



DATA PRIVACY AND SECURITY FOR AAC MARCH 30TH, 2021 — 11:00 AM TO 1:00 PM EASTERN (TORONTO) TIME

MODERATOR: TRACY SHEPHERD, ISAAC PRESIDENT-ELECT

PANELISTS: RUSSELL CROSS, PRC-SALTILLO

MELANIE FRIED-OKEN, OREGON HEALTH & SCIENCE UNIVERSITY

DAVE HERSHBERGER, PRC-SALTILLO

FIL MCINTYRE, TECHABILITY

DAVID NIEMEIJER, ASSISTIVWARE

ALYSSA HILLARY ZISK, UNIVERSITY OF RHODE ISLAND



WEBINAR AND PANEL DISCUSSION LOGISTICS



- All attendee microphones and cameras are muted.
- Attendee chat function is disabled.
- Attendees can type questions into the Zoom user interface “Question” pane at any time during the formal presentations.
- The agenda for today’s webinar and panel discussion is as follows ...



AGENDA



1. Introductions (Franklin Smith and Tracy Shepherd) – 10 min.
2. Individual Expert Panel Presentations (10 minutes each, in panelist surname alphabetical order) – 60 min.
 - a. Russell Cross
 - b. Melanie Fried-Oken
 - c. Dave Hershberger
 - d. Fil McIntyre
 - e. David Niemeijer
 - f. Alyssa Hillary Zisk
3. Questions and Panel Discussion (Moderator plus Full Panel) – 40 min.
4. Prize Draw and Wrap-Up (Franklin Smith and Tracy Shepherd) – 10 min



PANELIST PRESENTATIONS



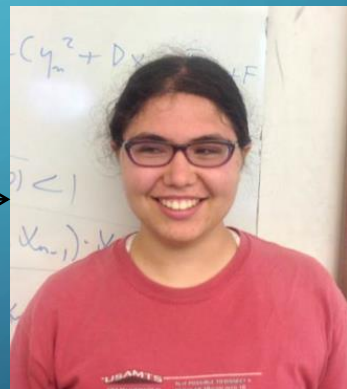
Russell Cross



Dave Hershberger



David Niemeijer



Alyssa Hillary Zisk



Melanie Fried-Oken



Fil McIntyre





PANELIST PRESENTATIONS



Russell Cross

Data Privacy and Security for AAC

- ▶ ISAAC International webinar and panel discussion: 30 March, 2010



Russell T. Cross
Language Systems Product Manager
PRC-Salttillo
russell.cross@prc-Salttillo.com

The Importance of Assessment (1)

- ▶ ASHA's *Preferred Practice Patterns for the Profession of Speech-Language Pathology* indicates that a comprehensive speech-language pathology assessment includes these components:
 - ▶ Standardized and/or non-standardized measures of specific aspects of speech, spoken and non-spoken language, cognitive-communication, and swallowing function, including observations and analysis of work samples
 - ▶ Identification of potential for effective intervention strategies and compensations
 - ▶ Follow-up services to monitor communication and swallowing status and ensure appropriate intervention and support for individuals with identified speech, language, cognitive-communication, and/or swallowing disorders

Preferred Practice Patterns for the Profession of Speech-Language Pathology; ASHA (p.27)

The Importance of Assessment (2)

- ▶ The UK's Health & Care Professions Council (HCPC) *Standards of Proficiency for Speech and Language Therapists* says that clinicians should:
 - ▶ be able to gather appropriate information
 - ▶ be able to undertake and record a thorough, sensitive and detailed assessment, using appropriate techniques and equipment
 - ▶ be able to administer, record, score and interpret a range of published and self-generated assessment tools to describe and analyse service users' abilities and needs using, where appropriate, phonetic transcription, linguistic analysis, instrumental analysis and psycholinguistic assessment

The Standards of Proficiency for Speech and Language Therapists;
HCPC

Informed Consent

- ▶ May be verbal, unless written consent is required; constitutes consent by persons served, research participants engaged, or parents and/or guardians of persons served to a proposed course of action after the communication of adequate information regarding expected outcomes and potential risks.

Confidentiality

- Individuals shall protect the confidentiality of any professional or personal information about persons served professionally or participants involved in research and scholarly activities and may disclose confidential information only when doing so is necessary to protect the welfare of the person or of the community, is legally authorized, or is otherwise required by law.

So Why Collect Language Data? (1)

- ▶ “Language sample analysis (LSA) is like flossing your teeth: it’s something we all know we should do, but the majority of us neglect to do so on a regular basis. And, those that are flossing regularly may not be doing it correctly; are you sliding the floss up and down each tooth? While there is overwhelming support from clinical texts, journal articles, and our national organization for the use of LSA in clinical practice, the reality is that many clinicians do not use it consistently.” (p.4)

Heilmann (2010). Myths and Realities of Language Sample Analysis. *Perspectives on Language Learning and Education*, 17(1), 4-8.

So Why Collect Language Data? (2)

- ▶ For any child receiving speech-language therapy services, ongoing assessment is essential for;
 - ▶ Progress monitoring
 - ▶ Responses to intervention
 - ▶ Treatment planning

Van Tatenhove, G. (2014). Issues in Language Sample Collection and Analysis With Children Using AAC. *SIG 12 Perspectives on Augmentative and Alternative Communication*, 23(2), 65-74.

How Can We Collect Data?

- Data collection for language analysis is as old as the profession of Speech-Language pathology itself;
 - Pen and paper
 - Cassette tapes
 - Video tapes
 - Digital recorders
 - Smartphones
 - AAC devices – optional feature

What Actions Can We Take?

