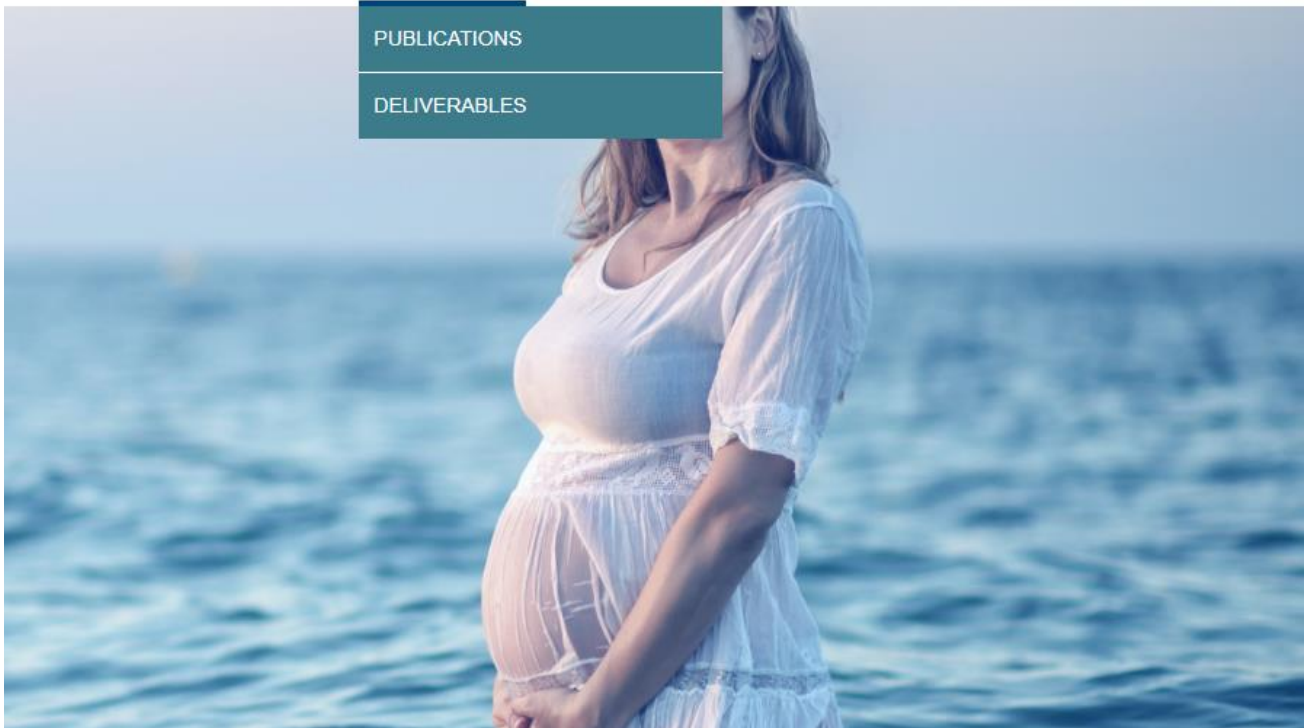


**Figure 19:** Wireframe showing how the top navigation can be expanded to include landing pages for content about the knowledge bank and ecosystem



**Figure 20:** Wireframe for new “about” section

HOME ABOUT ▾ NEWS RESULTS ▾ BIOBANK PREGNANCY & BREASTFEEDING ▾ CONTACT



**Figure 21:** Wireframe for the new results section

HOME ABOUT ▾ NEWS RESULTS ▾ BIOBANK PREGNANCY & BREASTFEEDING ▾ CONTACT



**Figure 22:** Wireframe for dropdown-menu on the landing page for communications aimed at women and health care professionals

## Governance structure

### Overview of who has authority to make decisions at the project level

Activity		Responsible person(s)
Decisions on general communication and dissemination policy		Management team
Approval of ad hoc messages		Coordinator & Project leader
Approval of ad hoc communications		Communications manager
Spokespersons to media and journalists	For ConcePTION general	Coordinator & Project leader
	For published results	First author
Coordinating communication efforts with IMI project officer and communications team		Communications manager
Tracking and storing consent to publish photo and/or video identifying an individual		Project manager

