

101034339 – PROMISE

Preparing for RSV Immunisation and Surveillance in Europe

WP2 – WP Preparation for future RSV product assessment

## D2.10 Report on the impact of the annual RSV awareness campaign in November 2022

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## Definitions

- **Participants** of the PROMISE Consortium are referred to herein according to the following acronyms:
  1. **UEDIN.** The University of Edinburgh (United Kingdom)
  2. **UMCU.** Universitair Medisch Centrum Utrecht (Netherlands)
  3. **UA.** Universiteit Antwerpen (Belgium)
  4. **Imperial.** Imperial College of Science, Technology and Medicine (United Kingdom)
  5. **UOXF.** The Chancellor, Masters, and Scholars of the University of Oxford (United Kingdom)
  6. **THL.** Terveystieteiden tutkimuskeskus (Finland)
  7. **RIVM.** Rijksinstituut voor Volksgezondheid en Milieu (Netherlands)
  8. **NIVEL.** Stichting Nederlands Instituut voor Onderzoek van de Gezondheidszorg (Netherlands)
  9. **TUCH.** Varsinais-Suomen Sairaanhoidopiirin Kuntayhtymä (Finland)
  10. **TEAMIT.** TEAM IT Research, S.L. (Spain)
  11. **ReSViNET.** Stichting ReSViNET (Netherlands)
  12. **SSI.** Statens Serum Institut (Denmark)
  13. **SERGAS.** Servizo Galego de Saúde (Spain)
  14. **PENTA.** Fondazione PENTA - For the treatment and care of children with HIV and related diseases - ONLUS (Italy)
  15. **FISABIO.** Fundación para el Fomento de la Investigación Sanitaria y Biomédica de la Comunitat Valenciana (Spain)
  16. **MLU.** Martin-Luther-Universitaet Halle-Wittenberg (Germany)
  17. **SP.** Sanofi Pasteur, S.A. (France)
  18. **GSK.** GlaxoSmithKline Biologicals, S.A. (Belgium)
  19. **JANSSEN.** Janssen Pharmaceutica, N.V (Belgium)
  20. **Novavax.** Novavax, Inc. (United States)
  21. **Pfizer.** Pfizer Limited (United Kingdom)
  22. **AZ.** AstraZeneca AB (Sweden)
  
- **Grant Agreement.** (Including its annexes and any amendments) The agreement signed between the beneficiaries of the action and the IMI2 JU for the undertaking of the PROMISE project (Grant Agreement No. 101034339).
- **Project.** The sum of all activities carried out in the framework of the Grant Agreement.
- **Work plan.** Schedule of tasks, deliverables, efforts, dates, and responsibilities corresponding to the work to be carried out, as specified in Annex I to the Grant Agreement.
- **Consortium.** The PROMISE Consortium, comprising the above-mentioned participants.
- **Consortium Agreement.** The agreement concluded amongst PROMISE participants for the implementation of the Grant Agreement. The agreement shall not affect the parties' obligations to the Community and/or to one another arising from the Grant Agreement.

## Abbreviations

Acronym / Abbreviation	Meaning
<b>EFCNI</b>	European Foundation for the Care of Newborn Infants
<b>PREMATURA</b>	Asociación de familias de niños y niñas prematuros (Association of families of premature children, in Spain)
<b>APREM</b>	Asociación española de padres y madres de niños nacidos prematuramente (Spanish association of fathers and mothers of children born prematurely, in Spain)
<b>RESCEU</b>	REspiratory Syncytial virus Consortium in EUrope
<b>WKZ</b>	Wilhelmina Children's Hospital, Utrecht, the Netherlands

## Abstract

The ReSViNET RSV Patient Network organises a notable yearly initiative known as “RSV Awareness Week” (RSV AW). The primary objective of this event is to enhance understanding and knowledge among the general public about Respiratory Syncytial Virus (RSV). The RSV AW is organised at the start of November, intended to highlight on RSV-related matters and to promote awareness during the expected start of RSV season, spanning from October to March in countries with a temperate climate in the Northern Hemisphere. This report provides a comprehensive overview of the second annual RSV AW as part of the PROMISE project, organised by the ReSViNET RSV Patient Network, titled "Share to be Aware", held from November 4-10, 2022. The report explores activities conducted during RSV AW'22 and evaluates their impact, with a particular focus on the effectiveness of various social media campaigns across multiple platforms.

# 1. Background and context

## 1.1. The organisation

Deliverable (D2.10) is led by the RSV Patient Network of the ReSViNET Foundation. The ReSViNET Foundation is a global network composed of renown investigators in the field of RSV. The foundation collaborates closely with the RSV Patient Network, which has been involved in various activities, including RSV education, awareness, and research activities. The RSV Patient Network was established in 2013 by a group of dedicated parents whose children were hospitalised with an RSV infection during infancy. The main commitment and goal of this network is to increase public awareness of RSV. The network is expanding its outreach and activities toward other RSV-vulnerable groups such as older adults and pregnant women.

The RSV Patient Network, started as a Dutch patient network, has been further developed under the REspiratory Syncytial virus Consortium in Europe (RESCEU) into an international patient network and is a relatively small yet significant group. Additionally, selected members of the RSV Patient Network represent the RSV Patient Advisory Board (PAB) in the Preparing for RSV Immunisation and Surveillance in Europe (PROMISE) project, which represents an invaluable insight to the initiative.

## 1.2. Aim

The report reviews the second annual RSV Awareness Week (RSV AW) under the umbrella of PROMISE, "Share to be Aware", which took place from November 4-10, 2022. In addition, it outlines the various initiatives undertaken during the event, analyses their impact, and evaluates the efficiency of the posts used in our social media platforms. The objective of this activity is to increase the awareness of RSV using mass campaigns amongst EU citizens. Also, by analysing the posts related to reach and growth during Awareness Week '22 (AW'22) and the other years, we can enhance the strategy of social media engagement for the upcoming Awareness Week '23 (AW'23). By examining the data, insights are gained regarding the posts that have positively influenced user responsiveness and the expansion of social media channels.

## 2. RSV Awareness Week 2022

### 2.1. Theme

For AW '22, the theme "Share to be Aware" was chosen by the members of the RSV PAB. With this theme, the RSV Patient Network invited parents and RSV patients to share their personal stories and the impact of RSV infection on their lives, with the aim that as many people as possible hear about RSV and consequently increase awareness. The Patient Network aims that all present and future parents and adults should know about RSV.

### 2.2. Social media platforms

The RSV Patient Network is active on Facebook ([www.facebook.com/rsvpatientnetwork](http://www.facebook.com/rsvpatientnetwork)), Instagram ([www.instagram.com/rsvpatientnetwork](http://www.instagram.com/rsvpatientnetwork)), Twitter ([\(\(20\) RSVPatientNetwork \(@rsvpatients\) / Twitter](https://twitter.com/rsvpatients)) and LinkedIn ([www.linkedin.com/company/65851211](http://www.linkedin.com/company/65851211)). The RSV Patient Network also has a private group on Facebook where parents can share their stories and where peer support is offered. The AW'22 was hosted on all these platforms to reach as many people as possible.