- ▶ The nature of Data Security and Privacy are not static: changes in attitudes, technology, and legal expectations are always in flux. There are four areas in which the AAC Community can work towards improving data security and privacy issues:
 - ▶ 1. Education aimed at AAC professionals in the field and how they can improve their practice
 - ▶ 2. Education for the general community raising awareness about privacy and security for PWUAAC
 - ▶ 3. Improvements in technology to further enhance data security
 - ▶ 4. Adherence to legal standards and lobbying activities to create new ones where needed



PANELIST PRESENTATIONS



Melanie Fried-Oken

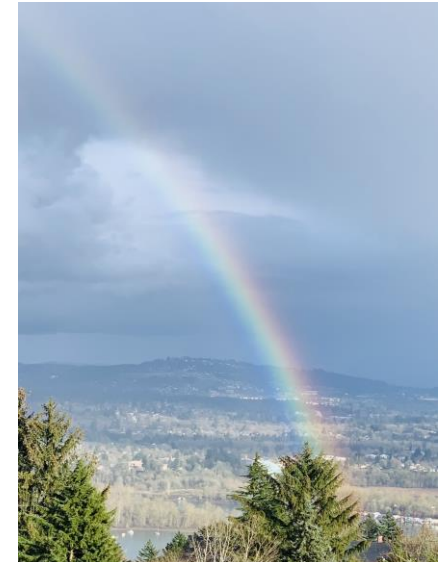


Data privacy and security in AAC: The clinical and research perspective



Melanie Fried-Oken
AAC Clinician & Researcher
Oregon Health & Science University
Portland, OR USA

Supported by NIH Grant #R01DE009834



Three points to discuss quickly

1. Need for and challenges of an AAC large word database
2. Privacy concerns expressed by potential end users
3. My clinician's view



#1: Large AAC databases



We need to build AAC large word databases that include the words and phrases used by people who rely on AAC devices. While a personalized lexicon can be built over time for a single device, the current databases for word prediction and increased speed of production do not adequately represent the end users or their lexica.

Will creating a large word database infringe on individual privacy?

#1: Current large databases



- Language sources for AAC devices are based on very large databases: Switchboard; This American Life; Enron emails; New York Times articles.
- Their words and phrases rely on the language from
 - *limited population groups* (highly educated, professional, literate)
 - language for *particular contexts* (work, news, culture and arts).
- Algorithms that take these databases as a starting point *privilege certain kinds of communication and potentially neglect others*.
 - Slang or personal terms may be auto-corrected to formal language.

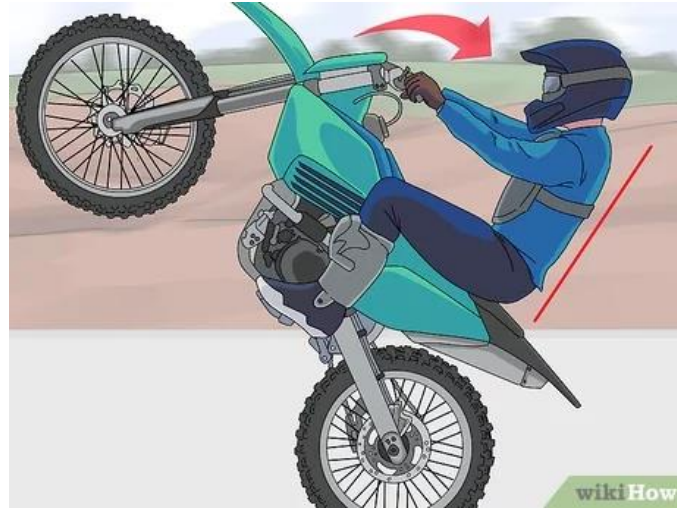


The choice of database could produce language predictions that do not represent individuals from certain groups, especially those with complex comm. needs or end users with limited or developing literacy skills.

The lexica used within AAC devices may contain words and phrases that are *not commonly present* in current very large databases.

Consider: Language Models are not bias-free

- The *wheelie*



- The ESL family who supports a daughter using an English AAC device with word prediction: Whose language is being predicted? How well are her partners understanding her messages?



BUT: The challenges for AAC databases

If we do start collecting large word databases from people who rely on AAC, how do we maintain their privacy and still increase frequency of lexicon-specific items?

How do we influence the bi-directional vocabulary needs for both speaker and listener in an AAC database?

#2: Privacy concerns from potential end-users



We asked:

What are some ethical issues involved in building personalized language models?

Would you like your vocabulary stored in your AAC device?



What is the study?

- We presented hypothetical value-based vignettes to
- 15 people in qualitative semi-structured interviews
- 50 people through online surveys
- Participants experienced a neurodegenerative disease and may choose an AAC-BCI communication system in the future
- Dx: ALS, PLS, MS, PD, PD+
- All were shown videos of a person using BCIs for communication
- A few participants already used an AAC device



Hypothetical value-based scenario

Asking your daughter, When are you having D..I..

Dinner

Divorce



Just a Taste[®]

- Responses to 4 questions
- From the interview data (N=15)
- We are currently interpreting the full data set.... Thanks for your patience!

Would you want your private words stored?



I understand in people's lives there are things you want to keep private. I would go for a less private way of approaching this.

I would say that I'd err on the side of full disclosure, and I just happen to think people don't have to worry about privacy.

I wonder if there is a way that the [vocabulary storage] program can be a little bit less personal. You can still get the language, but you wouldn't get personal information about family members. Because these patients are gonna be gone someday. And the people who are left dealing with all this personal information could really get impacted quite seriously.

There could be a downside to having all of that information. I would think a user would be able to delete any unfavorable words from the vocabulary before using it, thereby lessening the chance to be put in a compromised situation.



For the system to work, it's gonna have to know as much about you as it can. In other words, it's gonna know that I tend to use this word in this context. If you don't tell it that you do that, then it's never gonna do that because it doesn't know, right?

You're going to have to give up a lot of personal information in order for a system to work well.



[Storing my language] is personal, but for me, I don't mind sharing this stuff with others. Because at some point in my life maybe I would know – probably because I have some neurological illness – that I'm gonna need something to help me communicate with other people maybe one day. Probably if I share my “what do I feel” or “what do I know” or some personal information, how to communicate, it would be easier to have somebody around me understand what I'm trying to say or to send a message. I don't take it so personal; I'm okay with that. From my perspective, it will help a lot.

Should you change what language is stored?



It's important to edit information given to researchers to take out personal info, names, etc. I would want to edit out names, etc. to protect family, friends.

There are certain things that are part of my personal care or stuff that I prefer not to be made public.