**Table 9:** Governance structure for communications

## Routines in case of negative publicity

Actions to take in case of negative publicity	
<b>General</b>	<ul style="list-style-type: none"> <li>• Inform ConcePTION management team communications manager</li> <li>• Inform concerned organisation's leadership</li> <li>• Appoint spokesperson in organisation</li> <li>• Appoint spokesperson in ConcePTION</li> </ul> <p>All media requests should be directed to appointed spokespersons.</p>
<b>Anything related to <i>in vivo</i> studies</b>	<ul style="list-style-type: none"> <li>• Inform ConcePTION management team communications manager</li> <li>• Inform concerned organisation's leadership</li> </ul> <p>AND (very important)</p> <ul style="list-style-type: none"> <li>• Department of Veterinary Medical Sciences, University of Bologna</li> <li>• Covance</li> <li>• Ellegaard Göttingen Minipigs</li> </ul> <p>Contact information is stored on the ConcePTION member area.</p>

**Table 10:** Routines in case of negative publicity

## Appendix 1: Twitter campaign for survey recruitment

A campaign was developed to recruit survey participants (women and health care professionals) for task 5.1.3. The campaign used the ConcePTION Twitter channel as the main outlet, and instructions were shared with partners to encourage them to share in their own channels, together with pre-made graphics in English, explaining how Twitter works. The person responsible for the Twitter handle was also instructed about the frequency of tweets, varying the graphics, and re-tweeting other's tweets about the survey.

### The Twitter campaign

- Used adaptedm agreed-on messaging for social media
- Used inclusive images
- Almost doubled our Twitter following!
- And this is an indicator for raising awareness about
  - The project
  - The "problem"
  - And shows we can call women and HCP's to action!

The Twitter campaign was complemented by

- Consortium-wide requests to cascade
- Regular reminders & stats to create friendly competition
- 1-1 outreach to external stakeholders and KOLs & referrals
- Digital Advertising with support from consortium partners (e.g. through Safe Motherhood week channels provided by the Synergist).

### Tweets and instructions sent to the consortium

A list of proposed tweets was shared with the consortium and WP8 along with simple toolkits and pre-made Twitter graphics and instructions and information about how Twitter functions:

The Twitter basics:

- Tweets allow 280 characters. The tweets below will fit within this limit.
- Make shorter, more attractive links using [www.bitly.com](http://www.bitly.com) (already prepared below)
- Tweets that include graphics/photos/video do better. Tools to create images are available in the **Twitter toolkit for women** developed by the communications task force.
- Using hashtags and tagging people can help with reach.

**Twitter success depends on engagement.** If someone tweets about ConcePTION, make sure to retweet that. If someone retweets a ConcePTION tweet with a comment, make sure to retweet that (as long as it is appropriate and not spam). This is how you gain followers and build an audience. Everyone wants their 15 minutes of fame (or 15 seconds of Twitter fame).

Another trick is **tagging people** hoping they will retweet your content. I suggest you tag e.g. @MaternalRights in the images of some of these tweets and if you are lucky they will share the survey in their networks as well.

**Hashtags** sort content on Twitter. If you are a pregnant woman, you might be interested in reading about #pregnancy or #breastfeeding. So, you use and follow these hashtags to make other pregnant

people find your Tweet, and to find other #pregnancy related content. You can also use hashtags during, or referring to **special events**. E.g. international women's day, or #IWD2019.

Something to consider is **our choice of words**. For example, some women would look for “nursing advice” whereas others will look for “breastfeeding advice”. The same goes for “medicine safety in pregnancy” and “drug safety in pregnancy”. A similar conflict arises with “medicine” vs “drugs”. To cover our bases and make sure we cast as wide a net as possible, it is important to alternate the wording to make sure we show up in peoples' searches. Especially in communications targeting the general public.

Some hashtags often used by pregnant women are of course:

- #pregnancy
- #pregnant
- #nursing
- #breastfeeding
- **#maternalhealth** (recommended)

There are also specific hashtags related to treatment during pregnancy, such as:

- #MedsInPregnancy
- #SafeMotherhoodWeek (in October, used by the Motherhood Collective Impact Programme, @MaternalRights on Twitter)

## Tweets for recruiting women:

#Pregnant, #nursing or want to? We need YOUR help! Help us generate good information about the safety of your #medicines by answering the survey! <https://bit.ly/2RvvsbC> #MaternalHealth  
Considering #pregnancy? Help us build a tool that helps women and health care professionals find information on the safety of medicines during #pregnancy or #nursing. Fill out this survey: <https://bit.ly/2RvvsbC> #MaternalHealth

Help us generate good information on the safety of medicines for #pregnant and #breastfeeding women! Fill out our survey: <https://bit.ly/2RvvsbC> #MaternalHealth  
We want #pregnant and #breastfeeding women to have access to information about #MedsInPregnancy and #lactation. Fill out our survey to help us build the ideal tool: <https://bit.ly/2RvvsbC>