The RSV Patient Network is active in the following languages:

**Facebook:** English, Spanish, and Dutch; **Instagram:** English and Dutch; **Twitter:** English and **LinkedIn:** English

Prior to the AW, the event was introduced by a kick-off trailer posted on November 4<sup>th</sup>, 2022. This trailer featured the date, the theme, and the highlights of different posts throughout the week and practical information to advocate for following our social media accounts.

### 2.3. Recommendations from the AW'21 Report

The recommendations following the AW'21 report ([https://teamitresearch.sharepoint.com/sites/RESCEU2.0/\\_layouts/15/viewer.aspx?sourcedoc={364c650e-8a9a-4c29-ab04-3d4037c7b439}](https://teamitresearch.sharepoint.com/sites/RESCEU2.0/_layouts/15/viewer.aspx?sourcedoc={364c650e-8a9a-4c29-ab04-3d4037c7b439})) were implemented into AW'22:

- ✓ *More Engagement for exchange of information and interaction*  
To engage more interaction and provide more information exchange we included an online environment for parents and patients to share their own experiences in the videos.
- ✓ *Implementation of videos*  
Visuals, such as videos and infographics, attract a higher reach than written text, especially concerning the younger audience.
- ✓ *Professionals are mostly active on Twitter and LinkedIn*  
Since the parent testimonial videos were very well viewed by professionals during the last RSV AW, we made the decision not to make a further differentiation in the program for the general public and professionals.
- ✓ *Development of awareness tool*  
The awareness tool to continuously measure the level of awareness about RSV among its followers is still under development.

This tool will be useful to track the progress and deliverables of the annual AWs and our social media efforts throughout the years.

## 2.4. Schedule of AW'22

The AW'22 took place during the first week of November (November 7-11, 2022). However, the activities started on November 4<sup>th</sup> with the Kick-off video, "RSV Awareness Week '22", and was followed by videos, webinars, and infographics during the week. An overview of the content, description of the program and presentation format for Facebook, Instagram, Twitter, and LinkedIn is provided in Table 1 below.

**Table 1 - Content scheduled for AW'22 on Facebook, Instagram, Twitter, and LinkedIn.**

Day	Publication date	Post description	Type of item
Friday	November 4 <sup>th</sup>	<a href="#">Kick-off video RSV Awareness Week '22</a>	Video
Monday	November 7 <sup>th</sup>	<a href="#">Video with mother of an RSV patient: Rachael Thomas</a>	Video or link to video
Tuesday	November 8 <sup>th</sup>	<a href="#">Video with mother of an RSV patient: Sanne Hulsen</a>	Video or link to video
		<a href="#">Live webinar Q&amp;A Dr. Lieke de Vrankrijker</a>	Video or link to video
Wednesday	November 9 <sup>th</sup>	<a href="#">Video with mother of an RSV patient: Willemien ten Brink</a>	Video or link to video
		<a href="#">Written interview with Dr. Ann Falsey</a>	Visual + link
Thursday	November 10 <sup>th</sup>	<a href="#">Infographic: mother and midwife Lisa van Wissen</a>	Video
		<a href="#">Video with mother of an RSV patient: Esther Bleeker</a>	Video or link to video

## 2.5. Activities

The activities of RSV AW'22 were comprised of eight videos and one visual component. This year, the Patient Network had chosen to create various videos content based on personal stories. We learned from previous years that the use of visuals and videos creates more engagement for the younger target group compared to written text.

The videos gave voice to the diverse experiences and perspectives of parents and professionals. The Kick-off video on Friday, 4<sup>th</sup> November, marked the start of AW'22. See full description in Appendix 1.

Link for all videos: [Awareness Week - ReSViNET](#)

Link for the Kick-off video: [\(1\) RSV Awareness Week 2022 - Kick-Off Video - YouTube](#)

### 2.5.1. Monday, 7<sup>th</sup> November 2022: video with Rachael Thomas

AW'22 began with the heart-wrenching story of Rachael Thomas, a UK mother of six boys who lost her son Alexander to RSV at the tender age of 12 weeks. She passionately shared her story to raise awareness among parents and healthcare professionals about RSV's impact. Rachael advocates for education and prevention to save lives from this virus.

Rachael quote: **"With education and prevention maybe we can save some lives."**

Link for the video: [\(1\) The Impact of RSV - A parent's story - YouTube](#)

### **2.5.2. Tuesday, 8<sup>th</sup> November 2022: video with Sanne Hulsen and a live-streamed webinar**

Tuesday morning started with Sanne Hulsen, a mother from the Netherlands, who shared her story about her son Vik. Vik is six years old now. As a baby, Vik was hospitalised six times because of complications after he had been hospitalised with RSV. Despite getting his flu shot every year, each winter he would catch a cold. Probably because he is becoming older, Vik is doing better now. In the video, Vik elaborates on how his situation is.

Link for the video: [\(1\) The Impact of RSV - A mother tells her story about the long-term aftermath of RSV. - YouTube](#)

Tuesday afternoon, Dr. Lieke de Vrankrijker, (paediatrician at Wilhelmina Children's Hospital in Utrecht, the Netherlands) hosted a live webinar (RSV and long-term effects) via Instagram. The webinar provided viewers with an in-depth understanding of RSV, which was followed by an interactive Q&A session. Participants were able to ask the speaker their personal questions and learn from each other's experiences firsthand.

Link for the video:

<https://www.instagram.com/tv/CktGugsvwTt/?igshid=NjZiM2M3MzlxNA%3D%3D>

### **2.5.3. Wednesday, 9<sup>th</sup> November 2022: Willemien ten Brink and an interview with Dr. Ann Falsey**

Wednesday morning started with Willemien ten Brink's story, a mother from the Netherlands. Her experience with RSV was shared and the physical aftermath RSV has had on her daughter Lola and her family. Lola is now five years old but still suffers from the side effects of pneumonia. Willemien highlighted in her story the difficult and exhausting impact of Lola's hospitalisation due to RSV for her, her daughter, and their family. However, the phase afterward, when they were back home without all the professionals around them was even more challenging. This experience has had a significant impact on her and her family, which they are still learning to cope with.

Link to the video: [\(1\) The Impact of RSV - Long-Term Aftermath - YouTube](#)

In the afternoon we posted an interview with Dr. Ann Falsey. Dr. Falsey is a specialist in respiratory viral infections in older adults. She was interviewed about her experiences with RSV in older adults and the burden of the disease in this group.

Link to the interview: [Interview Dr. A. Falsey English.pdf - Google Drive](#)

### **2.5.4. Thursday, 10<sup>th</sup> November 2022: Lisa van Wissen and Esther Bleeker**

Thursday morning started with an infographic of Lisa van Wissen, a mother and a midwife. She explored, from the midwife perspective, how midwives can support parents to be better informed and prepared for RSV.

Link to the infographic: [Infographics RSV and Pregnancy English.mp4 - Google Drive](#)

In the afternoon we posted a video from Esther Bleeker, a mother of an RSV patient from the Netherlands. Esther talks about the psychological aftermath RSV has had on her and her family and

the support that was needed to get through this period. Often this side is forgotten and underexposed, which upholds the taboo and reluctance to discuss the topic. She believes it is important to break the taboo about this and make it easier for parents to seek support.

