Dr. Shelagh K Genuis, a Research Associate in the Division of Neurology at the University of Alberta, has a background in information science, health communication, rehabilitation medicine, and qualitative methodologies, including community-based participatory research. She works on a patient-oriented health communication research team focusing on people affected by Amyotrophic Lateral Sclerosis. She has used NVivo since 2008 and initiated work with itracks when leading the ALS Talk Project.

Dr. Shelagh K Genuis
Research Associate
Division of Neurology
University of Alberta

Westerly Luth (MSc) is a research associate in the Division of Neurology at the University of Alberta with a background in mixed methods research paradigms and the intersection of digital practices and everyday life. She works on a patient-oriented health communication research team focusing on people affected by Amyotrophic Lateral Sclerosis. She has used NVivo since 2012 for text, audio, and video analysis.

Westerly Luth, MSc.
Research Associate
Department of Neurology
University of Alberta

Leon Bourner An award-winning client development professional, Leon has spent the past three years as Director, Sales and Client Development at itracks. In this time, he has helped hundreds of clients realize their qualitative research goals using dedicated online focus group, interview, and discussion board solutions. His and his team's reception and translation of client feedback is a direct contributor to feature updates and the overall evolution of itracks solutions.

Leon Bourner
Director of Sales and Client Development
itracks

Dr. Stacy Penna has combined her educational and research experience with her work in the software industry and is delighted to be supporting and building a wider research community. Stacy earned a doctorate in education using NVivo for both her literature review and qualitative research. She has worked at QSR International, now Lumivero for 10 years and is excited for the future of research.

Dr. Stacy Penna
Customer Engagement and Enablement Director
Lumivero

The ALS Talk Project:
Asynchronous online focus groups for research with people affected by amyotrophic lateral sclerosis

Shelagh K Genuis, Westerly Luth

Health Communication Research Team (Dr. Wendy Johnston)

Division of Neurology, Faculty of Medicine and Dentistry

University of Alberta, Canada

May 16, 2023

Outline

The ALS Talk Project

Background & Objectives → **Methods** itracks NVivo → **Results** Focus on methodology

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Background

Improved clinical care

Associated with clear and frequent communication with people with ALS and families

Research gap

Guidance for health communication throughout the ALS disease course

Published Communication Guidance

Focuses on ALS diagnosis disclosure

Consensus-based guidance

Recommends regular discussion of life-sustaining therapies and end of life

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Objectives

- Gather data from a national sample of people living with ALS (PwALS) and family caregivers

- Develop patient-centred, empirical evidence to inform effective health communication practices throughout the ALS disease course

- Explore innovative methods for engaging PwALS and caregivers in research

METHODS

Rationale: Asynchronous, online focus groups
(AOFGs)

- **Safe environment:** investigation of personal and/or sensitive topics

- **Rich data:** individual expression, reflection on others' experiences, discussion of shared and different perspectives

- **Participation at one's personal convenience** (time and place)

- **Reduce participation barriers**
  - Physical disability
  - Functional communication challenges
  - Alleviate immediacy and response speed demands
  - Geographically distant/travel is burdensome
  - Time constrained (e.g. medical appointments, caregiving responsibilities)

Recruitment

- Recruited in 4 regions via multidisciplinary ALS clinics, ALS Societies, disease registry (CNDR)
- 7 focus groups
  - 4 PwALS groups
  - 3 Caregiver groups
  - n = 100

British Columbia

Alberta

Ontario

Eastern Canada

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Technology

- itracks Board^{TM} platform
    - Met institutional ethics requirements (anonymity, data storage etc.)
    - Accommodated a range of response options (text, audio, or video)
    - Open- (qualitative) and closed-ended (quantitative) question options
    - Allowed multiple, separate AOFGs within same platform; moderator control to post questions separately for each group
    - Individual and group notifications
    - Accommodated a range of devices
    - Captured data for duration of project
    - Automatically generated transcripts and recordings of audio/video data
    - Supported researchers at all stages, e.g. setting up and managing platform

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Research design: Discussion topics

Topic #	Weeks	Topic description
1		Register, 'welcome to the focus group', introductions
2	1 - 2	Communication around the time of ALS Diagnosis
3	3 - 4	Talking about ALS changes
4	5 - 6	Seeking information outside the health care system
5	7 - 8	Research participation; complementary and alternative therapies
6	9 - 10	Planning for future medical care
7	11 - 12	Conversations about death & dying
8	13 - 14	Improving ALS communication and support
Optional	15- 16	Participation in observational research and data sharing
Optional	Concurrent*	Covid-19 discussion

*Posted Mar 21/20 (AB, ON) and April 3/20 (BC, QC/NB/NS). Discussion of Covid-19 also occurred within other discussion topics

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Research design (con't)

- Topics posted bi-weekly; new questions posted weekly (Tuesday a.m.)

