

INTRODUCTION

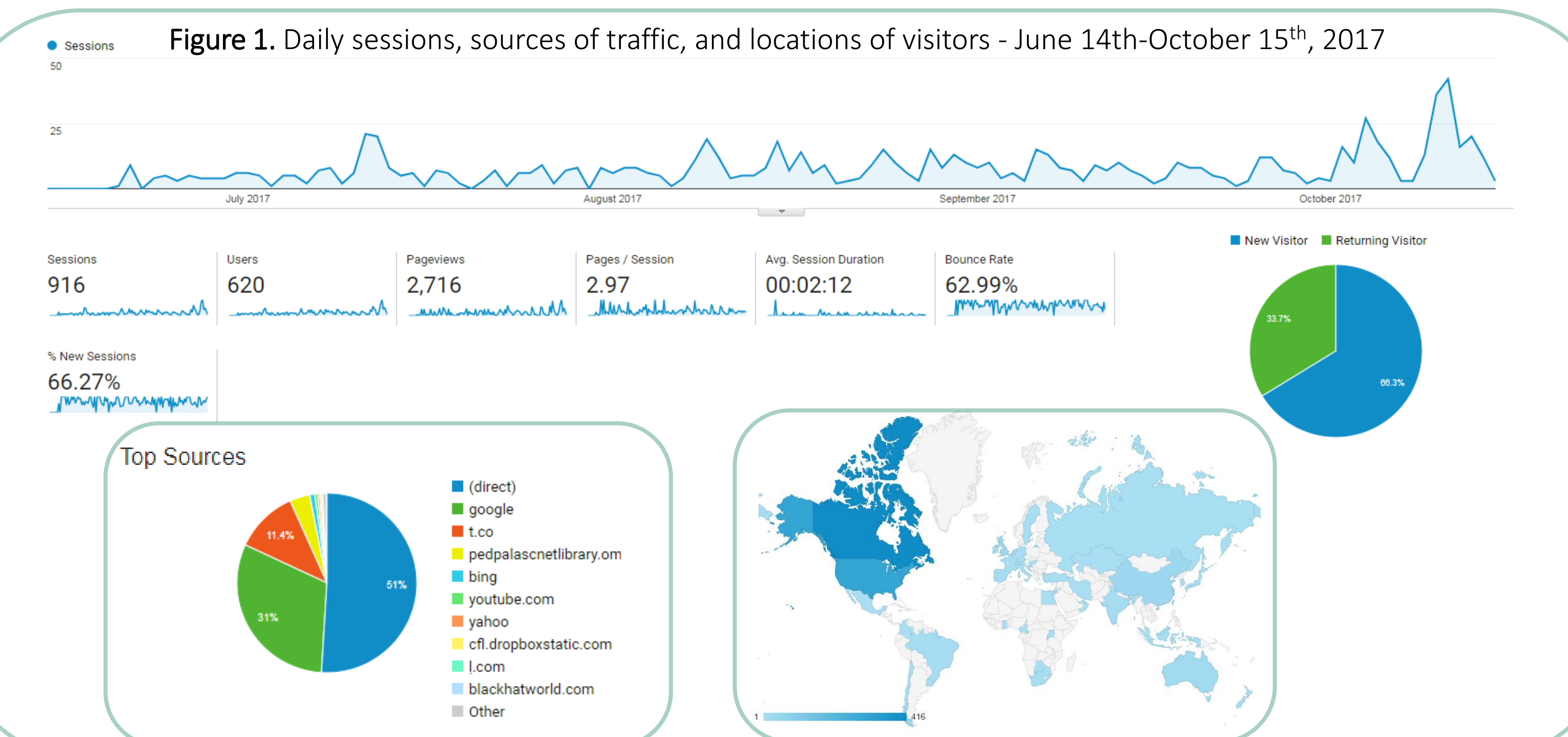
- For the last several months our team of clinicians and health librarians have been collecting analytics data via Google Analytics, Twitter analytics, and MailChimp analytics to inform the following projects as part of an outreach strategy:
 - The re-design and revision of an existing website showcasing a pan-Canadian collaboration (PedPalASCNET) between experts in pediatric palliative care. We have also begun drafting and designing a second website centered around a study titled "Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairments."
 - The re-evaluation of our social media presence, based on user engagement with our monthly citation list email campaigns, titled "Trends in Pediatric Palliative Care Research"
 - A digital library to showcase and make available the latest research in the area of pediatric palliative care, containing the metadata to over 500 carefully selected publications
- Our primary goal has been to communicate and translate the knowledge from our projects in a way which caregivers, clinicians, and researchers can readily understand. A second goal has been to promote and disseminate the knowledge from other researchers' projects. These goals have been enhanced by our ability to promote research via our social media presence and monthly mailing list, and by having a digital library to make pediatric palliative research more accessible and discoverable