Link to the video: [\(1\) The Impact of RSV - A mother talks about the impact her daughter's hospitalisation had on her. - YouTube](#)

### 3. Methods of data collection

For the announcement of AW'22, social media channels and mailing lists were used as the major channels of communication and dissemination. Besides the already known (cooperating) organisations, networks, and contacts, the RSV Patient Network also focused on general practitioners' and midwives' practices and their umbrella organisations. During the campaign period, an email was sent to the network daily with the topics of the day. In addition to the official partners, the RSV Patient Network has also extended its reach to other organisations and individuals (i.e., European Foundation for the Care of Newborn Infants (EFCNI), Asociación de familias de niños y niñas prematuros (Association of families of premature children, in Spain (PREMATURA), and Asociación española de padres y madres de niños nacidos prematuramente (Spanish association of fathers and mothers of children born prematurely, in Spain (APREM)). These organisations shared all posts and videos during AW'22, which further enhanced the outreach of the posts.

Further, the international network of parents has been highly active in liking and sharing the posts and videos. The help and support of all the partners, organisations and individuals was extremely important for AW'22 to reach the goal to make people aware of RSV.

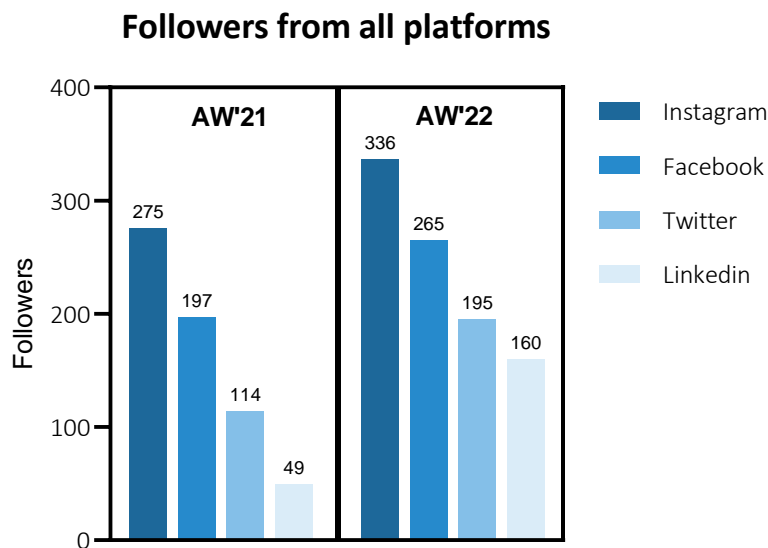
The data on outreach, followers, and engagement were collected from the different social media platforms. Also, we analysed the AW'22 dataset in comparison with data from AW'21.

## 4. Results

### 4.1. General findings

The international reach of accounts using different platforms was extended using videos, posts, and interviews regarding the impact of RSV on children and older adults. The results show that social media channels have significantly grown in the number of followers from 49 to 160 on LinkedIn, 114 to 195 on Twitter, 197 to 265 on Facebook and 265 to 336 on Instagram compared with last year (Figure 1).

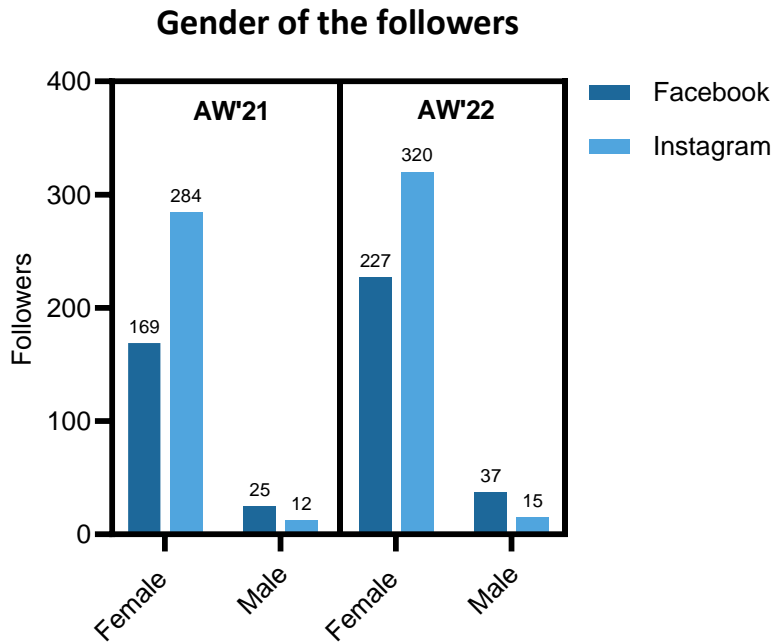
**Figure 1: International followers of the RSV Patient Network.**



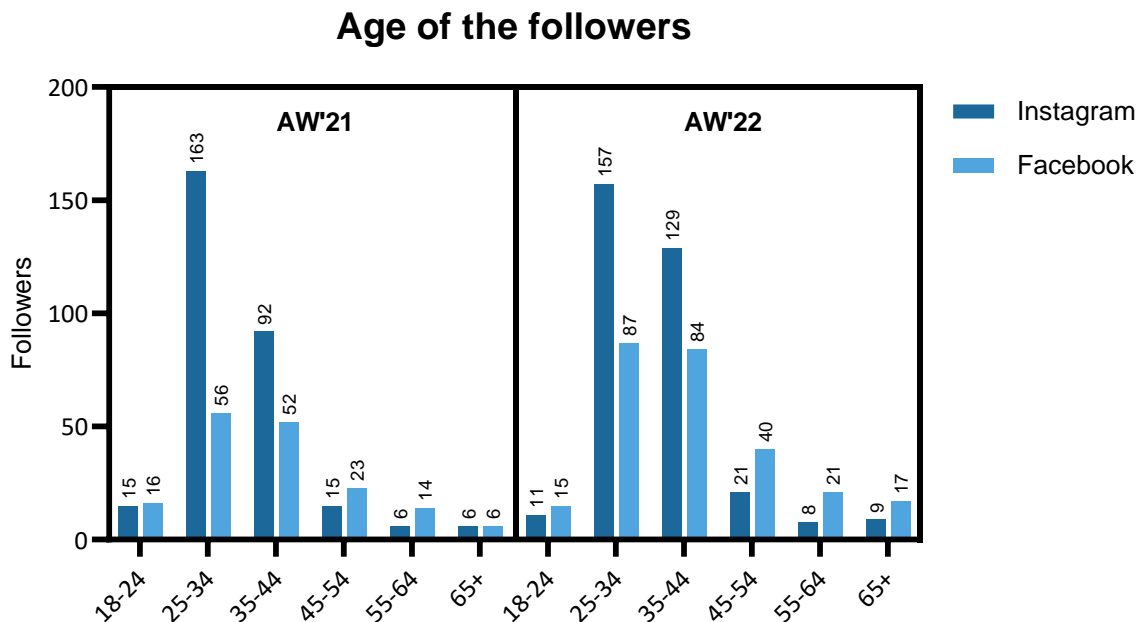
Among the followers on Instagram and Facebook (472 and 601 followers in 2021 and 2022, respectively) approximately 86% were women (Figure 2a) with the majority between 25 to 44 years old (86% for Instagram and 64% for Facebook). Comparing AW'21 and AW'22 showed an increase of female and male followers in both platforms. The other age groups have been constant in the number of users, having a more pronounced increase in the age range of 35-44 years old (Figure 2b). It is not feasible to retrieve this type of data for LinkedIn and Twitter.