- Questions posted in separate discussion 'threads'

- 'Uninfluenced' mode

- Open-ended and closed-ended questions
  - Primarily open-ended, no word restrictions
  - Multiple-choice, survey questions, and ranking exercises (n=9)
  - Summarizing lists to prioritize and make revisions as desired (n=2)

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Moderating a long-term AOFG

Group management

- Early relationship building, e.g. recruitment, on-boarding

- Weekly notifications from itracks platform, e.g. newly posted questions

- Individual reminders/correspondence as needed (email)

- Privacy mode available

Day-to-day discussion management

- Moderator: active 'presence' with a frequent, consistent pattern of interaction

- Respond to all posts (acknowledge or probe)

- Probing: encourage further input, clarify meaning, encourage group interaction

- Soft skills important, develop rapport

Analysis
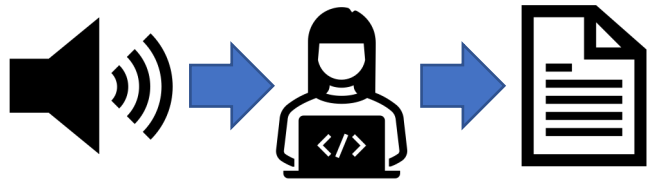
Quantitative data
- Descriptive statistics (itracks & NVivo)
- NVivo matrix coding queries

Qualitative data
- Content analysis and constant-comparative approach
- Kappa scores calculated for intercoder reliability (NVivo)

Analysis (con't)

1. Initial analysis: Data coded into broad nodes.

2. Code books: Line-by-line reading within broad nodes by experienced coder; code books collaboratively developed and verified

3. Coders trained; themes & definitions in codebook refined as needed

4. Intercoder agreement: Kappa coefficients calculated using NVivo 12™ analytics

5. Quantitative data
   - Descriptive statistics (itracks & NVivo), e.g. summarize participant characteristics
   - Matrix coding query (NVivo), e.g. identified discussion threads where Covid 19 data posted.
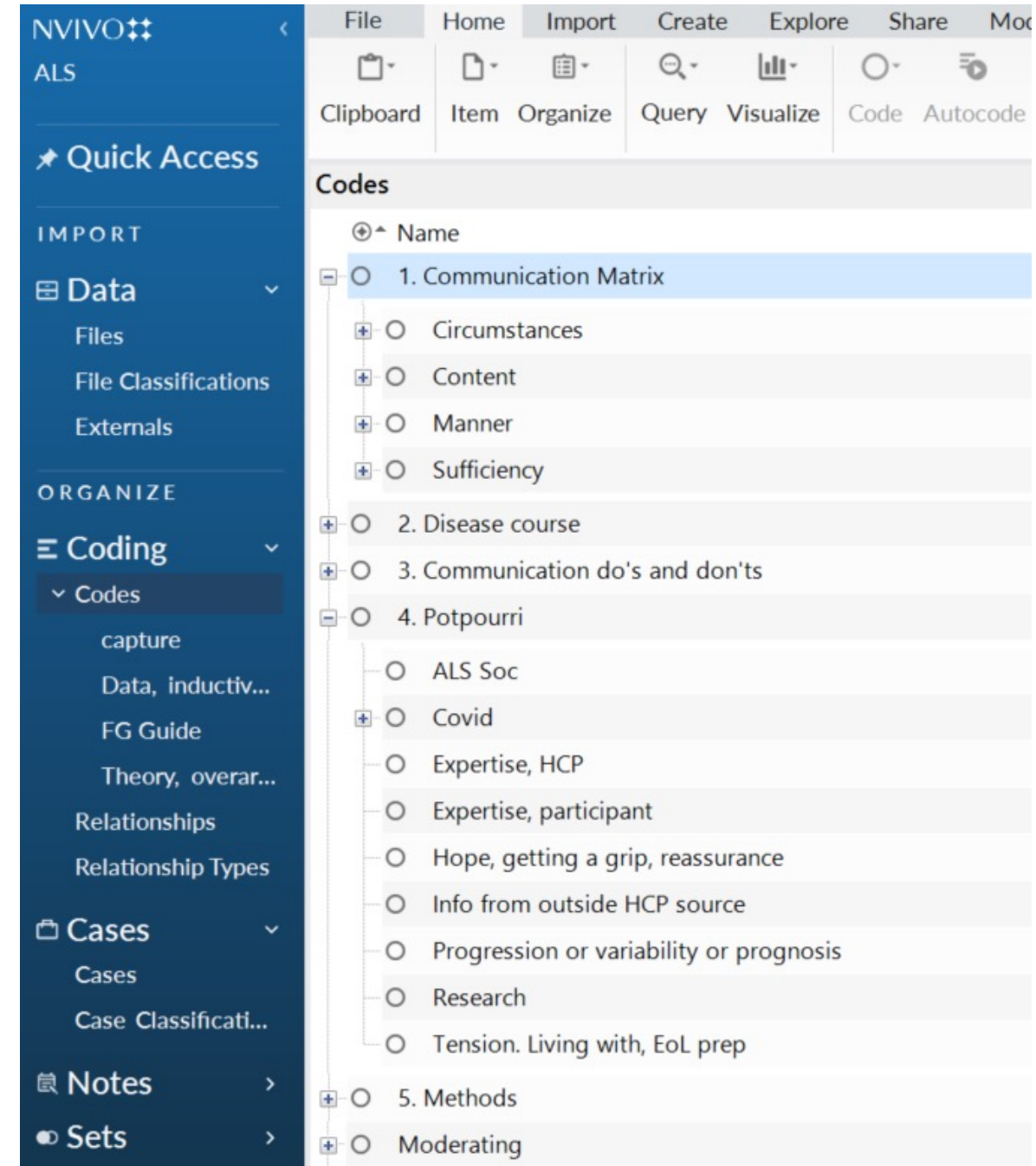
Data to publication

- What do people affected by amyotrophic lateral sclerosis want from health communications? Evidence from the ALS Talk Project *(under review)*

- Amyotrophic lateral sclerosis (ALS) health charities are central to ALS care: perspectives of Canadians affected by ALS. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2022.*

- Covid-19 threat and coping: application of protection motivation theory to the pandemic experiences of people affected by amyotrophic lateral sclerosis. *BMC Neurology,* 2022.