#Pregnant, #breastfeeding or want to? Give us 15 min of your time & help us generate good information about the safety of your #medicines! <https://bit.ly/2RvvsbC> #MaternalHealth  
Having children? We need your help developing a tool for #pregnant and #nursing women with questions about the safety of their drugs before, during and after #pregnancy. Share your experiences by filling out our survey: <https://bit.ly/2RvvsbC> #MaternalHealth

We are building a knowledge bank about the safety of medicines during #pregnancy and #breastfeeding for women and health care professionals! Help us build the ideal tool for you! Fill out our survey: <https://bit.ly/2RvvsbC> #MaternalHealth

Ever needed information about drug safety during #pregnancy or #breastfeeding? We are building a knowledge bank on the safety of medicines before, during and after pregnancy. Fill out this survey to help us shape the ideal tool: <https://bit.ly/2RvvsbC> #MaternalHealth

## Tweets for recruiting healthcare professionals

Hello #midwives & #OBGYNs! We are developing a knowledge bank on the safety of medicines during #pregnancy and #lactation for healthcare professionals and women. Help us build your ideal tool by filling out our survey: <https://bit.ly/2RvvsbC> #midwives2020 #MaternalHealth

Women who are #pregnant and #breastfeeding should have access to good information about the safety of the #medicines they use. Are you #pregnant, #nursing or working in #healthcare? Help us build an ideal tool by responding to our surveys! <https://bit.ly/2RvvsbC> #MaternalHealth

#Pregnant & #breastfeeding women need up to date quality safety information about the #medicines they use, built on strong science. Let us know what you need: <https://bit.ly/2RvvsbC>  
#Pharmacovigilance #nursing2020 #midwives2020 #MaternalHealth

Hello #nurses and #physicians! We are developing a knowledge bank on the safety of medicines during #pregnancy and #lactation for health care professionals and women. Help us build your ideal tool by filling out our survey: <https://bit.ly/2RvvsbC> #nursing2020 #MaternalHealth

Working in healthcare? We are developing a knowledge bank that will help you and #pregnant and #nursing women find information on the safety of #MedsInPregnancy and #lactation. Help us build it by filling out our survey: <https://bit.ly/2RvvsbC> #MaternalHealth  
We are building a European-wide knowledge bank for healthcare professionals and women with information on the safety of medicines during #pregnancy and #breastfeeding. Help us develop a tool that's fit for purpose! Fill out our survey: <https://bit.ly/2RvvsbC> #Pharmacovigilance

'Difficulties finding good quality information on the safety of medicines during #pregnancy and #lactation? Help us build a tool that helps healthcare professionals and women find what they need! Fill out our survey! <https://bit.ly/2RvvsbC> #Pharmacovigilance #MaternalHealth

