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Ethics, Data life cycle & eHealth

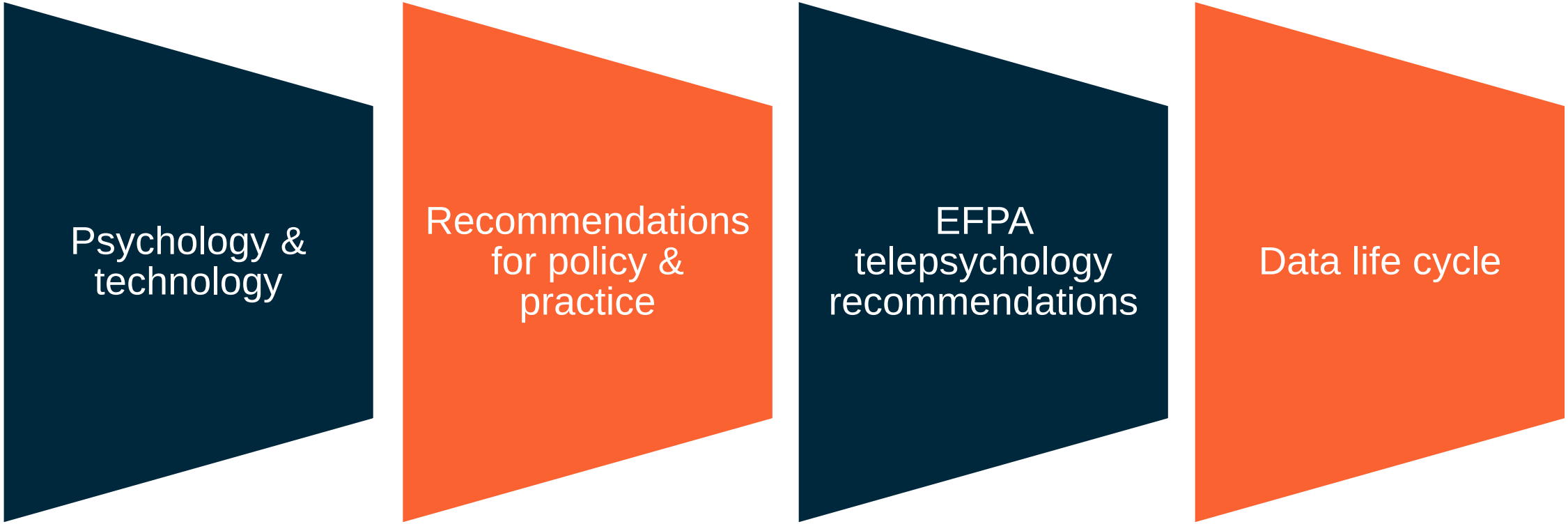
CYBER – 25 & 26 March 2024
Université Paris Cité
Tom Van Daele, PhD

Overview

Slides & hand-outs for today and tomorrow

https://epsychology.be/cyber/

Overview


Psychology & technology
Recommendations for policy & practice
EFPA telepsychology recommendations
Data life cycle

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Research line Psychology and technology

www.digitalmentalhealth.be

Psychology and technology

- Applied, practice-oriented research
- Field of psychology and technology
- Interaction between both domains

Linked to the department of Applied Psychology

- Course Digital Psychology

Team

RESEARCH LINE COORDINATOR

Tom Van Daele

Tom Van Daele (PhD) is research coordinator Psychology and technology in the People and Well-being research group. As a clinical psychologist, he conducts research on the added value of technology within mental health care.

RESEARCHER

Nele De Witte

Nele De Witte (PhD) is a researcher in the People and Well-being research group, research line Psychology and technology. Her areas of expertise include wearables and XR. She is also the scientific coordinator of LiCalab.

RESEARCHER

Eva Van Assche

Eva Van Assche (PhD) is a lecturer-researcher in the People and Well-being research group, research line Psychology and technology. She focuses on how digital applications (e.g., applications) can contribute to mental health care.

RESEARCHER

Sylvie Bernaerts

Sylvie Bernaerts (PhD) is a researcher in the People and Well-being research group, research line Psychology and technology. Her areas of expertise are immersive technology in (mental) health care and ethics committee applications.

VALORISATION STAFF - RESEARCHER

Fien Buelens

Fien Buelens (MSc) is a researcher and business developer in the People and Well-being research group, research line Psychology and technology. From her expertise, she facilitates the connection between research and practice.