Yeah, there could be sensitive material in there that I may not want people to see. I personally think that as far as memories or feelings that I need to leave much behind.

I would edit my emails before turning them over.

If I didn't make the decision to stop swearing or to swear more, why should I change it now? Because that's what people around me know and understand me to be.



Should we value privacy?

As far as information and information sharing and all that, I'm not bothered by somebody getting into even my old love letters or communication between my wife and I, or somebody even getting into my computer. It's like, "Help yourself. Seems like a waste of your time". So, for me, what it comes down to, I certainly don't want them to get into my bank account, but beyond that I'm pretty much an open book. My wife's a lot more concerned about security.

I mean, I want the intended recipient to only get what's intended for them. I don't necessarily want Sister A to hear Sister B's letter. That's my only concern.



There's not much that I keep from other people. And I'm not as concerned as I used to be about how people feel about me or what they think about me. And I know that sometimes that can be awkward for them or even for me sometimes, but not so much for me anymore. So, I've kind of given up on being concerned about other people's impressions, although I do. Again, I would like to be able to convey my thoughts as accurately as possible.

Should you give consent to store your words?



You're dealing with a personal document. Even if you're giving someone else this information, that needs to be with their permission.

Yes, anything that you shared or donated, you would need to understand that that would be public information.

Thank you to my collaborators

Eran Klein, MD and Michelle Kinsella, OTR





#3: Clinician's view

1. Donated devices must have a **fast and easy way to wipe the device clean** of all stored vocabulary and images before giving it to another client.
2. Loaner devices from manufacturers **must be wiped clean** of vocabulary and images before they are loaned to others.
3. Clinic devices must obtain **informed consent** if personal page sets (vocabulary and photos) are shared with potential end users.
4. Devices should be **password protected** for each user (including separate passwords for multi-user devices).

Some thoughtful questions and issues



On to the next presenter.....



PANELIST PRESENTATIONS



Dave Hershberger

Data Security and Privacy

30 March, 2021

Dave Hershberger

Data Used to Improve Device Design

- Collected from individuals who may be utilizing the equipment
- Used to represent the needs, wants and preferences of a group of people
- Data should be recorded, stored, and analyzed as anonymous, aggregate information

Data used to Customize Individual Configurations

- Collected from the individual using the device
- Data is acted upon by the device, rather than humans
- There is no need to make the data accessible outside of the device

Data used to Guide Clinical Intervention

- Specific to the individual using the device
- Data is acted upon by humans
- Protecting this type of data
 - Full disclosure and consent
 - 'Opt In' data collection
 - Ability to toggle collection on and off
 - Visual indication that data collection is on
 - Privacy password to protect data file
 - File encryption



PANELIST PRESENTATIONS



Fil McIntyre

AAC and Data

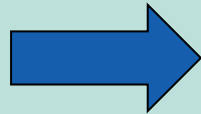
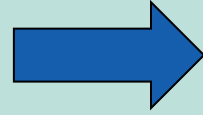
What should organisations be doing?

Fil McIntyre

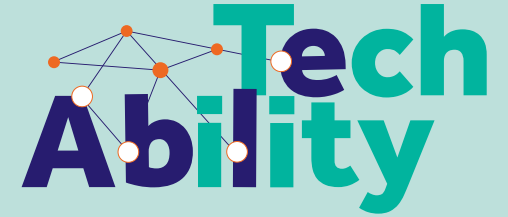
Manager and Assistive Technology Lead

TechAbility (UK)

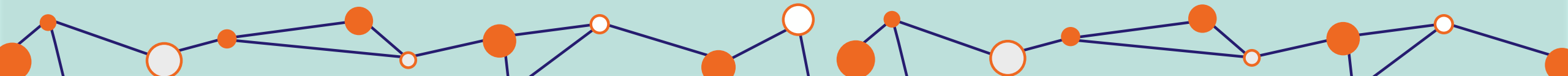




What data got lost?



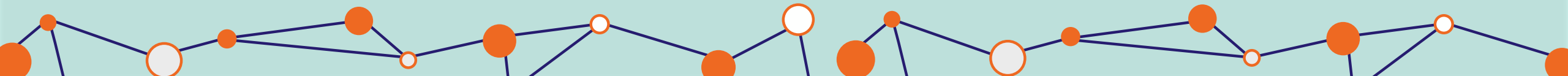
- First name
- Photo
- Age + birthday
- School attended
- Town of residence
- Place of education
- Names and photos of other students
- Names and photos of staff





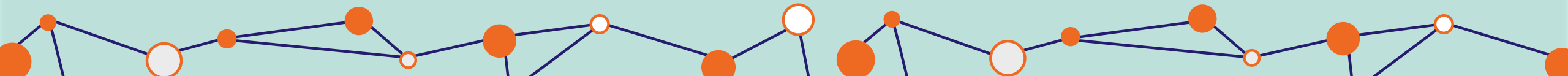
Total number of individuals impacted?

117





Why should I be bothered?





Why should I be bothered? Respect

Treat others' information as
you would your own.



Why should I be bothered? Prosecution

The UK GDPR and DPA 2018 set a maximum fine of £17.5 million (\$2m) or 4% of annual global turnover – whichever is greater.



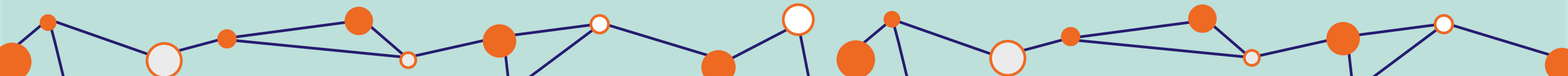
Why should I be bothered?

- The device belongs to the organisation so is likely to be covered by data protection law
(General Data Protection Regulation in UK and EU)
- The device contains information which may result in a risk to people's rights and freedoms.
- Under the GDPR loss is considered to be a **Personal Data Breach** which must be reported within 72 hours
- Check your own data laws!





Right to speak vs. Data law



Right to Speak vs. Data law

You have a right to talk about
someone...