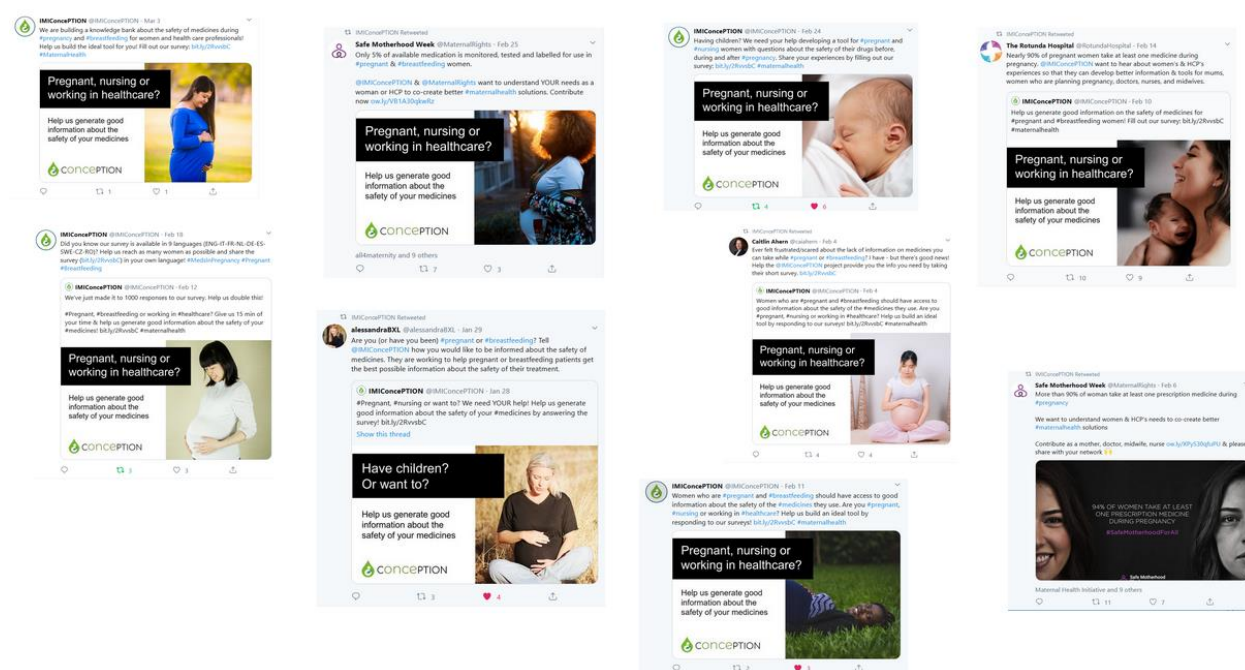


Figure 23: Examples of Tweets using the tools and tactics developed for this campaign

## Annex 2: Action plan for external-facing activities

<b>Timing</b>	<b>Communication intent</b>	<b>Communication format</b>	<b>Communication channels &amp; multipliers</b>	<b>Lead</b>	<b>Contributors</b>	<b>Status</b>
Q1-Q2 2020	Meetings with WP leads to discuss communication needs	Meeting	Internal process	Helena Harnik	Josepine Fernow, Roxana Radu,	Completed
30 January – 6 April 2020	Survey recruitment	Twitter campaign to recruit women and health care professionals	Twitter	Josepine Fernow	Anna Holm	Completed
Jan-March 2020	Presenting the project	Plain language video	YouTube, web & Twitter	Josepine Fernow	Communications task force	Completed
6 March	YouTube channel launch	Channel launch	YouTube	Juul Klassen	Anna Holm	Completed
4-10 May 2020	Awareness raising on mental health, pregnancy and medicines	Twitter campaign for maternal mental health awareness week	Twitter	Josepine Fernow	Sally Stephens	Completed
Q2 2020	Audience messaging workshop	Webinar	Internal process	Helena Harnik	Josepine Fernow, Roxana Radu, Anna Holm & Maximiliane Rauch	Completed
15 April 2020	Communication to women in Dutch (Bouwen aan een kennis)	Translated plain language video	YouTube, Twitter <a href="https://youtu.be/7QtAdRhK">https://youtu.be/7QtAdRhK</a>	Juul Klassen	Anna Holm	Completed

	genererend ecosystem)					
7 July 2020	Communication to women in Italian (Ricerca sulla sicurezza dei farmaci in gravidanza)	Translated plain language video	YouTube, Twitter <a href="https://youtu.be/K_1Ff-V3Sec">https://youtu.be/K_1Ff-V3Sec</a>	Anna Holm	Alberto Elmi	Completed
7 July 2020	Communication to women in Swedish (Forskning om läkemedelssäkerhet under graviditet och amning)	Translated plain language video	YouTube, Twitter <a href="https://youtu.be/TJFYxCn5-Nc">https://youtu.be/TJFYxCn5-Nc</a>	Josepine Fernow	Anna Holm	Completed
12-18 October 2020	Awareness raising during Safe Motherhood Week	Twitter campaign	Twitter	Josepine Fernow	Anna Holm	Completed
2-8 November 2020	Awareness raising during #MedSafetyWeek	Twitter campaign for Uppsala Monitoring Centre's #MedSafetyWeek	Twitter	Josepine Fernow	Anna Holm	Completed
15 December 2020	Media training webinar	Webinar	Process	Josepine Fernow	Anna Holm	Completed
27 Jan 2021	Communication to women in Spanish (Investigación sobre la seguridad de los medicamentos durante el embarazo y la	Plain language video translation	YouTube, Twitter <a href="https://youtu.be/7qXYLNNIGyA">https://youtu.be/7qXYLNNIGyA</a>	Gabriel Zarsosa	Joanna Stepek	Completed