RESEARCHER

Toon Colman

Toon Colman (MSc) is a researcher in the People and Well-being group, research line Psychology and technology. As an experimental psychologist, he wants to leverage his methodological expertise for the benefit of (mental) health.

Activities

Projects relating to

- AR for specific phobia
- Immersive mental health & VR relaxation
- VR for therapy
- Adoption & implementation of DMH
- Immersive Care
- Wearables

AR exposure

- Testing prerequisites for AR exposure
- Smartphone (PHOBOS AR) and HoloLens 2 headset (custom application available at GitHub)
- Behavioral approach tasks & preferences

De Witte, N. A. J., Buelens, F., Debard, G., Bonroy, B., Standaert, W., Tarnogol, F., & Van Daele, T. (2022) Handheld or head-mounted? An experimental comparison of the potential of augmented reality for animal phobia treatment using smartphone and HoloLens 2. *Frontiers in Virtual reality*. https://doi.org/10.3389/frvir.2022.1066996

De Witte, N. A. J., Scheveneels, S., Sels, R., Debard, G., Hermans, D. & Van Daele, T. (2020) Augmenting Exposure Therapy: Mobile Augmented Reality for Specific Phobia. *Frontiers in Virtual reality, 1, 8*. https://doi.org/10.3389/frvir.2020.00008


HoloLens 2
Reset experience
Restart configuration

Immersive mental health

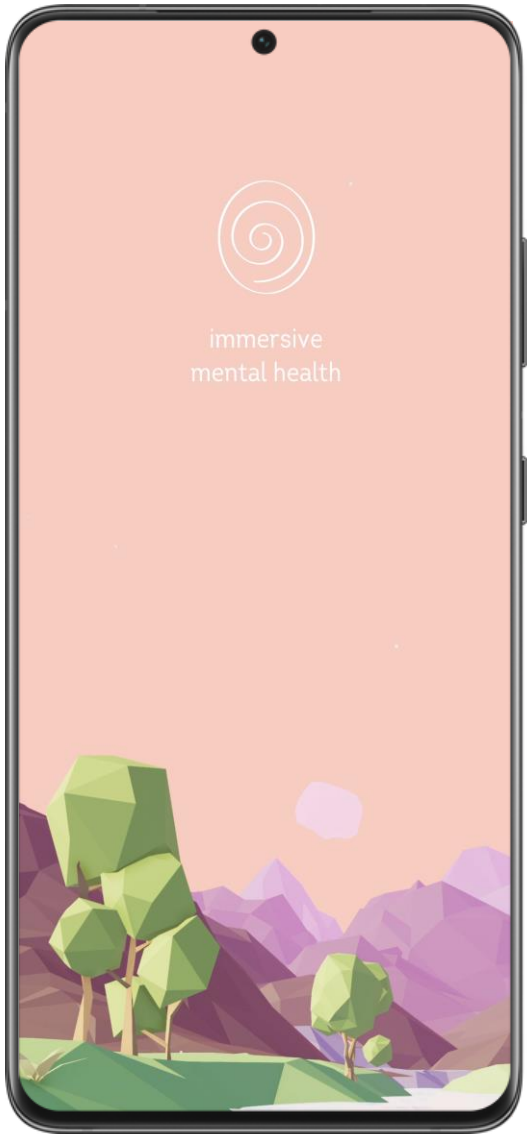
- 3 environments
  - Beach
  - Mountains
  - Snow + northern lights
- 3 types of relaxation
  - Mindfulness
  - Progressive muscle relaxation
  - Presence in VR nature
- Personalization audio guidance
  - Male or female voice
- 15 min