- Asynchronous online focus groups for research with people living with amyotrophic lateral sclerosis and family caregivers: A methodological investigation of feasibility and effectiveness *(under review)*
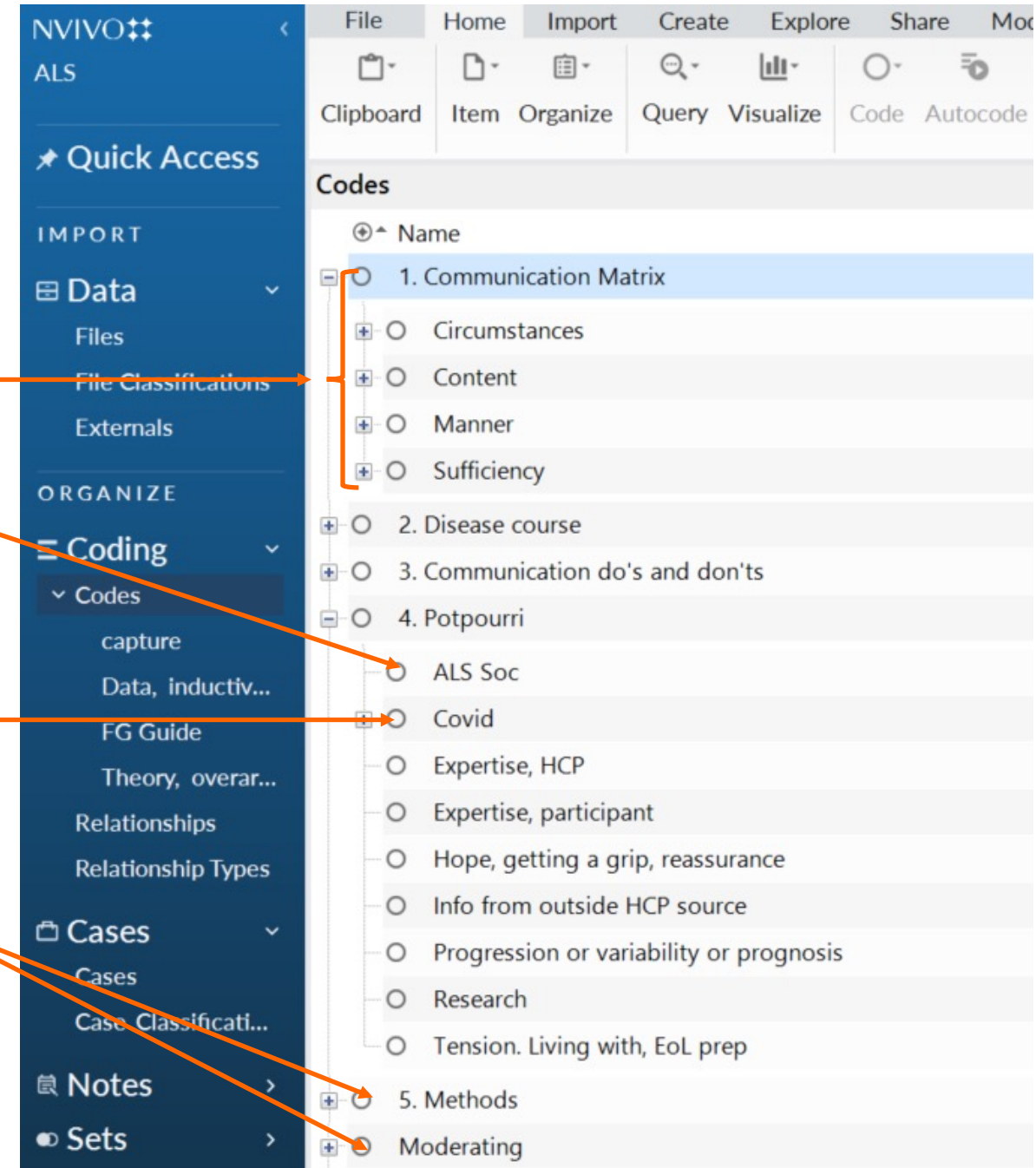
RESULTS
Focus on methodology

Participant characteristics

Participant Characteristics		People with ALS (n=51)		Caregivers (n=49)		Total (n=100*)
Gender	Female	19	37%	38	78%	57
	Male	31	61%	8	16%	39
	Unassigned	1	2%	3	6%	4
Province	Alberta	15	29%	17	35%	32
	British Columbia	10	20%	16	33%	26
	Ontario	17	33%	16	33%	33
	Quebec, New Brunswick, Nova Scotia	9	18%		0%	9
Age	18-29		0%	3	6%	3
	30-39	1	2%	3	6%	4
	40-49	4	8%	10	20%	14
	50-59	10	20%	15	31%	25
	60-69	21	41%	10	20%	31
	70+	14	27%	5	10%	19
	Unassigned	1	2%	3	6%	4

*Completed introduction on itracks™ platform

Technology

- Primarily used text modalities

- Some participants reported using eye-gaze and/or other assistive technologies

- Participants tended to contact research team for technical support

- Onboarding challenges, primarily navigating mobile app and personal devices

- Reported challenges: 'losing' messages before posted, difficulties with tablet app, scrolling long discussions, navigating between questions and topics.

Figure withheld

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Engagement within AOFGs

- Data set: 3646 participant posts >1 word long = 406220 words

- Mean post length=111.48 words (SD=11.47)

Figure withheld

- 1041 threads contained interactive posts between participant and moderators, and/or other participants

- 523 threads consisted of participant response without further interaction

- Threads varied from single responses to 12-post threads

Figure withheld

Participant experience, methodology

[The moderators'] comments tell me you have read and heard my input...the clarifying questions coming back to me stimulate me to think more.

I found the study a little bit too long, with some of the topics a bit overlapping.