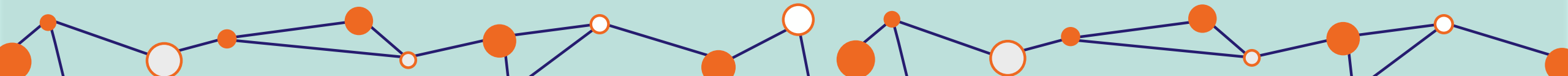
even if they hate you.



UDHR Article 19:

Everyone has the right to freedom of
opinion and expression

about people by corpus delicti from the Noun Project



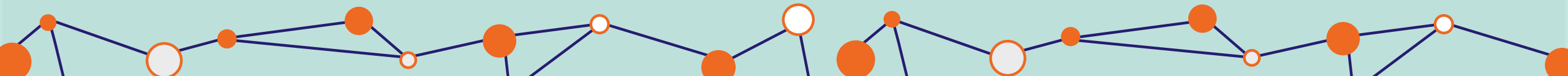
Right to Speak vs. Data law

You have a right to talk about
someone...

who needs to be reported.

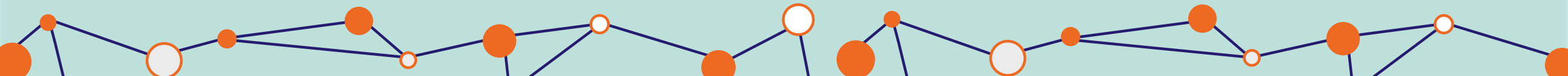


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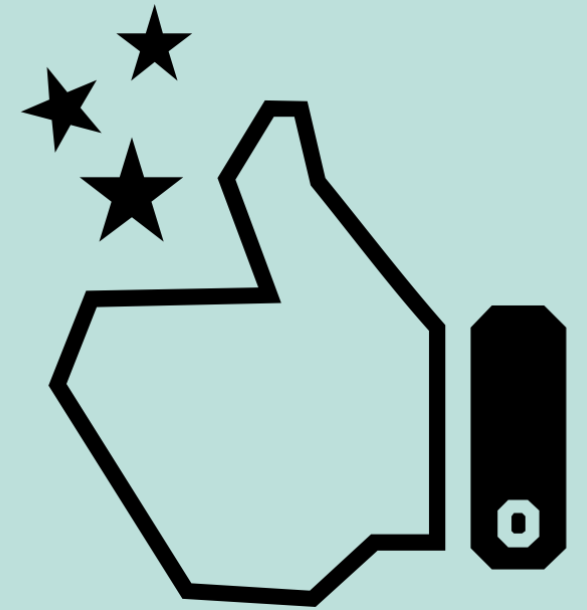


**You still need to
do the right thing**



Doing the right thing (UK version)

- Lawful Basis / Legitimate Interests
- Minimum data possible
- Prevent loss
- Procedure for lost data
- Report any breaches