Smartphone VR relaxation

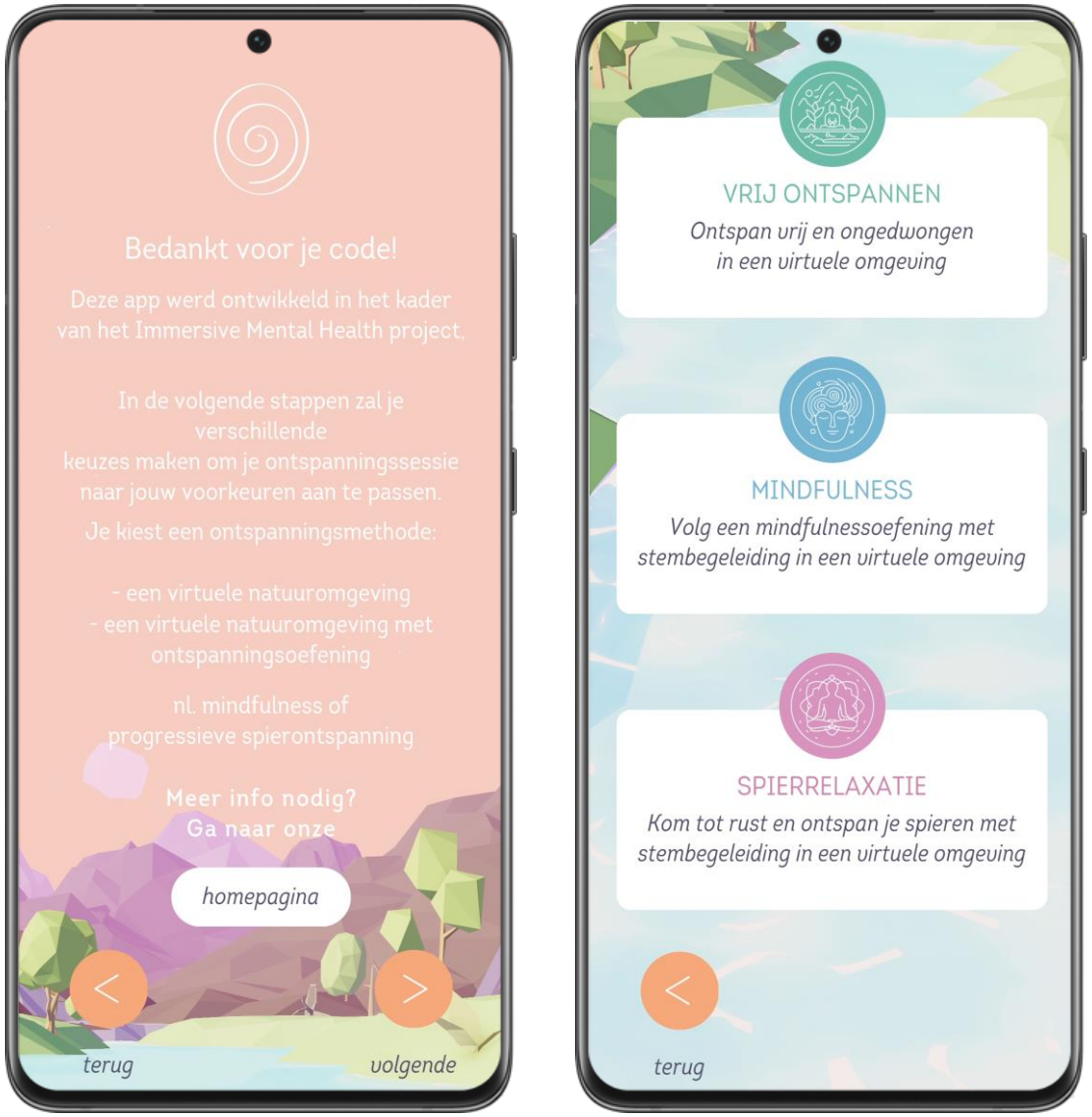
- 3 environments
  - Beach
  - Mountains
  - Snow + northern lights
- 3 types of relaxation
  - Mindfulness
  - Progressive muscle relaxation
  - Presence in VR nature
- Personalization audio guidance
  - Male or female voice
- 15 min