- Moderator role
- Peer interaction
- Flexibility
- Study duration
- Technology

[The focus group] was long, but it allowed for continuity and a sense of membership.

Seeing other participant's responses and sometimes getting a bit of conversation going was a nice difference from other studies that were simply questionnaire or interview based.

I like the format of this focus group. The pressure of immediate response can affect the way I interact.

It was simple to navigate, even for a computer dinosaur like me.

The platform was difficult for me because I use an eye gaze computer. It's low resolution so that meant a lot of scrolling left and right. Plus, selecting questions could be difficult because of the precision required.

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Lessons learned (selected!)

- **AOFG platform**
  - Platform that meets research needs & objectives is critical

- **Fostering participant engagement**
  - Prolonged recruitment phase associated with attrition
  - Moderating: key to establish 'presence' within groups
  - Huge time investment (consider HR and budget implications)
  - 10 weeks may be maximum recommended duration for this population

- **Real world flexibility - adaptations in response external and internal events**
  Examples:
  - Covid 19 lockdowns
  - Patient input on a research proposal

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Acknowledgments

- We are deeply grateful for the rich contributions of our study participants.

- Thank-you to the ALS Talk Project collaborators who assisted with study recruitment.

- Funding was provided by the James and Jeanie Brown ALS Research Fund.

itracks GO

Everything you need, together

Sign into GO and access all itracks projects and activities, regardless of type.

Better project management

Manage participants and observers, discussion guides, media and communications efficiently, saving you time.
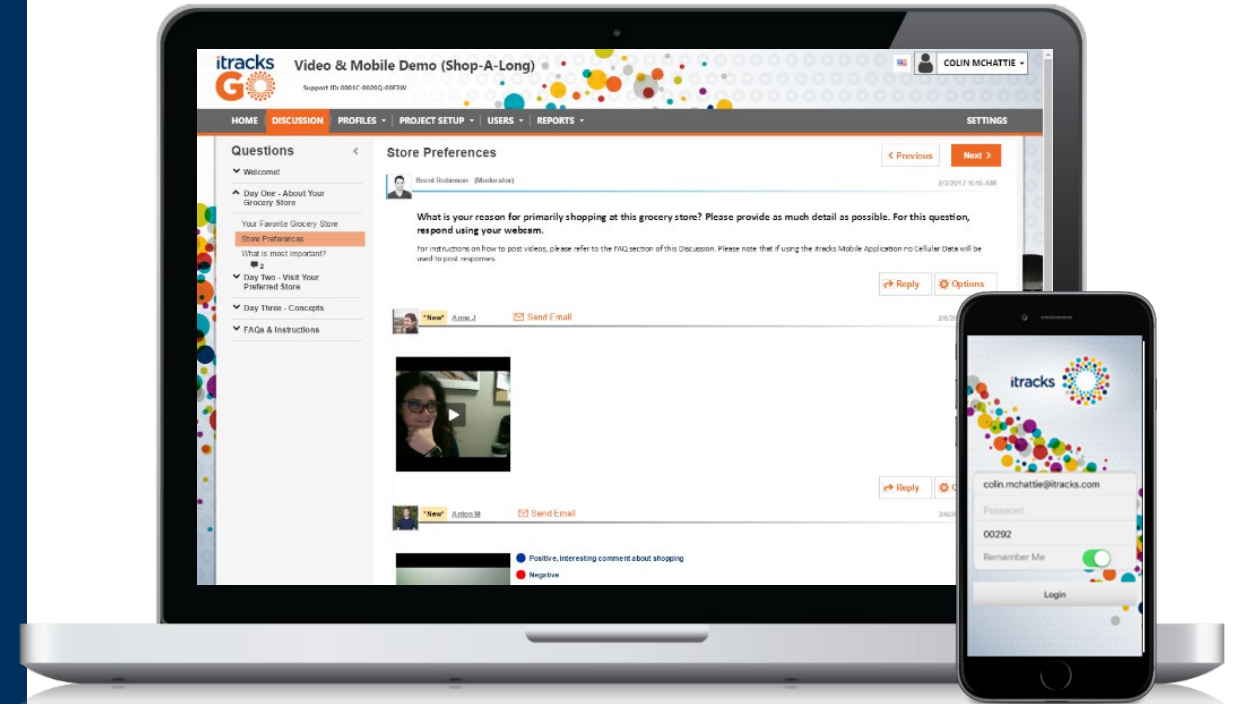
Safe and secure

All of your research data is safe within GO. Dictate who has access and authority in each project for further security. GDPR and HIPAA compliant.
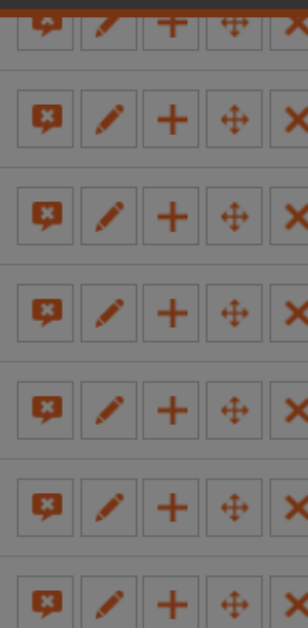
itracks Board

itracks Board provides a platform for asynchronous online discussion boards or focused community projects. Manage small groups or hundreds of participants to engage in depth on research topics.