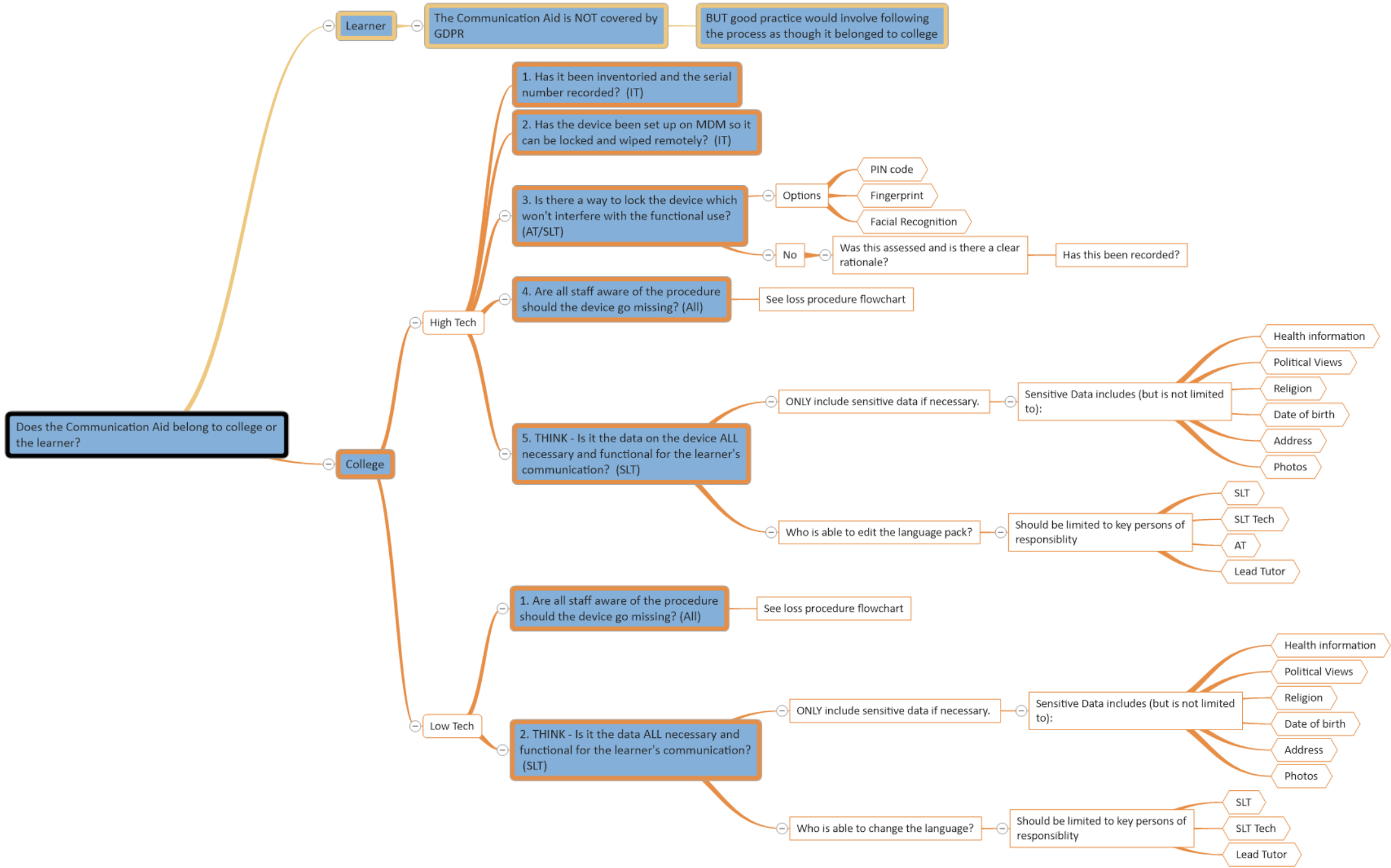


excellent by Kangrif from the Noun Project

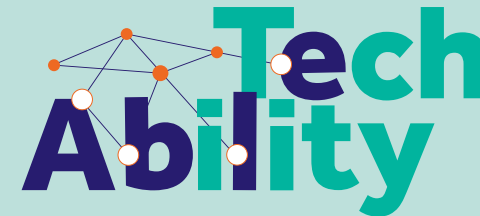


A process for data and AAC

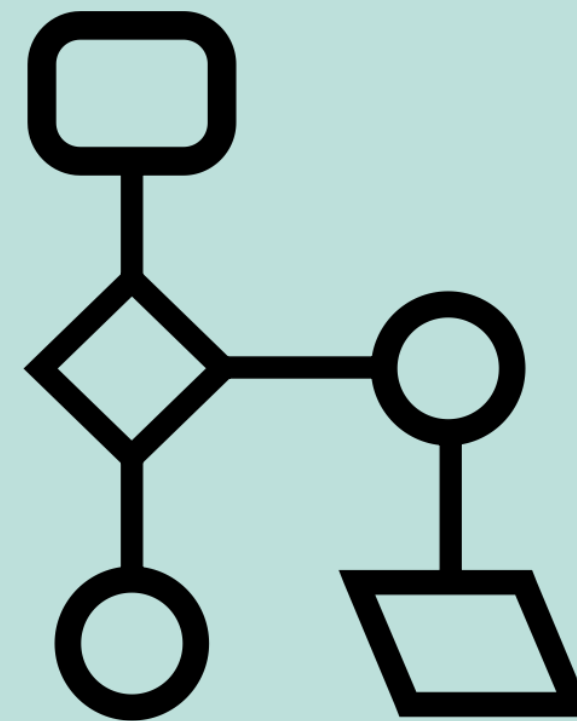




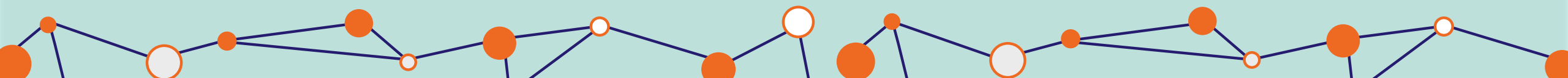
Final piece of advice:



**Put procedures
in place
AND
follow them**



Flow Chart by Jhun Capaya
from the Noun Project





Contact



fil.mcintyre@natspec.org.uk



[@filmcintyre](https://twitter.com/filmcintyre)





PANELIST PRESENTATIONS



David Niemeijer

AAC data collection and privacy

ISAAC webinar on Data Privacy and Security for AAC - 30 March 2021



David Niemeijer

AssistiveWare Founder & CEO

 @NiemeijerD



AAC users have an absolute right to privacy

AAC users rely on a device to express their most personal and intimate thoughts

Therefore:

- AAC users should have an absolute right to privacy of conversation
- Irrespective of age, conversations should stay in the room
- An AAC device should not be used to police language

Automated Data Logging (ADL) in AAC

What is it and why is it done?

- Many AAC products offer a form of Automated Data Logging such as Language Activity Monitoring (LAM)
- When turned on, these systems automatically capture every word, letter, and sentence spoken (with a timestamp) in a log file
- Data logs are used for AAC research and to provide language data to therapists to help AAC users improve their language

Pros of Automated Data Logging

- Data capture is complete, automatic and easy
- Data analysis can provide powerful insights

Cons of Automated Data Logging

Lack of context

- Multi-modal communication is not taken into account
- Both sides of the conversation are not captured
- The context of communication partner competencies and environment is missing

Privacy

- Consent is given by parents or guardians for minors
- Consent relies on understanding the implications of data collection
- Access to sensitive data is limited through policies and access restrictions

Consent is not abuse-proof

Automated Data Logging (ADL) in AAC

Who offers data logging?

Data logging is included in most popular AAC apps and devices

AssistiveWare does not and will not support this kind of data logging

Product analytics in AAC

What, why and who of product analytics

- Product analytics captures user and usage data for a product
- It can include user identification or be anonymous
- Product analytics is used to improve products and support business operational processes
- Several AAC vendors use product analytics
- AssistiveWare only uses anonymous analytics and asks for consent for anything beyond basic operational data