AEROPLANE

Immersive Mental Health

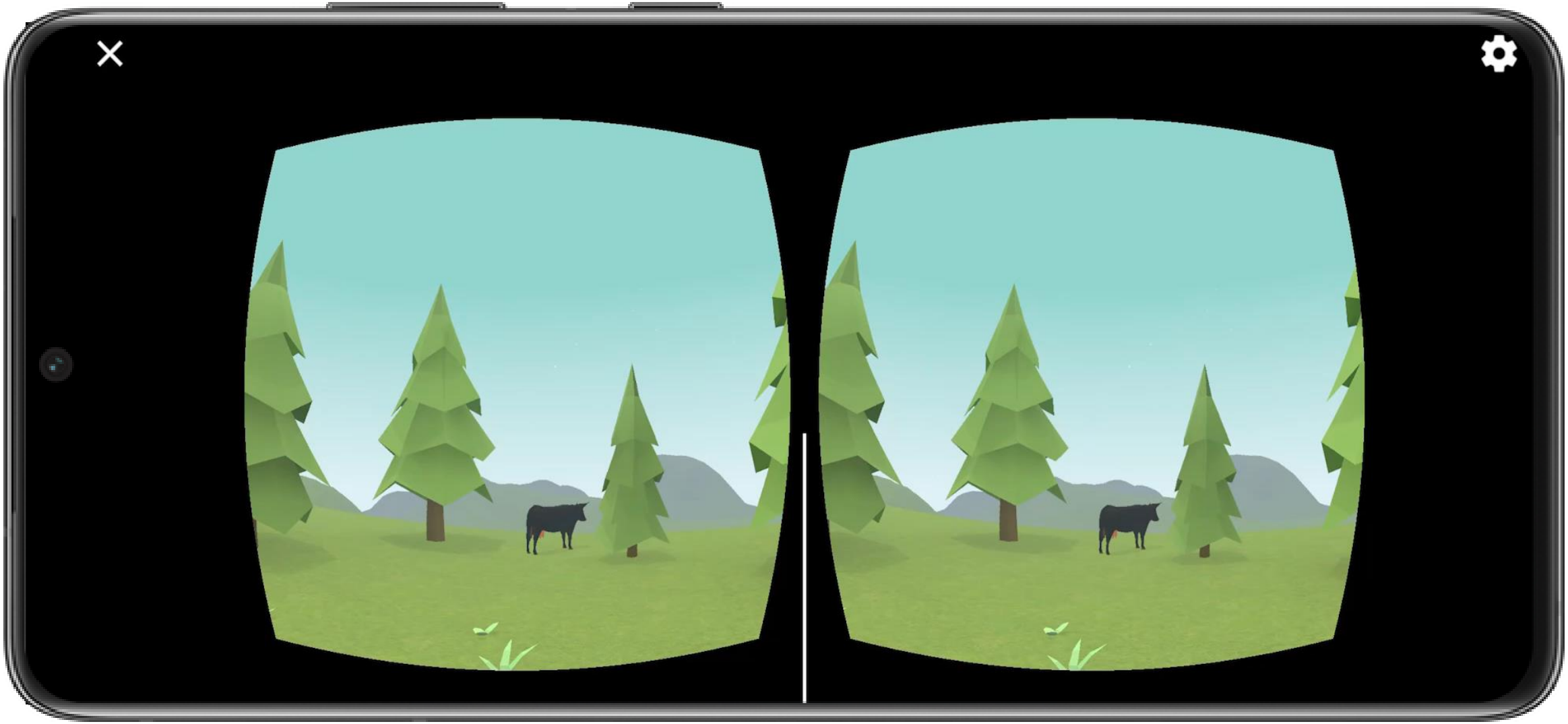


Immersive Mental Health



Immersive Mental Health


Focus 3 seconden op de startknop
om de ervaring te beginnen
Focus 3 seconden op de startknop
om de ervaring te beginnen



VR for Therapy

Collaboration with QUEEN'S UNIVERSITY BELFAST

- Photogrammetry to recreate specific trauma sites for trauma treatment
- Literature and app overviews of VR & 360°video for mental health treatment

Best, P. Kupeli-Holt, S., Elliot, A., Duffy, M., D'Arcy, J., & Van Daele, T. (in press). *Low-Cost Virtual Reality to support imaginal exposure within PTSD treatment: A case report study within a community mental healthcare setting.*

Best, P., Meireles, M., Schroeder, F., Montgomery, L., Maddock, A., Davidson, G., Galway, K., Trainor, D., Campbell, A., & Van Daele, T. (2021). Freely Available Virtual Reality Experiences as Tools to Support Mental Health Therapy: A Systematic Scoping Review and Consensus Based Interdisciplinary Analysis. *Journal of Technology in Behavioral Science*, 1-15. https://doi.org/10.1007/s41347-021-00214-6

Ionescu, A., Van Daele, T., Rizzo, S., Blair, C., & Best, P. (2021). 360° videos for immersive mental health interventions: a systematic review. *Journal of Technology in Behavioral Science, 6,* 631-651. https://doi.org/10.1007/s41347-021-00221-7