**Figure 2 – International followers’ profiles on Facebook and Instagram (a) Gender of the followers; (b) Age of the followers.**

a.

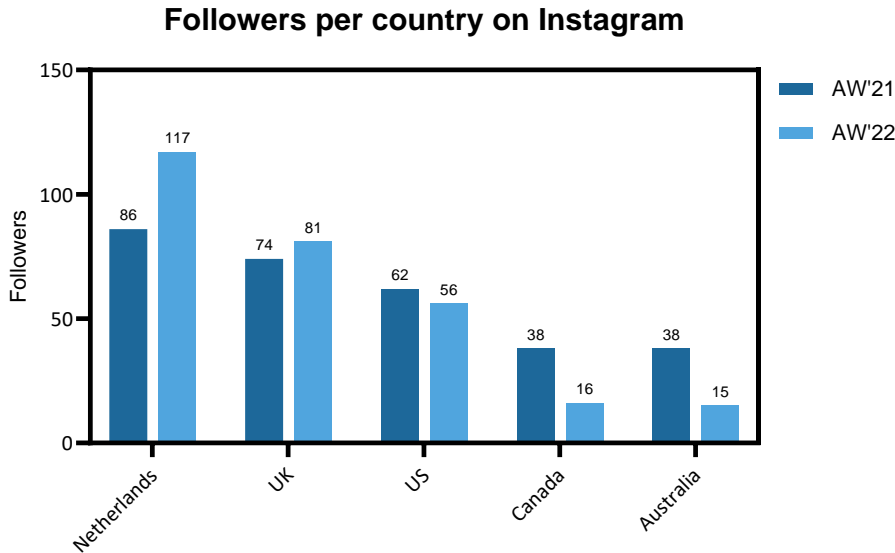


b.

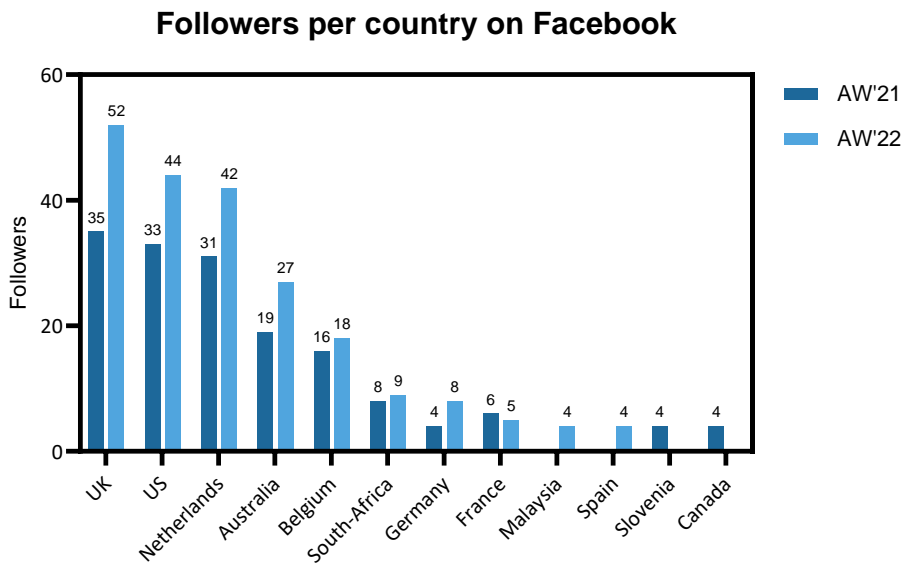


Most followers on Instagram and Facebook were from the United Kingdom (UK), United States (US), Australia, and the Netherlands. Interestingly, it was possible to reach more countries with Facebook (12 countries) in comparison to Instagram (only five countries) (Figures 3a, b).

**Figure 3: Followers per country (a) on Instagram and (b) on Facebook.**  
a.



b.



## 4.2. Analyses of the individual social media outcomes over AW'21 and AW'22

This section describes different social media outcomes analyses and comparisons among various platforms. The raw data is visualised in Table 2.

**Table 2: Raw data from the social media outcomes.**

	AW'21	AW'22
<b>FACEBOOK</b>		
Followers	197	265
Referring posts (#posts)	10*	9*
Reach of posts	4836**	1777
Engagement posts	158	507
Page likes	175	221
<b>INSTAGRAM</b>		
Followers	275	336
Referring posts (#posts)	10	9
Reach of posts	2800	1985
Engagement posts	3330	2809
Profile visitors	240	424
<b>TWITTER</b>		
Followers	114	195
Referring of tweets (#tweets)	5	9
Engagements	568	348
Reach posts	7120	8226
Profile visitors	2998*	227
<b>LINKEDIN</b>		
Followers	49	160
Referring posts (#posts)	5	9
Reach posts	207	2821
Page visitors	15	80

**Reach:** The number of unique people who have seen your content.

**Likes:** Every like can be seen as a social confirmation. You see that others like your post.

**Engagement:** Indicates to what extent people find your social media posts interesting

**\*Referring posts:** the number of posts we posted.

**\*\*Please note that the number of Facebook "Reach of posts" and the "Profile visitors" on Twitter were remarkably high in 2021 because of the video regarding RSV symptoms. This video was viewed more than 10,000 times during AW'21.**

The number of referring posts (#posts) show a relatively modest influence on the dissemination of awareness during the designated week (Table 2).

The reach of posts had an oscillating effect/trajectory over the two years, with Twitter having the higher numbers (>4500). We were able to establish a substantial increase in reach of the posts on LinkedIn (207 in 2021 to 2821 in 2022) and Twitter (7120 in 2021 to 8226 in 2022) compared to the previous year. However, the reach of posts on Facebook (4836 in 2021 to 1777 in 2022) and Instagram (2800 in 2021 to 1985 in 2022) showed a decrease. The total results of posts that were displayed on our four international social media accounts during AW'22 is illustrated in Table 2. This AW'22 data will be explored in-depth in the next section.

The level of engagement can be measured through metrics such as likes, comments, shares, and other forms of user interaction. Overall, these metrics remained constant over the years with higher

numbers on Instagram.

Facebook, Instagram, and LinkedIn prioritise user-friendliness with their algorithms. Using AI technology, they aim to present personalised content to users based on factors like interactions, post age, user behavior, and content type. By leveraging these insights, the platforms strive to enhance user engagement and satisfaction, providing a more enjoyable and tailored social media experience for their users.