AIM

Collect analytics data via Google Analytics, Twitter analytics, and MailChimp analytics, and use them as part of an outreach strategy to inform the design and content of our websites, online library, and social media outreach

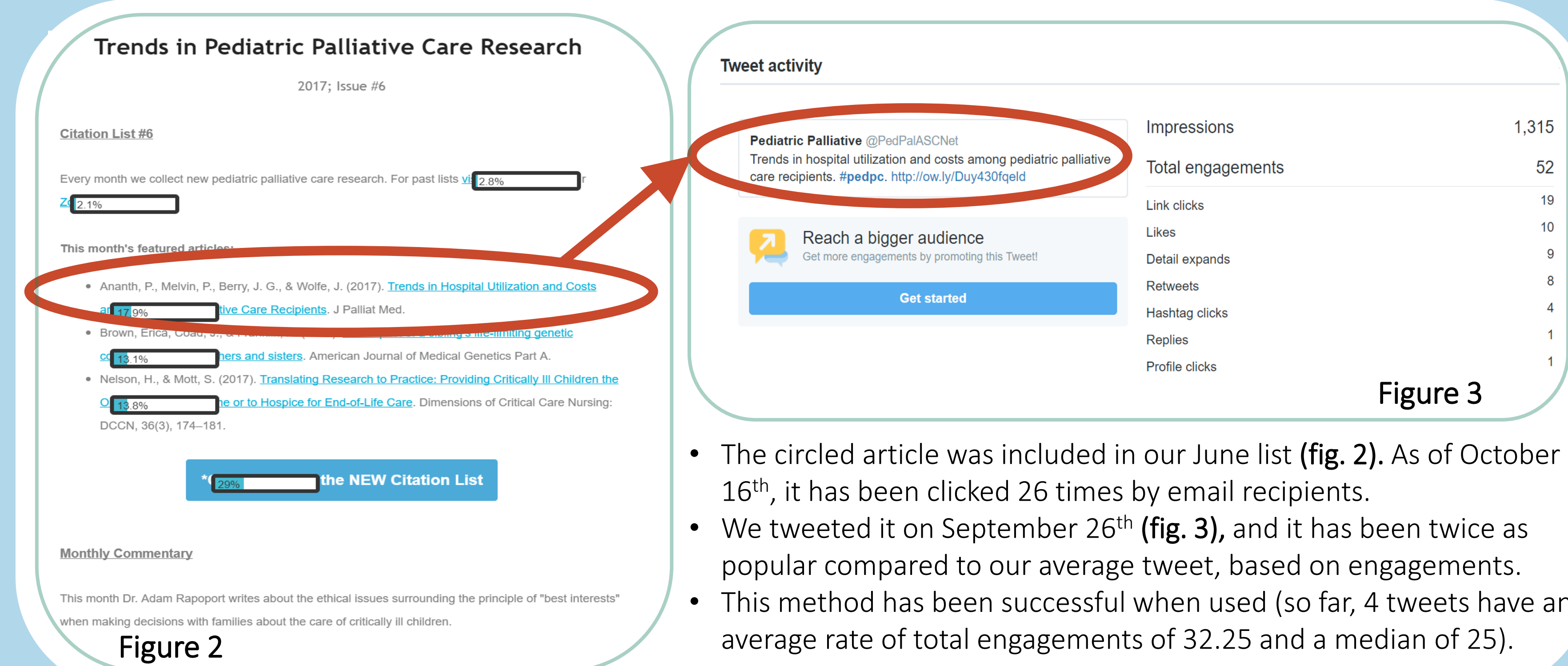
METHODS: GOOGLE ANALYTICS

- Since June 14th we have tracked and paid close attention to the following metrics on PedPalASCNET's website via Google Analytics:
 - Number of page visits, to measure which pages are most popular/unpopular
 - The nations, cities, and service providers of visitors (to clarify, service provider indicates if it's a university, hospital, or private internet network)
 - Bounce rates (percentage of users who do not interact with the page and left the website)
 - Data trends have been visualized in Tableau and the Google Analytics interface (see Fig. 1)