	lactancia)					
4 Feb 2021	Communication to women in French (Écosystème de Preuves de la Sécurité)	Plain language video translation	YouTube, Twitter <a href="https://youtu.be/C4ftX1cphcE">https://youtu.be/C4ftX1cphcE</a>	Gabriel Zarsosa	Joanna Stepek	Completed
8 Feb 2021	Communication to women in Portuguese (Construindo um ecossistema de evidências de segurança   ConcePTION)	Plain language video translation	YouTube, Twitter <a href="https://youtu.be/AYQ7LeXhVrs">https://youtu.be/AYQ7LeXhVrs</a>	Gabriel Zarsosa	Joanna Stepek	Completed
Q1 2021	Video explaining the value of a public-private partnership	Video premiere on Twitter 8 March	YouTube, Twitter	Josepine Fernow	Management Team	Completed
8 March 2021	Public-private partnership (pre-emptive risk mitigation strategy)	International women's day Twitter campaign	Twitter, partner's websites and channels	Josepine Fernow	All partners	Completed
14 April 2021	SWOT workshop	Brainstorming session at the GAM	Process	Josepine Fernow	Anna Holm	Completed
3-7 May 2021	Awareness raising on mental health, pregnancy and medicines	Maternal mental health awareness week	Twitter campaign	Josepine Fernow	Sally Stephens, Annelouise Assaf	Completed
30 May 2021	Completion of social media and web strategy & plan	Process	Deliverable report	Josepine Fernow	Anna Holm	Under review
Q2 2021	Adding unique	Website update	Website	Josepine	Joost de Jonge	Ongoing

	URL's to the home page news feed when a news item is displayed			Fernow		
Q2 2021	Ensuring the website is responsive, supporting social media use	Website update	Website	Josepine Fernow	Joost de Jonge	Ongoing
Q2 2021	Updating top navigation, removing events & webinars landing page & changing "participate" to "biobank"	Website update	Website	Josepine Fernow	Joost de Jonge	Ongoing
Q2 2021	Removing redundant pages in results structure (Abstracts, Protocols, Posters and presentations)	Website update	Website	Josepine Fernow	Joost de Jonge	Planned
Q2 2021	Landing page for communicating with women and health care professionals	Website update	Website, multiplied in social media	Josepine Fernow	Sally Stephens, Annelouise Assaf, Joost de Jonge	Planned
Q2 2021	LinkedIn	Channel launch	LinkedIn	Anna Holm	Josepine	Planned

	presence				Fernow	
Q2 2021	Comparing ConcePTION to PRGLAC	Editorial content	Web, Twitter	Josepine Fernow	Ida Nickason	Under development
Q2 2021	Publicity for paper presenting ConcePTION	Result publicity & editorial content	Web, Twitter	Anna Holm	Miriam Sturkenboom	Draft under review
Q2-Q4 2021	Plain language video about ConcePTION in national and minority languages	Video translation	YouTube, Twitter	Gabriel Zarzosa	Joanna Stepek	Planned
Q2-Q3 2021	Placing ConcePTION as an important actor in the European Health Data Space	Editorial content, Twitter strategy	Web, Twitter	Miriam Sturkenboom	Josepine Fernow	Planned
Q3 2021	External newsletter issued	Channel launch	Mailchimp	Anna Holm	Josepine Fernow, Gabriel Zarzosa	Planned
17 Sept 2021	Awareness raising & patient audience building through participation in Word Patient Safety Day 2021	Campaign focusing on safe maternal and newborn care <a href="https://www.who.int/news-room/events/detail/2021/09/17/default-calendar/world-patient-safety-day-2021">https://www.who.int/news-room/events/detail/2021/09/17/default-calendar/world-patient-safety-day-2021</a>	Twitter, Web (editorial content)	Josepine Fernow	Anna Holm, Gabriel Zarzosa	Planned
Q3 2021	Awareness-raising through participation in Safe Motherhood Week	Online campaign	Twitter	Helena Harnik	Roxana Radu	Planned

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Q3 2021	Awareness-raising & encouraging reporting through participation in #MedSafetyWeek	Online campaign	Twitter	Josepine Fernow	Gabriel Zarzosa	Planned
Q1 2022	Awareness-raising in relation to International Women's day	Online campaign	Web, Twitter	Josepine Fernow	Anna Holm	Planned
Q2 2022	Awareness-raising about maternity, mental health, and medicines	Participation in maternal mental health awareness week/month	Web, Twitter	5.3	Josepine Fernow & Anna Holm	Planned
Q3 2022	Awareness-raising through participation in Safe Motherhood Week	Online campaign	Twitter	Helena Harnik	Roxana Radu	Planned
Q3 2022	Awareness-raising & encouraging reporting through participation in #MedSafetyWeek	Online campaign	Twitter	Josepine Fernow	Gabriel Zarzosa	Planned

**Table 1:** Action plan (living document)