### 4.3. Reach of different posts from AW'22

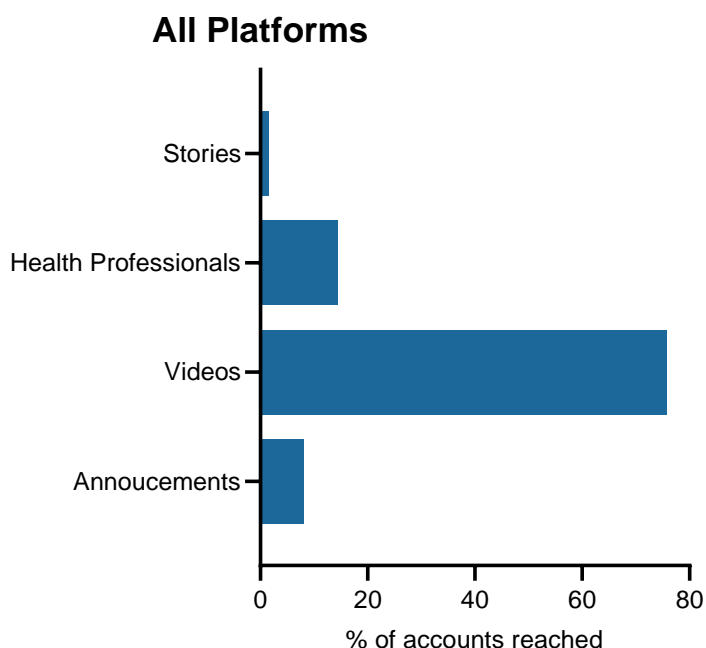
#### 4.3.1. General findings

During AW'22 different strategies were applied to increase the reach of accounts on the different platforms and as a result, a total of 21,592 accounts were reached. Videos generated the largest reach (76%) followed by health professionals' webinars (14.5%), announcements (8%), and stories (6%) (Figure 4). The life-experience videos shared had the largest impact and reach (62%). The videos of Dutch mothers had the highest reach on Dutch social media channels. Rachael's video had the highest reach (7441 accounts reached) and was responsible for almost half (45%) of the reach on videos. All the raw numbers are visualised in Table 3.

Compared to the data regarding Facebook on scores in AW '22, the target audience of Instagram had less viewer retention (data not shown). In the coming year it will be useful to analyse whether there are any demonstrable reasons for this and whether this should be addressed. For example, by sharing shorter videos that are more catchy, concise, and summarised in nature, purely to generate and increase interest.

In this section, it is important to note that certain data points are not disclosed and, therefore, we do not have this data. Examples of such data include viewer retention, recommendations, and likes of the posts.

**Figure 4: Accounts reached on different platforms using different strategies.**



**Table 3: Number of accounts reached on different platforms**

		TWITTER	LINKEDIN	INS INT	INS NL	FB INT	FB NL	
	DESCRIPTION OF THE POST	NUMBER OF PERSONS REACHED						TOTAL
Announcements	Announcement AW '22			92	118	149	78	<b>437</b>
	Announcement Q&A live webinar			100	49	96	79	<b>324</b>
	Save the date Q&A live webinar	209	297	87	156			<b>749</b>
	We're now live on Instagram (Q&A)	90	76		59			<b>225</b>
Videos	Kick-off video AW'22	325	457	1501	161	374	127	<b>2945</b>
	Video experience Rachael Thomas	4817	1088	293	64	1095	84	<b>7441</b>
	Video experience Willemien ten Brink	83	202	348	91	176	1700	<b>2600</b>
	Video experience Sanne Hulsen	491	433	132	58	89	589	<b>1850</b>
	Video experience Esther Bleeker	577	110	223	85	346	201	<b>1542</b>
Health Professionals	Recording Q&A Dr. Lieke de Vrankrijker			104	65	80	73	<b>322</b>
	Text interview Dr. Ann Falsey	121	151	91	198	77	91	<b>729</b>
	Video infographic Lisa van Wissen	1251	239	89	217	200	86	<b>2082</b>
Stories	Story: What is your experience with RSV?			94	56			<b>150</b>
	Story: What measures are you taking?			61	40			<b>101</b>
	Story: Experience complaints after admission			60	35			<b>95</b>

INS=Instagram, FB=Facebook, NL=Netherlands, INT=International

### 4.3.2. Facebook

From the international Facebook accounts that were reached, 40% was reached by the video of Rachael. This is in line with the findings of the Dutch Facebook page in which Dutch-language video content received a significantly better response rate for Dutch-speaking viewers (79%). English-spoken videos with Dutch subtitles did better on international social media channels. While Dutch-spoken videos with English subtitles did better on Dutch social media channels (Figure 5).

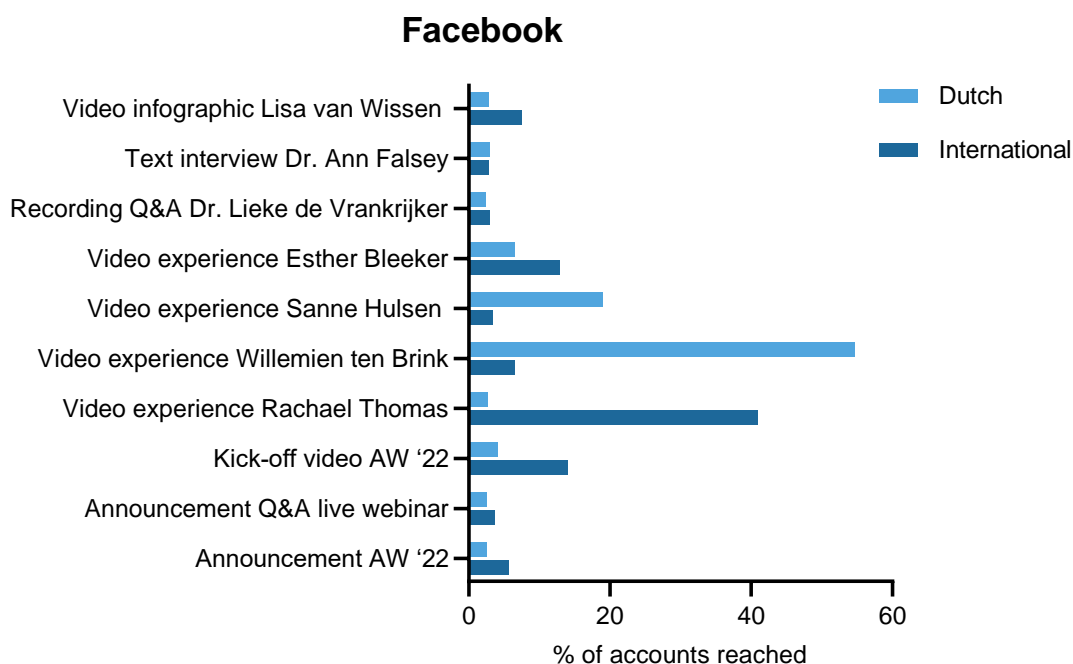
Therefore, despite well-kept subtitles, there is a clear preference by viewers for spoken videos preferably in their own (native) language. In addition, the informative posts 'Infographic video Lisa' scored very well on both the number of views and viewer retention (data not shown). This may indicate a greater interest in or need for short, animated, informative, and movie-format posts.

Overall, the 'Recommendations' feature provided by far the most reach to posts (data not

shown). This is a feature built into Facebook that makes recommendations to Facebook users (via 'Suggested to you' and 'Pages you might like') regarding content, accounts, and entities. 'Followers', on the other hand, constitute a relatively low level of reach and responsiveness. Pursuing more followers would greatly benefit from the reach of 'Recommendations' before building out its posts, but pursuing more follower reactivity does not equate to this. Shared actions and likes, besides 'Recommendations', also prove to be a huge boost to the reach of posts.