Privacy best-practice

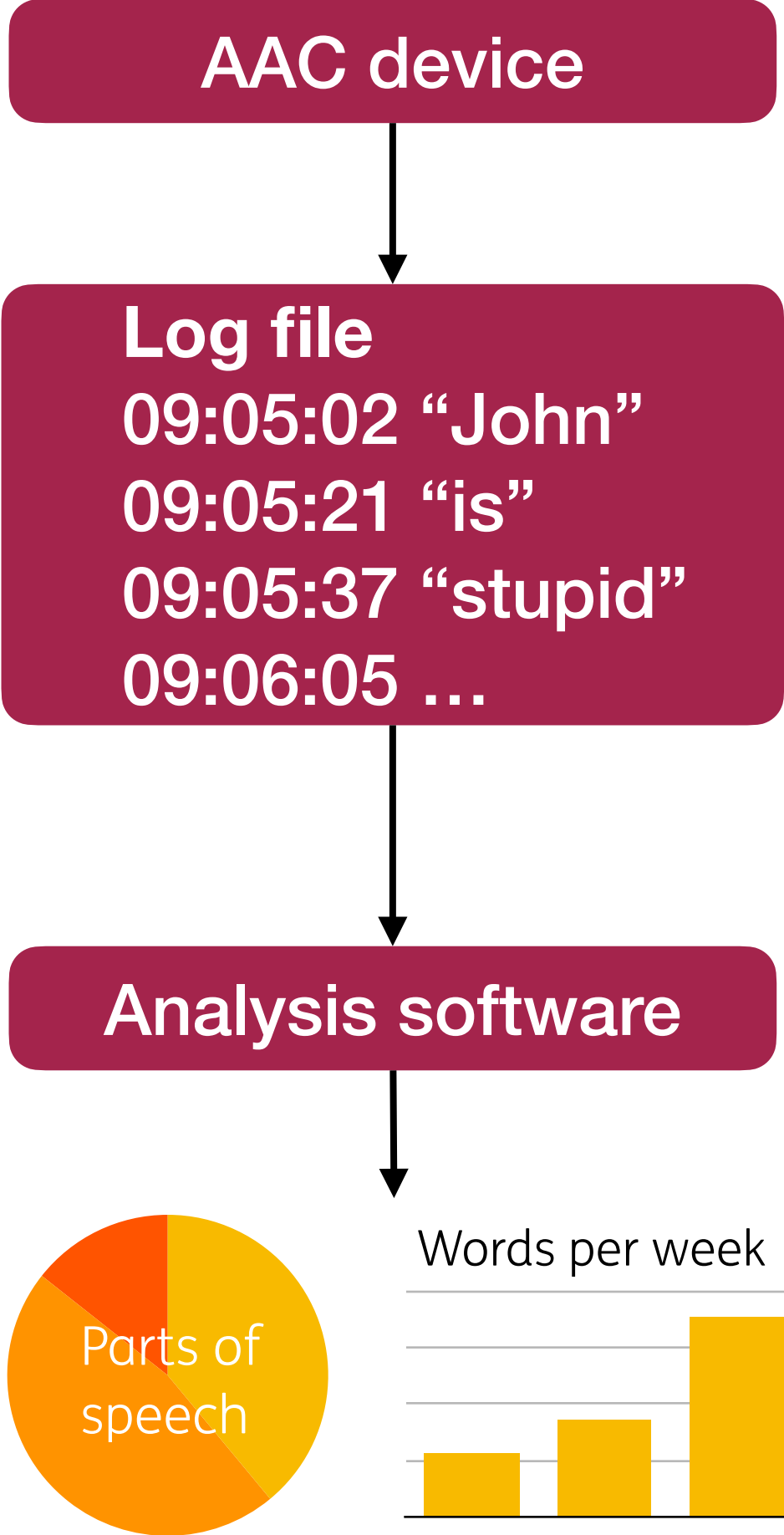
Privacy by design

- Collect only essential data
- Whenever possible aggregate and anonymize data to protect people's privacy

Every piece of data that leaves a device poses a risk

Traditional approach vs privacy-centric

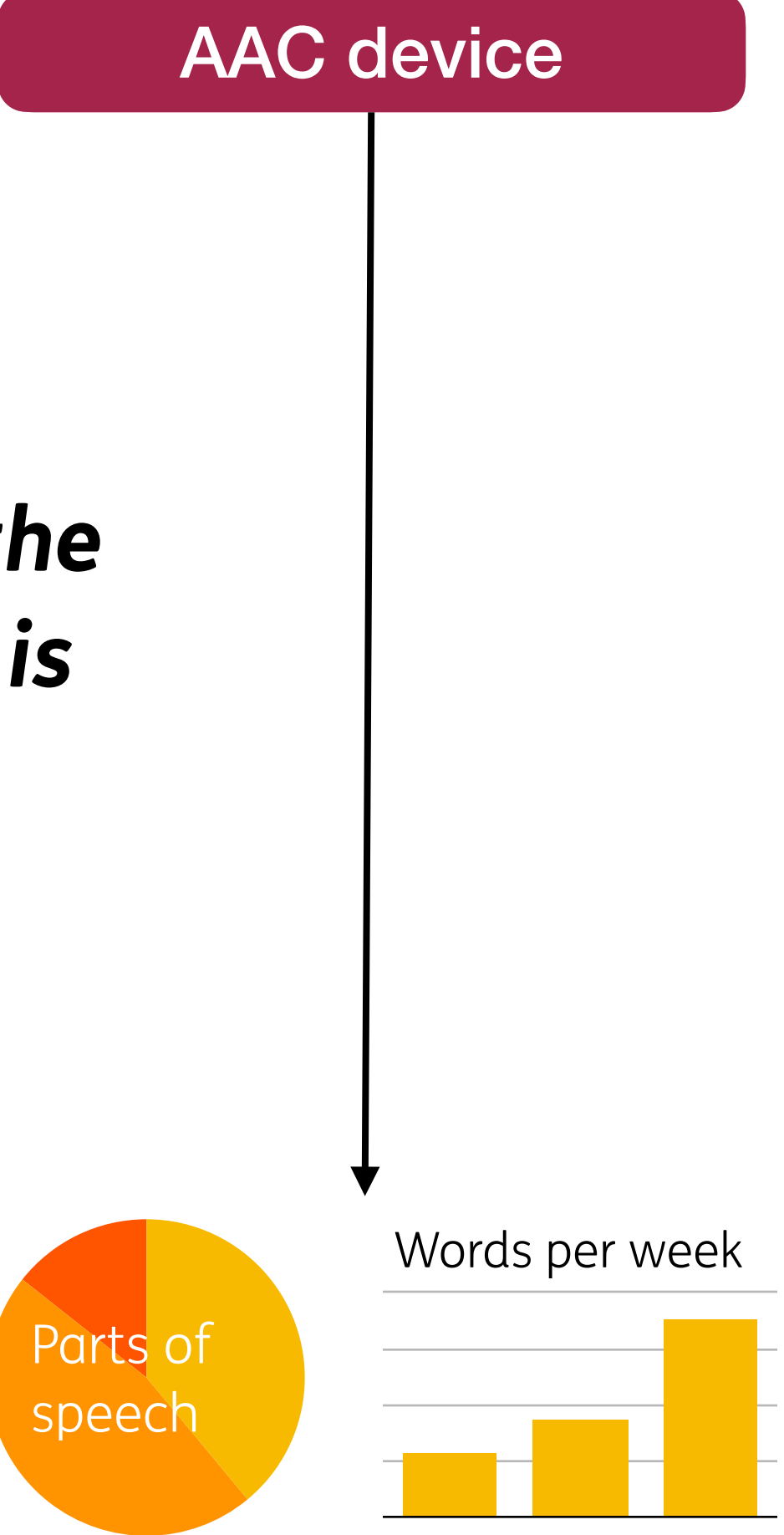
- 1. Kim uses her AAC device
- 2. Rita exports log file
- 3. Rita reads log file
- 4. Rita feeds log file into analysis software
- 5. Rita reviews the report