- Capture responses from anywhere as they happen
- Text, audio or video responses
- Use "uninfluenced question" mode to encourage honesty, hiding group responses until respondents have completed a response
- Flexibility for respondents and researchers
- Difficult-to-reach segments become easier to attain
- Studies happen over days, weeks or years
- Participants and moderators can access via mobile app
- Conduct media markup exercises and generate heatmaps within all your Realtime activities with iMarkIt Pro.

itracks Board

ADD QUESTION   ✕

▾ Question 3: Chat GPT

▾ Question 3b: Chat GPT

▾ Question 4: Chat GPT

▾ Recent News/videos

🖉 Design   ◇ HTML

▾ Influence in the future

▲ Whiteboard

▾ Open Discussion

Select Media   Inherited From Project   ▾

▾ iMarkit

▦ **Add Poll**

▲ Response Details

Question Response   Text   ▾   Required   ▾

Question Mode   Uninfluenced   ▾

Regular

▾ Question Details   Uninfluenced

Interview

Back To Top

▾ Group Options

Questions ‹

All Groups ▾

⌃ Chat GPT

Welcome

Introductions
💬 5

Question 1: Impressions of AI
💬 6

Question 2a: AI usage

Question 2b: AI usage
💬 6

Question 2c: AI usage
💬 6

Question 3: Chat GPT
💬 6

Question 3b: Chat GPT
💬 7

Question 4: Chat GPT
💬 9

Recent News/videos
💬 9

Influence in the future
💬 10

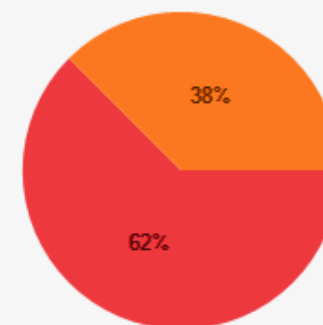Open Discussion
💬 7

iMarkit

Question 2a: AI usage

‹ Previous   Next ›

Dan Weber
Moderator   4/13/2023 11:07 AM

Have you used Artificial Intelligence in the past 7 days?

(10/16 - 62%)   ○ Yes
(6/16 - 38%)   ○ No

38%

62%

⬇ **Download Chart**

⚙ **Options**

Leon   (Age:36-45, Employed:full-ti ...) 📄 View User Transcript •••   2/8/2023 3:44 PM

● ◉ Yes

Questions ‹

All Groups ▾

∧ Chat GPT

Welcome

Introductions
💬 5

Question 1: Impressions of AI
💬 6

Question 2a: AI usage

Question 2b: AI usage
💬 6

Question 2c: AI usage
💬 6

Question 3: Chat GPT
💬 6

Question 3b: Chat GPT
💬 7

Question 4: Chat GPT
💬 9

Recent News/videos

Influence in the future
💬 10

Open Discussion

iMarkit

Recent News/videos

[‹ Previous]   [Next ›]

Dan Weber
Moderator

2/9/2023 1:40 PM

It seems there is more information about AI coming each and every day with many people expressing different opinions. Please upload any links, articles, videos or images that you have seen recently or have found interesting. I will start.

Which Sectors Are Working With OpenAI?

Number of companies/organizations using Open AI in their business processes worldwide, by sector* (as of Jan. 2023)

251 Technology

209 Education

98 Business services

89 Manufacturing
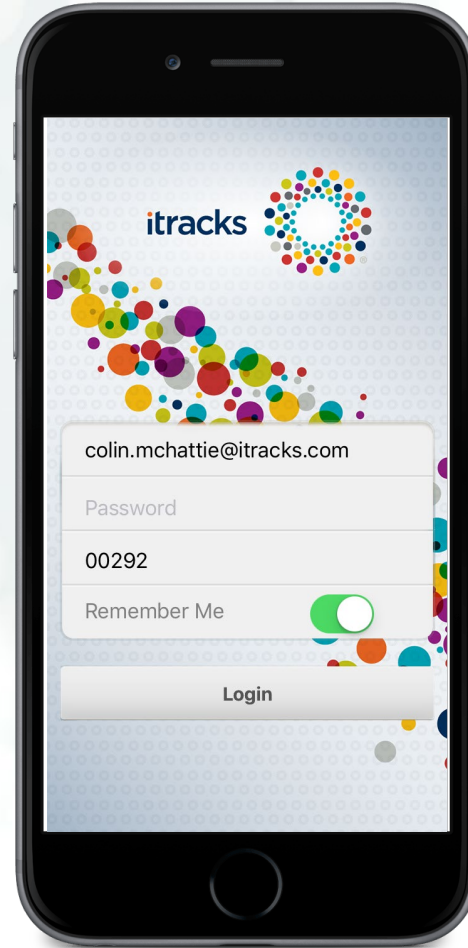
Total
902

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Real-Time Probing

Mobile qualitative research app that allows researchers to probe participants in real-time.