After a post has already been shared once, it exceeds the reach of followers at least three times and can even increase to 12 times. Prime examples of this are the video posts in which mothers talk about their lived experiences. The sharing actions and likes ostensibly take place within personal circles.

**Figure 5: Accounts reached on Facebook using different strategies.**



### 4.3.3. Instagram

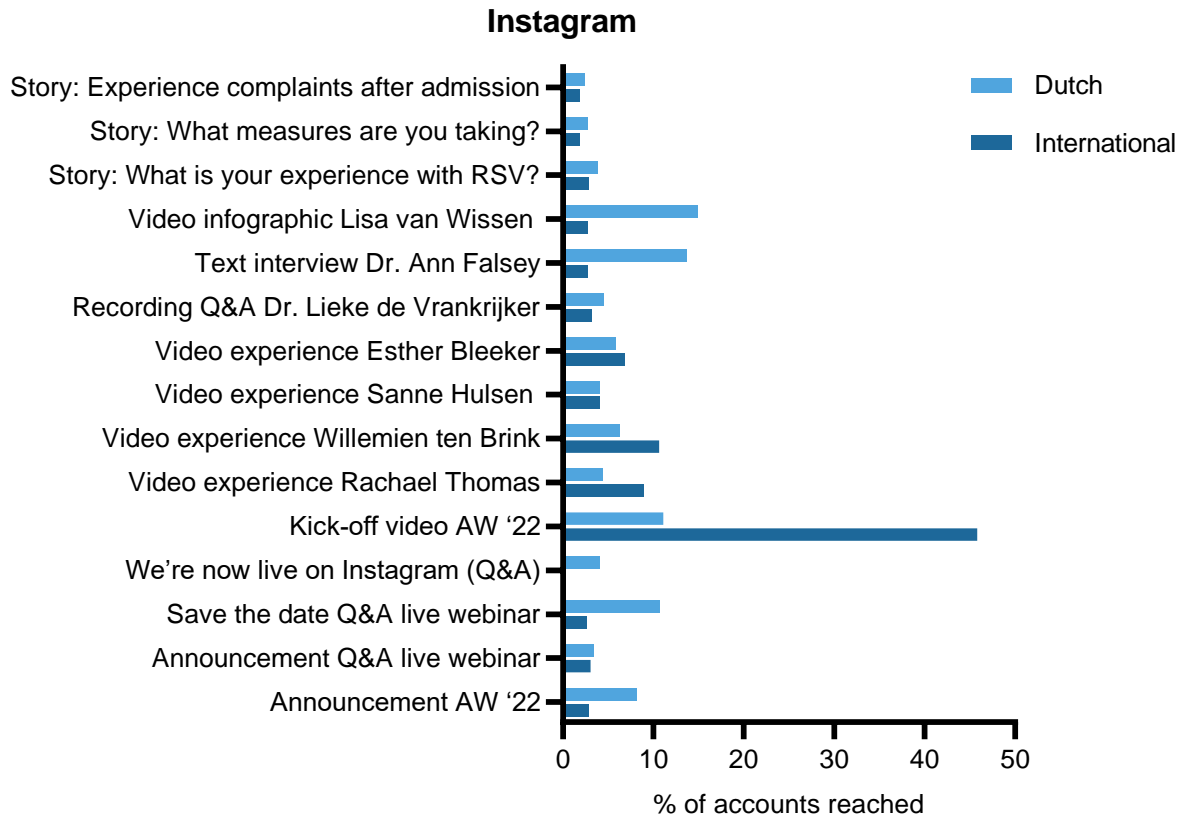
In Figure 6, a chart showing the percentage of accounts reached on Instagram is displayed. The kick-off of AW'22 on the international Instagram account had the highest number of accounts reached (45%).

For the Instagram page, the greatest reach was among non-followers. 'Via profile' is one of the most valuable ways in which viewers interact with the content. An attractive feed (overview posts) is, therefore, of value to enhance the possibility of profile viewers to click on many posts. In addition, 'via home page' is also an important way non-followers get in touch with posts. This has to do with the 'recommendations' they are presented with.

The effect of 'sharing' is not accounted for in Instagram Analytics (where it is with Facebook). It has, therefore, not been possible to display the 'sharing effect', but seeing this on Facebook, we assume that this is of great value. Focusing on the (personal) stories and continuing to tie unique accounts to the content that will be posted, could effectively increase visibility.

In addition, it is useful to continue investing in the use of hashtags, as this seems to provide extra attention to almost every post.

**Figure 6: Percentages of accounts reached on Instagram using different strategies.**



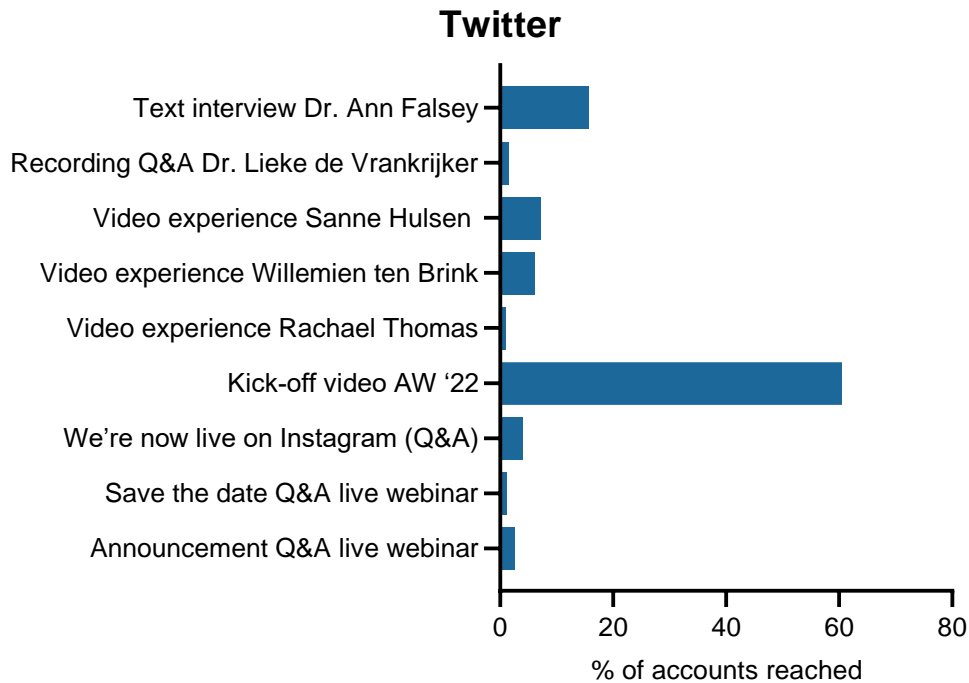
#### 4.3.4. Twitter

In Figure 7, a chart showing the percentage of accounts reached on Twitter is displayed. The kick-off of AW'22 had the highest number of accounts reached (60%). The tweets that generated significantly higher reach were the ones with the most likes and shares. It is useful to build out the amount of sharing actions, especially by tagging large accounts, thus emphasising the collaboration factor.

Furthermore, it is useful to generate more awareness by not just focusing on getting likes, but also by investing time to like relevant tweets from others, which helps increase our own account's visibility and encourages people to look at or follow the account.