- 1. Kim uses her AAC device

Data never leaves the device. All analysis is done in the device

- 2. Rita exports and reviews the report



Measuring without invading privacy

Some examples from the literature

computer software). Analysis measures applied to both cases include **total number of utterances** using utterance terminators, **number of activations**, **average activations per word**, **words spelled**, **bits**, **selection rate**, **rate index**, **mean syntactic length**, **predicted MLU in morphemes**, **use of word prediction features** (e.g., Kovacs & Hill, 2015, 2017; Van Tatenhove, 2014), **word frequency** (from Realize Language), **parts of speech used** (from Realize Language), **number of core words within the top 10 words** (supplementary measure), and **percentage of core words used** (supplementary measure).

From:

Mooney, A., A. Bean and A.M. Sonntag (2021) “Language Sample Collection and Analysis in People Who Use Augmentative and Alternative Communication: Overcoming Obstacles” *American Journal of Speech-Language Pathology* Vol. 30: 47–62.

These could be:

- Computed “on device”
- Aggregated over time

AssistiveWare's AAC data collection principles

1. Only collect data if there is a clear purpose
2. Ask for permission to collect data for product improvement
3. Only collect anonymous data
4. Do not collect more details than necessary
5. Do not collect personal data
6. Do not share raw data with third parties

Conclusions

Value of data collection

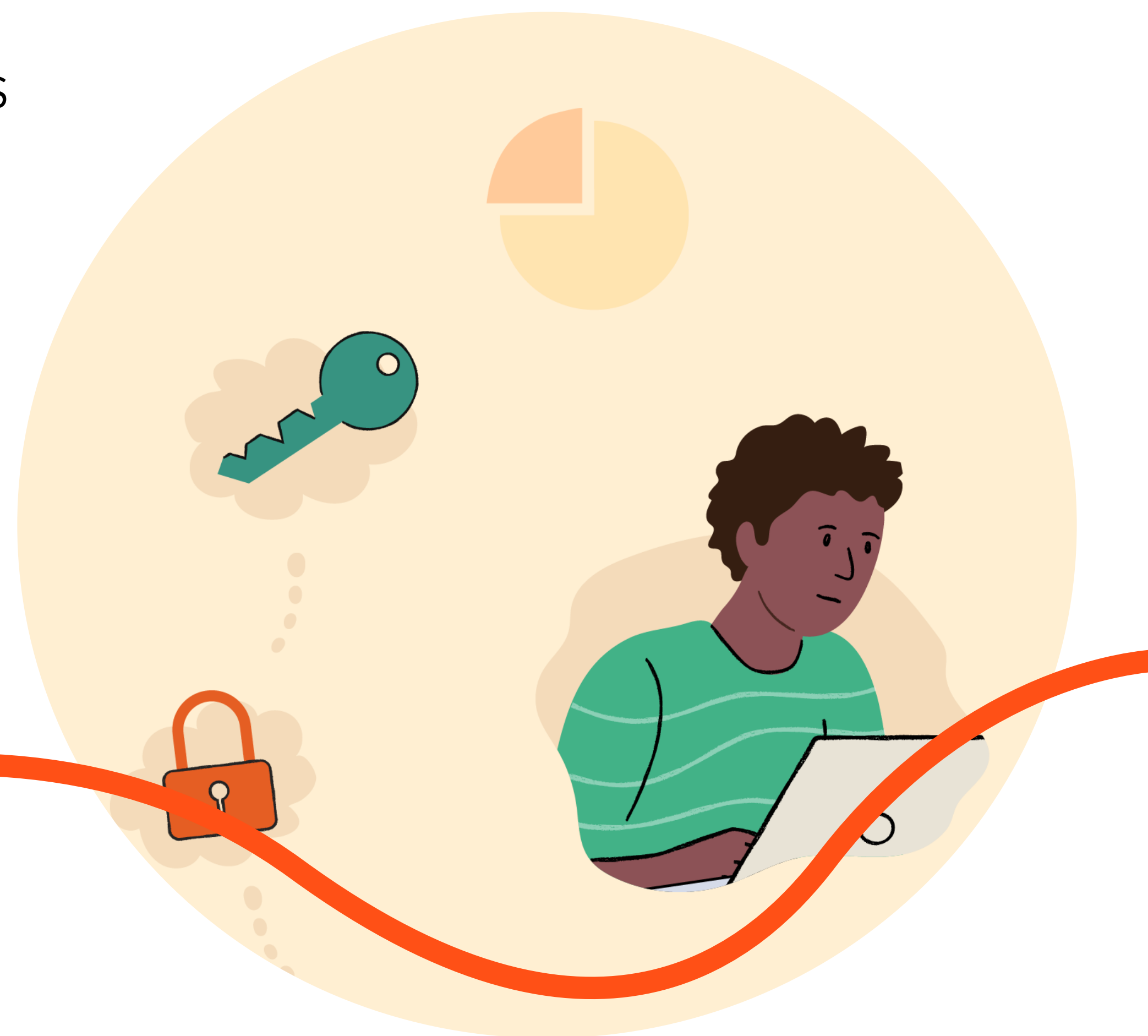
Data collection can improve both AAC products and AAC practice

- For AAC product improvement aggregated anonymous data is sufficient
- For AAC practice improvement much less detail is needed than what is collected currently through ADL in AAC apps and devices

Conclusions

Responsibility

It is our responsibility as AAC developers and practitioners to safeguard the privacy of conversation of AAC users



Conclusions

Rethink what data we collect

- The AAC field needs to reduce the amount of data and the detail of data that is collected
- That way we can guarantee AAC users that what they say, when, and where remains private
- AAC users need to be a key part of this conversation

**AAC users have an absolute
right to privacy**





PANELIST PRESENTATIONS



Alyssa Hillary Zisk

AAC and Privacy

Alyssa Hillary Zisk ¹

University of Rhode Island, Interdisciplinary Neuroscience Program

March 30, 2021

¹Pronouns: they/them/theirs
Email: AlyssaZisk@uri.edu; AlyHillary@gmail.com

So who is this human?