METHODS: MAILCHIMP ANALYTICS

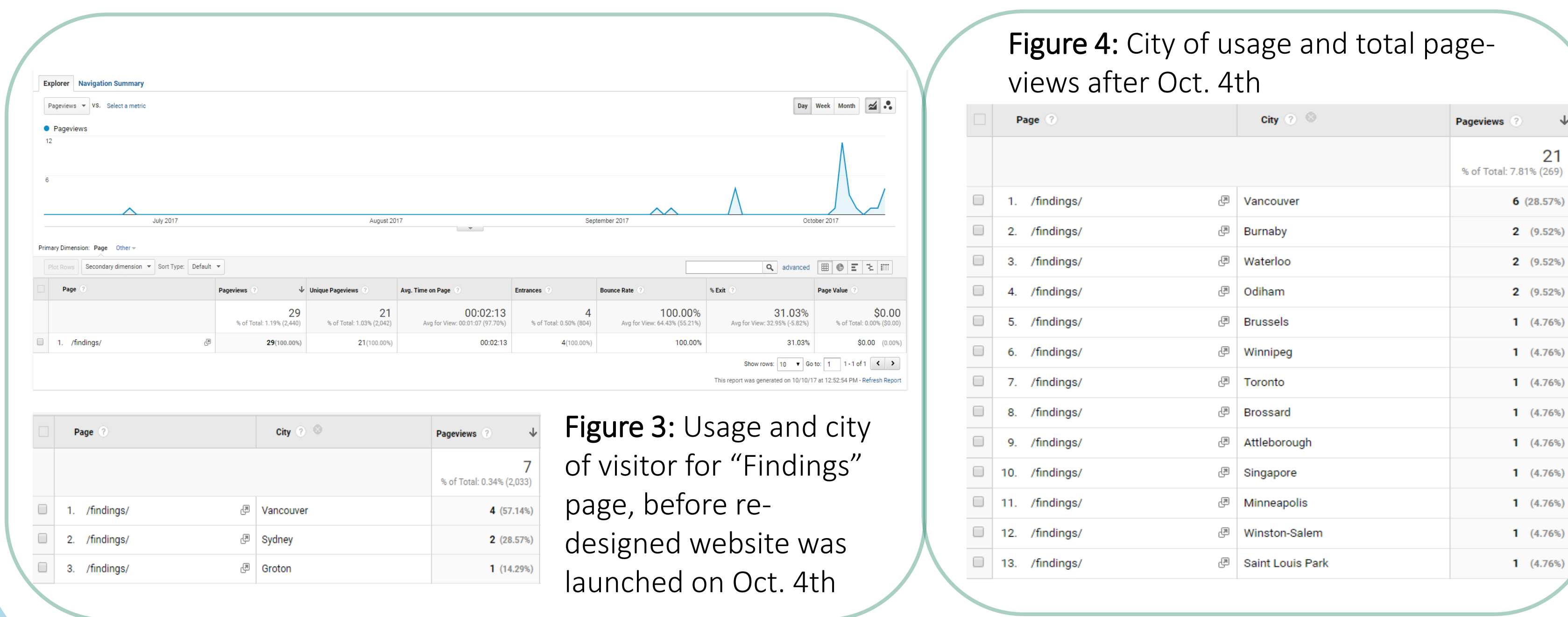
- Since May we have used MailChimp's analytics to track usage of our "Trends in Pediatric Palliative Care Research" (TPPCR) mailing list. Roughly 120 people subscribe to this monthly email which contains a citation list with 30-40 relevant and recently published articles. The average campaign receives over 200 opens and over 100 link clicks
- MailChimp's analytics allows us to better understand what links are being clicked
- Each month we have list subscribers choose between 3-5 articles. This data creates a strong rationale when deciding which articles to tweet to our 710 Twitter followers
- For our June list, the most popular link within the email (fig. 2), produced a highly popular tweet (fig. 3)



RESULTS: GOOGLE ANALYTICS DATA INFORMING WEB-CONTENT

- Major Findings:
 - Webpages for the network's team-members, blog posts, and recent publications were among the most visited
 - Service providers used by visitors seem to suggest a broad user base with researchers from hospitals, universities, and private internet providers all visiting our site regularly
 - We see that there is often a group of returning users and a group of new users
- Based on these findings we implemented the following content:
 - We decided to include more links to member publications and projects on the team page
 - The creation of a "Where to Publish Page" based on trends in our citation list data and publication page visits
 - The "Analysis & Commentary" was placed front and center based on usage, and we made it more visually appealing by inserting thumbnails beside each blog post
 - We tried to improve access to research projects conducted by PedPalASCNET by putting links to the summary "Findings" page and to individual team studies on the homepage. See Fig. 3 and Fig. 4 for more information

PedPalASCNET WEBSITE RE-DESIGN: "FINDINGS PAGE"



GOALS & OUTCOMES: PEDIATRIC PALLIATIVE LIBRARY

- Main Goals:
 - Provide a database that can be used as a tool by researchers, students, and caregivers to find reliable research
 - Avoid having people look through numerous collections, and instead provide the option to search by title or concept
 - Avoid having millions of articles to look through
- Outcomes:
 - Tags are available and create linked connections between metadata elements
 - We created "simple pages" which include links to collections, allowing users to browse by:
 - Publications authored by individual PedPalASCNET team members,
 - Citation list month,
 - Most popular journals of publication in the area of pediatric palliative research
 - The home page contains a plugin which displays a featured item (see Fig. 6). This allows users to come to our home page and see articles which might be of interest to them.