Viewer activity cannot be analysed when only a link to a YouTube video is added in the tweet. Nevertheless, it seems effective to include a short video with the tweet (for example, the first 20 seconds or a summary of the video) and at the end of it to reference such as, "Watch further" or "Click the following link". In fact, Twitter includes the feature that when scrolling through tweets, a short video plays automatically so the viewer is already unwittingly introduced to the content of the video.

**Figure 7: Accounts reached on Twitter using different strategies.**



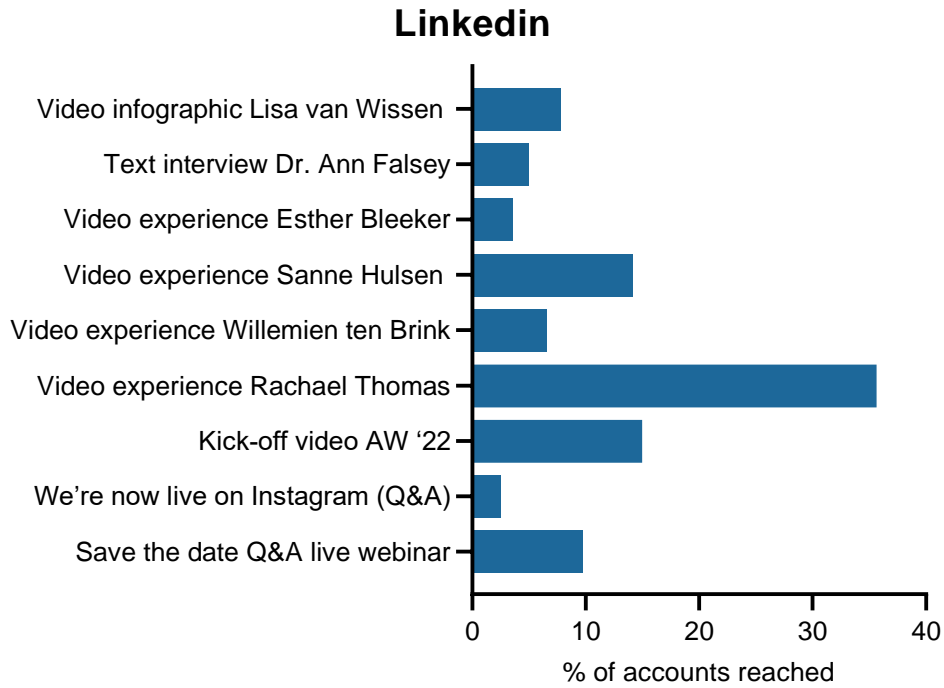
#### 4.3.5. LinkedIn

In Figure 8, a chart showing the percentage of accounts reached on LinkedIn is displayed. The video experience of Rachael Thomas had the most significant reach (35%), followed by the Kick-off video AW'22 (15%) and the Sanne Hulsen video experience (14%). The least reach (less than 10%) was observed for the “Instagram Q&A announcement”, a text interview with Dr. Ann Falsey, and video experience with Esther Bleeker.

The reach of these accounts is most likely influenced by the likes the posts received. On other platforms, a “like” is just an important token of appreciation, whereas a “like” on LinkedIn has an extra dimension: if a user likes a post, this post will also appear in the timeline of his/her connections. There is a lot to be gained by making posts on LinkedIn extra 'likeable'. If the LinkedIn posts are liked more frequently, the connections could grow as the post might reach the 2<sup>nd</sup> or 3<sup>rd</sup> circle of influence of a follower, thereby reaching accounts outside of your network.

In addition, LinkedIn uses a ‘Golden-Hour’ principle; posting when your target audience is active. The rate of interactions that occur within an hour of posting is crucial for LinkedIn’s assessment of being seen. In addition, LinkedIn tagging can be used to generate quick interaction by having a relevant, engaged person or organisation join the conversation (liking, responding, or reposting).

**Figure 8: Accounts reached on LinkedIn using different strategies.**



## 5. Conclusions

This report provides a comprehensive summary of the second annual RSV AW during the PROMISE project, known as "Share to be Aware," organised by the RSV Patient Network of the ReSViNET Foundation. The report outlines the various initiatives undertaken during this period, analyses their influence, and evaluates the effectiveness of the diverse activities conducted on our social media platforms. The sharing of the videos, posts, and interviews focusing on the impact of RSV on children and older adults has yielded remarkable outcomes, as we successfully reached a substantial audience. The overall goal of the patient network is to raise awareness in general. We are doing this through the awareness week on our social media channels. The awareness tool we are developing is another way of looking at general awareness of RSV in the future.

As a patient network, we also see the negative posts on social media channels about vaccinations in general. Especially after COVID-19, people are posting about this issue on a regular basis. But we believe that in addition to creating RSV awareness, sufficient independent, reliable information should be available for people to make their own choice.

For AW'22, it was decided to share the same content on all social media channels as AW'21 showed us that professionals are also interested in parents' personal experiences and stories.

Notably, all our social media channels have experienced noteworthy growth in terms of follower counts. We achieved a three-fold increase in followers on LinkedIn, while on Twitter we doubled the number of followers as compared to the previous year. However, there was a marginal decrease in the reach of posts on Facebook and Instagram, the reasonings behind this are yet to be further explored. It is worth highlighting that most of our followers are predominantly from the UK, the US, Australia, and the Netherlands. The RSV Patient Network is continuously working on extending its reach and further improving RSV awareness.

One of the challenges for the next campaign is to maintain the interest of the people throughout the entire week. Post-launch engagement in an awareness week online campaign is about nurturing an active community through continual engagement with fresh and user-generated content, consistent social media interaction, innovative contests or challenges, insightful online events, collaborations with influencers, exclusive behind-the-scenes content, regular follow-up emails, soliciting and acting on feedback, all within a framework of constant improvement and adaptation.

Potential considerations and areas for enhancement for the upcoming RSV AWs include:

1. Continuing with the implementation of hashtags: this seems to provide extra attention with almost every post.
2. Investing time to be active on the platforms: for example, liking other relevant posts, as it enhances visibility on Twitter or building an attractive feed in Instagram.
3. Focusing on the (personal) stories and continuing to tie unique accounts to the content that will be posted, which could effectively increase visibility.
4. Including more content with English or if possible native spoken audio: English-spoken videos with Dutch subtitles did better on international social media channels. Dutch-spoken videos with English subtitles did better on Dutch social media channels.
5. Including different media formats: The Infographic video scored very well on both number of views and viewer retention. This may indicate a greater interest in or need for short, animated, informative, and movie-format posts.
6. Increasing Collaborations: Seek opportunities to collaborate with additional organizations, healthcare professionals, community leaders who can amplify the reach and impact of the campaign.
7. Diversifying Content: Explore different forms of content, such as videos, infographics, or testimonials, to engage a broader audience and convey the message effectively.
8. Exploring possible ways to engage the public more in our activities.

These ideas aim to enhance the effectiveness, reach, and engagement of the awareness week campaign, ultimately maximising its impact on the target audience and achieving the desired outcomes.

## 6. Appendix

### 6.1. Full description of the videos

#### 6.1.1. Monday, 7<sup>th</sup> November 2022: video with Rachael Thomas

Rachael (PAB member from the UK) is a mother to six boys. In this video she shared her experiences about the impact RSV can have on a family. Rachael's third son Alexander was a healthy baby boy, born full-term, and exclusively breastfed.