itracks

colin.mchattie@itracks.com

Password

00292

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With dedicated Board and Realtime apps, users are able to participate in discussion boards, interviews and focus groups using their mobile phones, for the ultimate in accessibility.
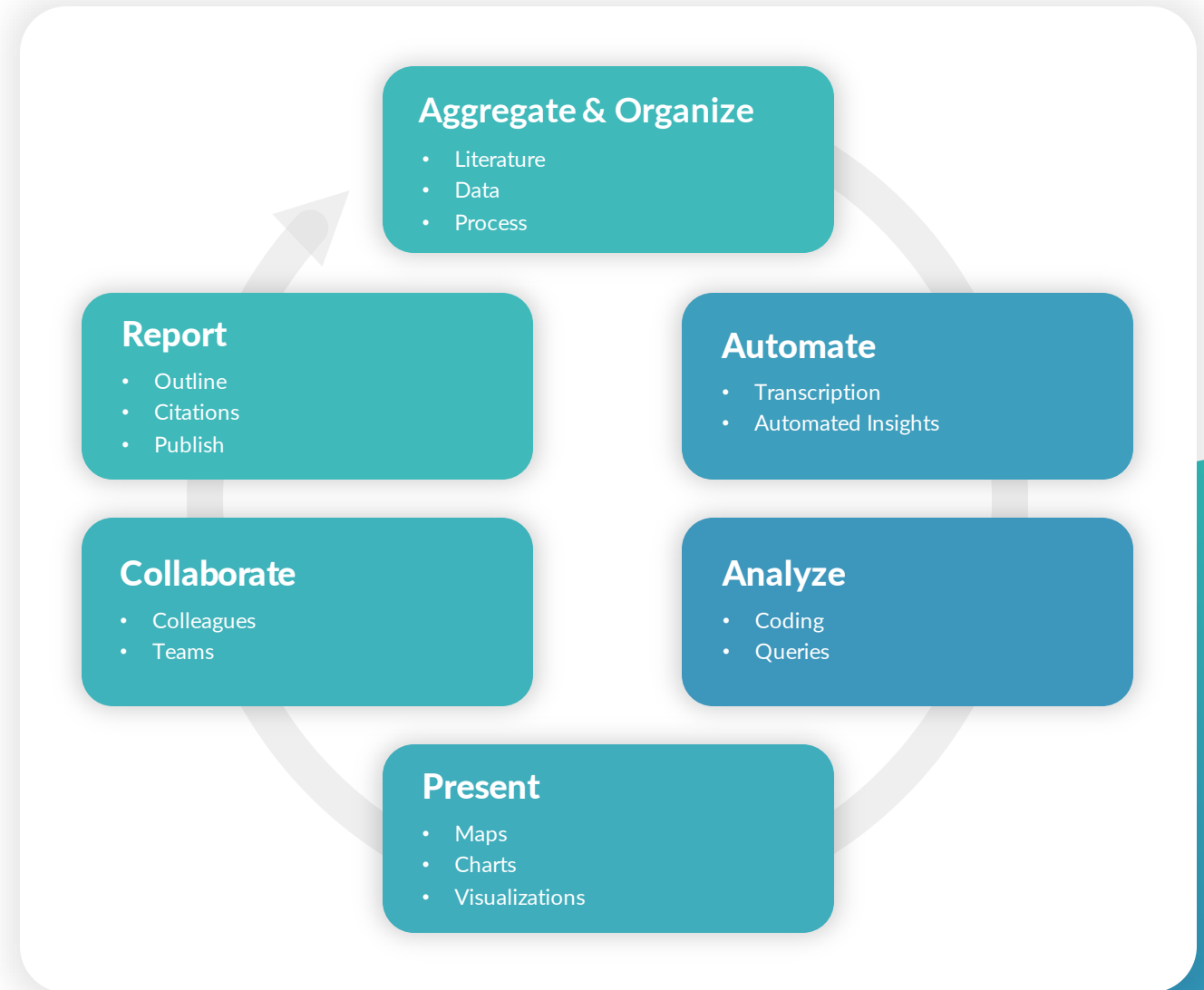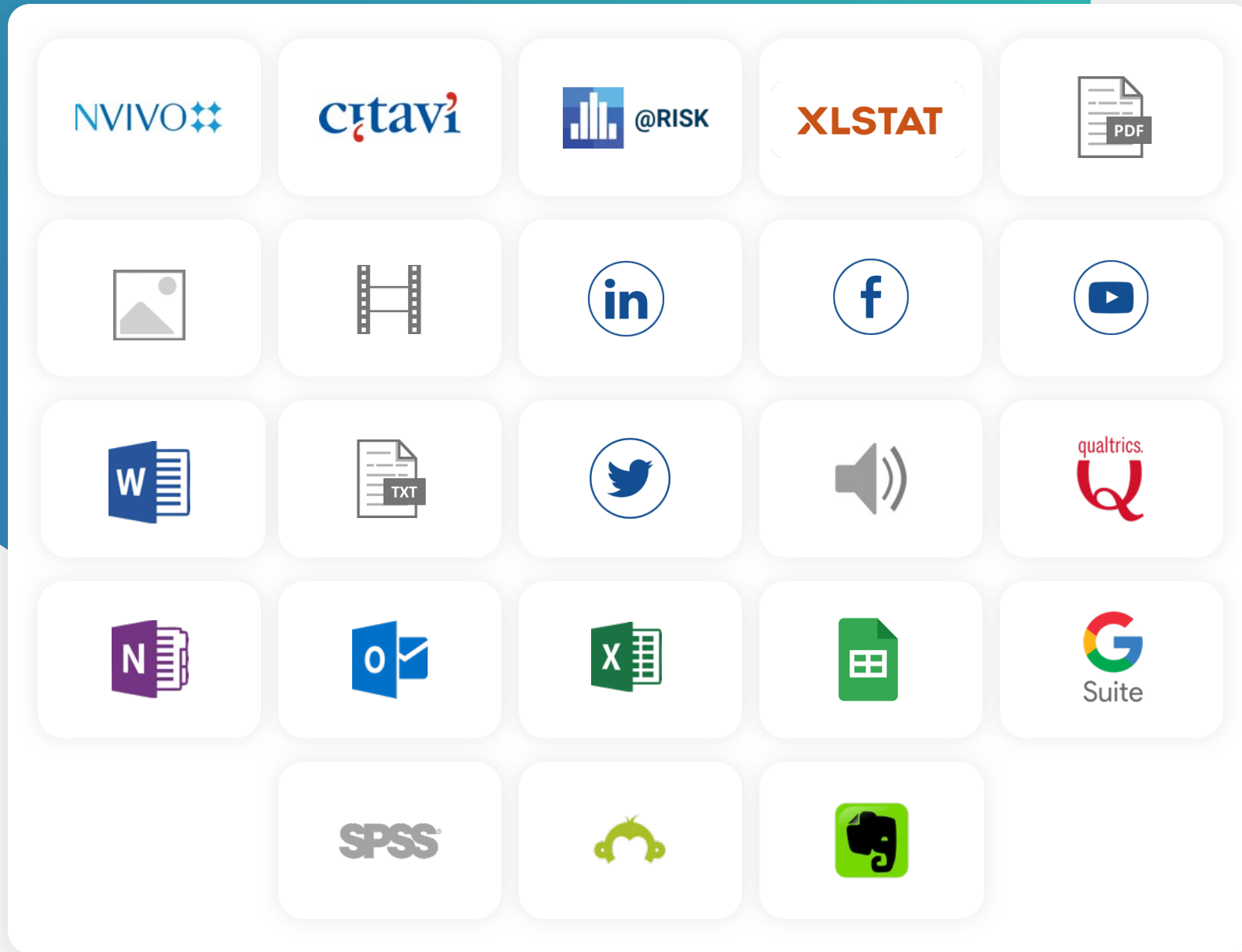
itracks Board