Me! Hi, everyone!

So who is this human?



Me! Hi, everyone!

I am an Autistic* PhD student in the Interdisciplinary Neuroscience Program at the University of Rhode Island. Among other areas, I study Augmentative and Alternative Communication, both in the form of brain computer interfaces and as used by autistic adults. I also use AAC part time.

So who is this human?



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* No, I don't mean "a PhD student with autism."

How do we understand privacy?

- Physical privacy – body, personal possessions

¹McCreary [2008]

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- Information privacy – likes, dislikes, conversations

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- “Self-possession: custody of the facts of one’s life, from strings of digits to tastes and preferences” ¹

¹McCreary [2008]

How do we understand privacy?

- Physical privacy – body, personal possessions
- Information privacy – likes, dislikes, conversations
- “Self-possession: custody of the facts of one’s life, from strings of digits to tastes and preferences” ¹
- Decisions about who we do (or don’t) allow information

¹McCreary [2008]

WHO CONTROLS ACCESS TO OUR POSSESSIONS AND INFORMATION?

Design Choices

What is a LAM logfile?

A LAM logfile represents the use or events associated with a given AAC system; the selections made by the user. The logfile starts with a time stamp (24 hour clock) and then the event, e.g. word, message or control feature selected. For example:

01:20:10 "I"

01:20:20 "like"

01:20:22 "you"

A series of events makes up a language sample and can be transcribed and analyzed to measure communication performance. The time stamp is critical to accurately measure communication and selection rates for someone.

ICAN™ Talk clinicians suggest these steps:

- * Upload the weekly logfile when clients arrive at clinic to view and help customize the therapy session.
- * Use the session logfile to create a transcript and analyze using PeRT to monitor performance during treatment.
- * Compare performance in therapy with communication activity across other daily activities, environments and partners.
- * Receive logfiles from clients who want their performance reviewed when they cannot come to the clinic.
- * Revise LAM intervention strategies to maximize gains based on all the evidence.

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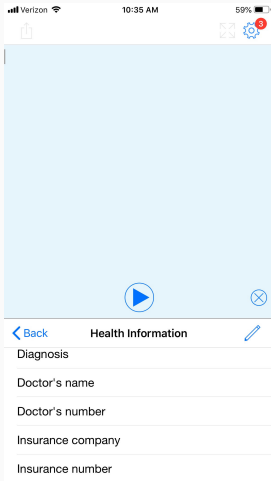
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Design Choices

What is a LAM logfile?

A LAM logfile represents the use or events associated with a given AAC system; the selections made by the user. The logfile starts with a time stamp (24 hour clock) and then the event, e.g. word, message or control feature selected. For example:

01:20:10 "I"

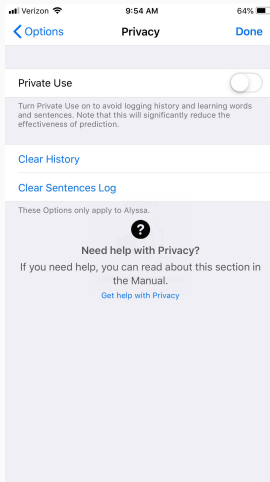
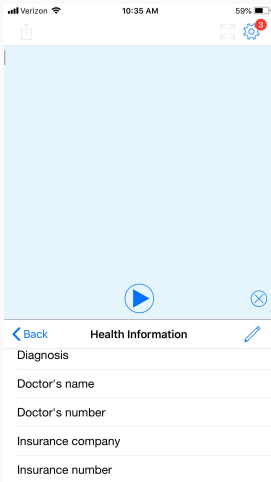
01:20:20 "like"

01:20:22 "you"

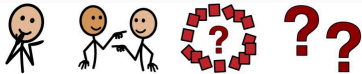
A series of events makes up a language sample and can be transcribed and analyzed to measure communication performance. The time stamp is critical to accurately measure communication and selection rates for someone.

ICAN™ Talk clinicians suggest these steps:

- * Upload the weekly logfile when clients arrive at clinic to view and help customize the therapy session.
- * Use the session logfile to create a transcript and analyze using PeRT to monitor performance during treatment.
- * Compare performance in therapy with communication activity across other daily activities, environments and partners.
- * Receive logfiles from clients who want their performance reviewed when they cannot come to the clinic.
- * Revise LAM intervention strategies to maximize gains based on all the evidence.



A “justified” privacy violation is still a privacy violation



Thank you . Any questions?

Home



I	is	can	will	do	don't	what	where	who	when	why	how	big	little	not	more
you	we	could	want	like	need	have	get	to	from	with	now	later	again	too	all done
he	she	would	stop	go	come	give	make	here	away	in	on	up	good	bad	different
it	this	should	taste	drink	use	take	put	there	over	out	off	down	all	some	one
they	that	think	eat	wait	change	open	turn	about	under	for	of	at	yes	maybe	no
the	a	know	help	say	tell	ask	show	call	before	next	after	by	other	please	thank you
any	find	move	see	look	watch	listen	sit	try	but	if	so	and	Help	Feelings	Chat
every	let's	play	work	let	Actions	A-Z Verbs	start	feel	because	then	as	or	Numbers	Time	Clues
People	Family	Friends	Things	Food	Describe	A-Z Adjectives	Places	Fun	Questions	Where?	Which?	Conjunctions	Expressions		More



References I

Lew McCreary. What was privacy? *Harvard Business Review*, 86(10):123–30, 2008.



QUESTIONS AND PANEL DISCUSSION



PRIZE DRAW



WEBINAR WRAP-UP

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