WELCOME TO OUR RESEARCH NETWORK

OUR GOAL
The ultimate goal of PedPalASCNET is to determine, through research, the interventions that are most effective in strengthening positive and mitigating negative outcomes of children with life-threatening conditions and the relative impact on their families. PedPalASCNET links researchers located across Canada, and engages in resource sharing, capacity building and knowledge translation.

ANALYSIS & COMMENTARY
Each month our team selects the most recent research published in the pediatric palliative care community. From these articles we select 1-3 articles to analyze and comment on. We circulate these citations and commentaries through our mailing list.

LATEST PUBLICATIONS
PedPalASCNET team members have published extensively nationally and internationally about pediatric palliative care. Click above to find out more about publications featuring one or more of our team members. Some of the articles are available for free while others are subscription based.

LIBRARY
A pediatric palliative library featuring a searchable database of the files, journals, and authors from every article listed in our monthly Trends in Pediatric Palliative Care citation lists. Also included are the archived commentaries on recent publications of interest. This resource is easily searchable and provides a good overview of current research in pediatric palliative care throughout the world.

PedPalASCNET LIBRARY

Figure 6 (below): Pediatric Palliative Care Library homepage. Notice the "Featured Item" and "Recently Added Items." Both are designed to facilitate easy access and browsing.

PEDIATRIC PALLIATIVE CARE LIBRARY

BROWSE CITATIONS BY...

- PedPalASCNET team member
- Popular pediatric palliative journals
- The TPPCR citation list they were featured in

RECENTLY ADDED ITEMS

Children with life-threatening conditions are denied the support they need, says charity

Children who require palliative care are being treated cheaper or ignored, according to a survey of parents in England by the charity, Nippon...

FEATURED ITEM

Establishment Of Specialized Pediatric Palliative Home Care In The Medical Valley Of The European Metropolitan Area Nuremberg

How holistic nursing can enhance the quality of life of children with cystic fibrosis

Cystic fibrosis (CF) is one of the most common life-threatening genetic conditions. This article presents a case study of a teenager with one of the...

The AAP Resilience in the Face of Grief and Loss Curriculum

Figure 5 (above): Section of PedPalASCNET's homepage. Includes direct link to the digital library (right)

NEXT STEPS & CONCLUSIONS

- Next steps:
 - Google Analytics has been set up as a plugin for the library, and early data is being tracked, as of October 4th. So far we've seen some longer sessions and increased usage after the TPPCR list was sent out.
 - Each month there will be 20-40 new articles added to the library, and we have created a working-group to decide whether or not to broaden the scope in terms of content.
 - We are currently gathering data and testing content for a second website centered around a study titled "Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairments." The study objective is to create new clinical guidelines by evaluating the efficacy of a critical pathway for assessing and managing pain and irritability in children with neurological impairment. This website will be public before the end of the year, and we will interview caregivers to get testimonials on the value of patient oriented research.
- Conclusions:
 - Analytics can be worthwhile to confirm or disprove assumptions when conducting outreach and when promoting knowledge translation.
 - The impact of our research depends on our ability to reach out and convey our process, findings, and their importance to a broad audience. We are learning that a comprehensive outreach strategy includes an understanding on behalf of academics, practitioners, patients, and their families. The power of various web analytics tools enhances this outreach.

RESULTS: CREATION OF PEDIATRIC PALLIATIVE LIBRARY

- Rationale:
 - Through MailChimp we noticed that there was low traffic on the public Zotero library. At the same time we noticed that there was significant attention to certain citations within the list and on the website's pages listing team-member publications.
 - This led us to believe that if we created a more accessible and searchable version of the citation library that we might get more traffic and improve our dissemination of these hard-to-find publications.
- We created a digital library in Omeka (for free), and registered it under pedpalascnetlibrary.omeka.net
- Metadata (subject headings, abstract, rights, DOI's, creators, publishers, etc.) were pulled from our Zotero library as .csv's and imported through an Omeka plugin.