Reporting

itracks Board offers extensive reporting options including:

- Word doc transcripts, Excel Response Grid, and TXT Format transcripts
- Ability to filter by participant, user type, question(s), post(s), deleted and private posts
- Completion reports by user
- Participation statistics
- Media and graphs
- All available immediately or as your study progresses for easy upload to NVivo
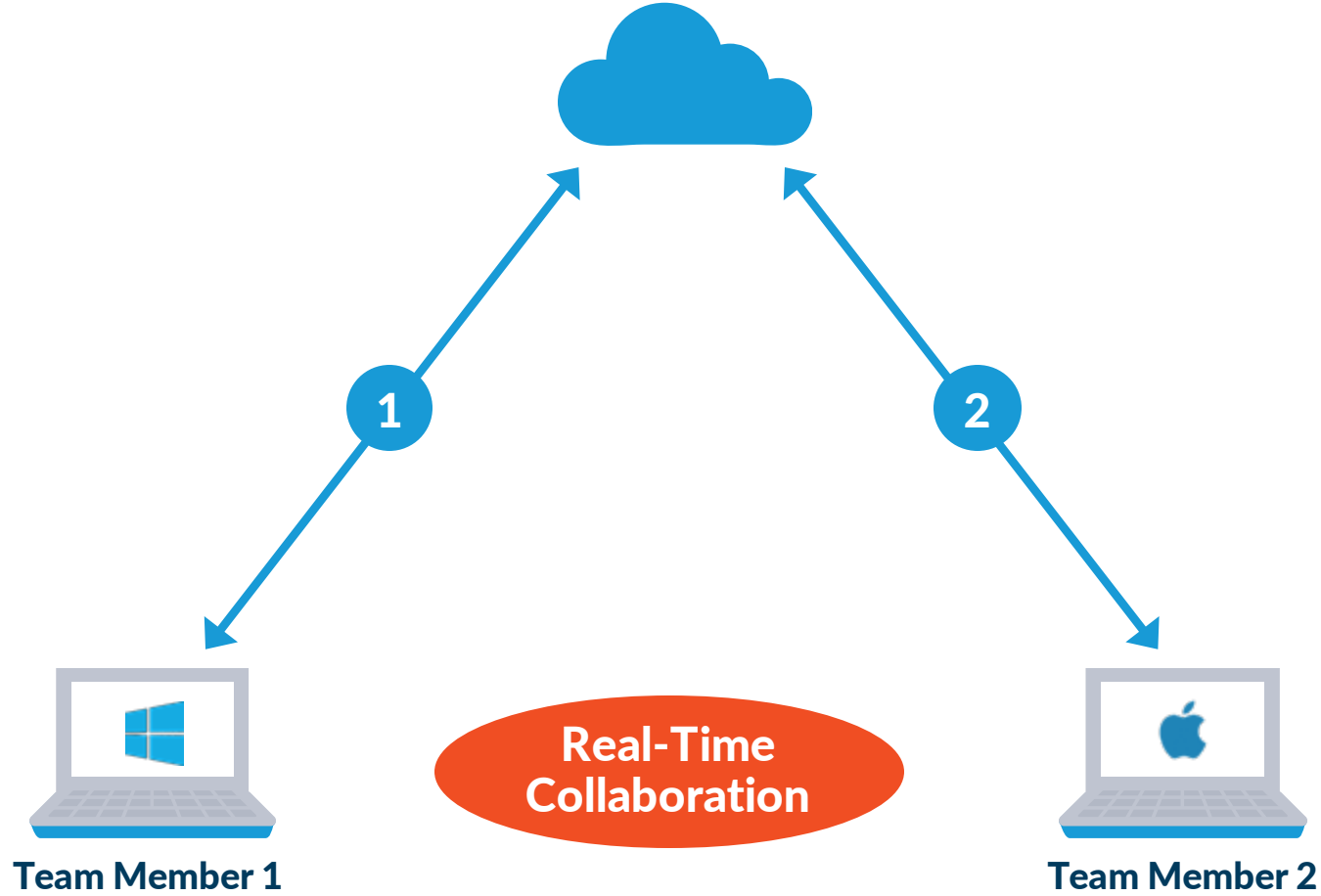
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- Podcast: Between the Data
- Lumivero Virtual Conference 2023