At the age of 12 weeks, Alexander experienced cold-like symptoms with a runny nose, a cough and was generally miserable. He didn't have a fever, was still alert and still feeding. But he wasn't right. Because of these symptoms he was taken to their local doctor who diagnosed bronchiolitis and advised some liquid paracetamol if needed. The same evening Alexander woke up and started to cry. It was not a normal cry; it was high-pitched and hysterical. Rachael dialed 999 and when going down the stairs Alexander stopped breathing and went white and floppy.

Rachael started resuscitation of her son.

In the emergency room his heart stopped again and a resuscitation process of about 2 hours began. The resuscitation was successful but a couple of hours later Alexander lost his battle with RSV. He died in his mother's arms when she was singing to him like she did every night.

If he heard her voice, she thought, hopefully he wouldn't be scared.

Since Alexander died 13 years ago due to RSV, Rachael has been on a personal mission to help to raise awareness of RSV.

She discovered that many of us are not educated in what RSV is. Not just parents and carers and caregivers that need to be aware but also medical professionals are not trained on RSV education. As Nelson Mandela once stated: Education is the most powerful weapon which you can use to change the world.

Rachael: With education and prevention we can save some lives.

#### 6.1.2. Tuesday, 8<sup>th</sup> November 2022: video with Sanne Hulsen and a live-streamed webinar.

Sanne (PAB member from the Netherlands) is a mother of two boys. Her youngest son Vik was in the hospital with an RSV infection when he was 7 weeks old. It started with a nasty cough and spitting out his bottle of milk with a lot of mucus. That didn't feel right to Sanne.

She contacted the emergency room, where the doctor decided to admit him to monitor the oxygen level in his blood. Vik had significant chest withdrawals.

Vik was getting increasingly ill, so they decided to transfer him to the intensive care unit of the university hospital. They found Vik to have 3 different viruses: Rhinovirus, Influenza, and RSV. RSV caused him the most trouble. Fortunately, Vik didn't need a ventilator.

When Vik was allowed to go home, it was both nice and very exciting. Sanne had to learn to trust her child again on what she was seeing, at home there is no monitor to rely on.

After 6 months, Vik got sick again and ended up in the hospital. Finally, he was hospitalised 6 times in the first 3 years of his life due to respiratory infections. That had a great impact on the family. Nowadays, Sanne always has medication for Vik with her. In addition, every year Vik gets his flu shot. Now that Vik is getting older, he seems to be doing better.

In the video Vik is elaborating how he is doing now.

### 6.1.3. Wednesday, 9<sup>th</sup> November 2022: Willemien ten Brink and an interview with Dr. Ann Falsey

Willemien (PAB member from the Netherlands) is a mother of 2 daughters. Lola was a healthy baby, developing well until a few weeks after birth. She developed noisy breathing, was stuffy and could not take the usual amount of milk. At the infant support services, they indicated that this noise just belonged to her, there was no reason for concern.

However, Lola became sicker and sicker and was eventually admitted to the intensive care unit. She spent 5 weeks on the ventilator and was hospitalised for 8 weeks. Besides RSV she was also infected by the Rhinovirus. During these 5 weeks, there were several attempts to remove her from the ventilator, but unfortunately every time Lola had acute respiratory distress after a couple of hours. In one of these attempts her trachea was damaged by the tube. For this fast-growing scar problem Lola was operated on several times. After being transferred to the paediatric ward, Lola had to kick off all medication she had been given. Lola's discharge from the hospital was not just joyful. Willemien found herself alone with her husband without all the care from the hospital, with a child who was vulnerable, and a toddler at home with snot bubbles. That was a difficult time. Lola did not go to daycare; she did frequent cleaning and kept sick people out.

This proved effective; it took a few months for Lola to catch a cold again. As Lola grew older, these rules could not be maintained, which very quickly led to more colds and, unfortunately, more hospitalisations. Lola is now 5 years old and in addition to all her respiratory problems, her growth is lagging. In the video, Lola told us what she found so frustrating about being sick so often.

In the afternoon we posted an interview with Dr. Ann Falsey. Dr. Falsey is a specialist in respiratory viral infections in older adults in the US. She was interviewed about her experiences with RSV in older adults and the burden of disease in this group.

In her opinion, the awareness of RSV is a problem. Most of the older adults are unaware of RSV. The symptoms of RSV can be very mild, like a cold. But it can also be very severe bronchitis, or it can progress to pneumonia and respiratory failure. Healthy older adults without (significant) underlying diseases (like heart failure and COPD) recovered well from RSV infection. Most of them were not hospitalised, however, for some of them it took a month or two to get back to normal life. The people who were hospitalised were quite ill. These people are mostly high-risk patients with significant underlying diseases, like heart failure and COPD. In these group there is a 7- 8% death rate, some people need to be admitted to the intensive care unit.

One of the most important parameters is that of the people who entered the hospital with severe RSV disease and living on their own, 8% were not able to live independently after their hospitalisation.

According to Dr. Falsey, RSV is very similar to influenza. Many countries have surveillance for influenza based on a case definition of influenza-like illness. Almost every definition includes fever, which is not a big part of RSV. RSV is always underestimated because the right people were not tested. RSV and influenza were evaluated in different studies. The disease burden of RSV was very similar to that of influenza A.

It is important to create more awareness of RSV in the elderly in the community, but also among health professionals.

### 6.1.4. Thursday, 10<sup>th</sup> November 2022: Lisa van Wissen and Esther Bleeker

In the morning we started with an infographic of Lisa van Wissen (PAB member), a mother and a midwife from the Netherlands. As a midwife, Lisa didn't know that RSV is the number 2 cause of death in children, that the impact of RSV can be so great, and that tube feeding and ventilation may be necessary for a "cold". In her experience, there is a lack of information and knowledge among general

practitioners, midwives, and healthcare agencies. Since her daughter suffered from an RSV infection, Lisa, as a midwife, is actively talking about RSV during maternity week.

She joined the RSV patient network to create awareness within the professional group and to give guest lectures at academics for obstetrics.

In the afternoon we posted a video from Esther Bleeker, a PAB member and mother of two daughters in the Netherlands. Her daughter, Elynn, has been infected with RSV twice; at the age of 4-5 months and at 8 months. Both times Elynn was admitted to the paediatric intensive care unit.

Esther talked about the psychological aftermath RSV has had on her and her family and the support that was needed to get through this period.

After discharge from the hospital, Elynn was very defensive about anything in the mouth/nose area. Wiping her mouth/face, brushing her teeth, wiping a snot bubble; this was absolutely not possible as she became very anxious.

Fortunately, the family doctor took Esther seriously and she was referred to a child psychologist. Elynn has had several eye movement desensitisation and reprocessing (EMDR) sessions with a positive effect. They were more and more able to touch her face, wipe her mouth or snot bubble.

Esther also looked for help for herself. She was having flashbacks, thinking with every cough that something serious was going on. This made her very anxious. Esther was helped a lot by writing down her whole story, literally writing it off.

By telling her story, Esther wants to break the taboo of finding help for psychological problems or just because the situation is difficult.