Connect

- Product User Group Meetings
- Research Online Groups

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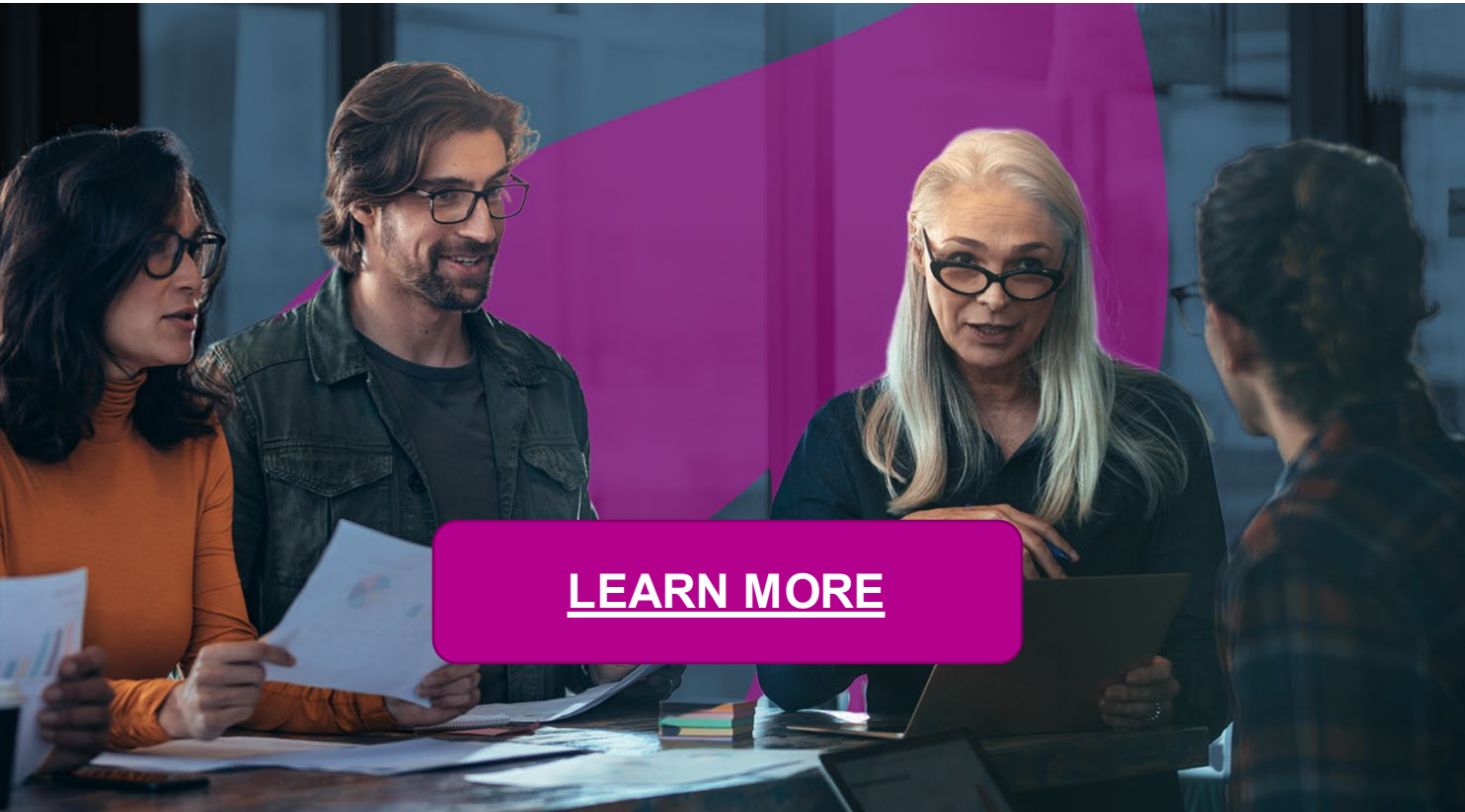
- Early Career Researcher Grant - 2024

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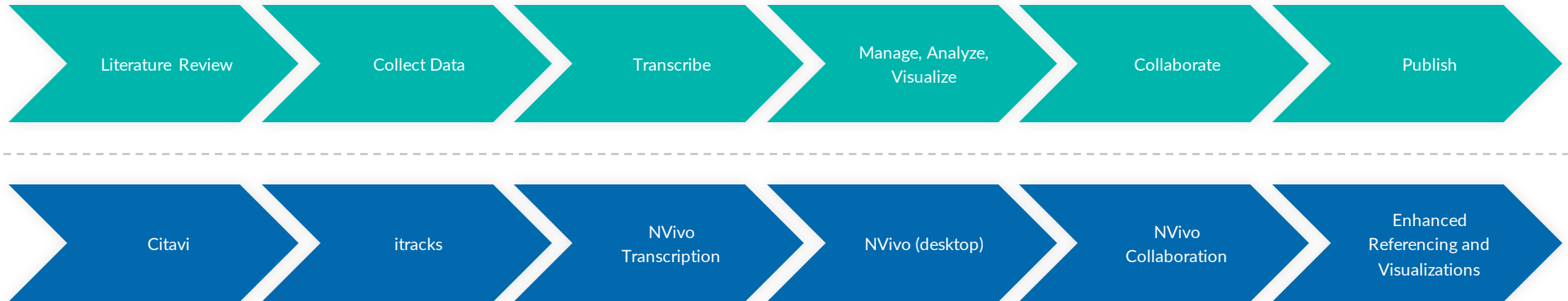
The focus of the call for presentations is on the impact of data analysis methods and student placement management. We welcome presentation proposals exploring, but not limited to:

- Statistical Methods and Applications
- Qualitative Research Methods
- Mixed Methods
- Risk Management
- Collaboration
- Student Placement and Work Integrated Learning
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