Best, P., McKenna, A., Quinn, P., Duffy, M., & Van Daele, T. (2020). Can virtual reality ever be implemented in routine clinical settings? A systematic narrative review of clinical procedures contained within case reports for the treatment of PTSD. *Frontiers in Virtual Reality, 1,* 23. https://doi.org/10.3389/frvir.2020.563739

VR Photoscan

QUEEN'S UNIVERSITY BELFAST

Propeer

VR Photoscan

QUEEN'S UNIVERSITY BELFAST

Propeer

VR Photoscan

VR Photoscan

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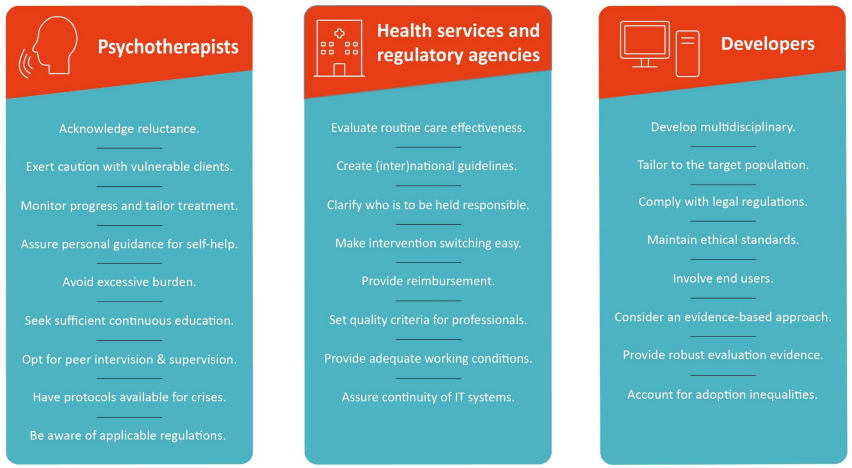
Propeer

Adoption & implementation

Collaboration with efpa European Federation of Psychologists' Associations

- Recommendations for policy and practice of digital mental health
- Research on uptake, adoption, and implementation of specific tools



Buelens, F., Luyten, P., Claeys, H., Van Assche, E., & Van Daele, T. (2023). Usage of unguided, guided, and blended care for depression offered in routine clinical care: Lessons learned. Internet Interventions, 34, 100670. https://doi.org/10.1016/j.invent.2023.100670

Van Daele, T., Karekla, M., Kassianos, A. P., Compare, A., Haddouk, L., Salgado, J., Ebert, D. D., Trebbi, G. (on behalf of the EFPA Project Group on eHealth), Bernaerts, S., Van Assche, E., De Witte, N. A. J. (2020). Recommendations for policy and practice of telepsychotherapy and e-mental health in Europe and beyond. Journal of Psychotherapy integration, 30(2), 160-173. http://dx.doi.org/10.1037/int0000218

De Witte, N. A. J, Carlbring, P., Etzelmueller, A., Nordgreen, T., Karekla, M., Haddouk, L., Belmont, A., Øverland, S., Abi-Habib, R., Bernaerts, S., Brugnera, A., Compare, A., Duque, A., Ebert, D. D., Eimontas, J., Kassianos, A. P., Salgado, J., Schwerdtfeger, A., Tohme, P., Van Assche, E., & Van Daele, T. (2021). Online Consultations in Mental Healthcare During the Covid-19 Outbreak: An International Survey Study on Professionals' Motivations and Perceived Barriers. Internet Interventions, 25, 100405. https://doi.org/10.1016/j.invent.2021.100405

Bührmann, L., Van Daele, T., Rinn, A., De Witte, N. A. J., Lehr, D., Aardoom, J. J., Loheide-Niesmann, L., Smit, J., & Riper, H. (2022). The feasibility of using Apple's ResearchKit for recruitment and data collection: considerations for mental health research. Frontiers in Digital Health. https://doi.org/10.3389/fdgth.2022.978749

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Recommendations for policy and practice

COVID-19 as accelerator for digital mental health

Guidelines on how to provide
high-quality psychological care to patients

Target groups

- psychotherapists & counselors
- health services and regulatory agencies
- developers

Acknowledge and involve clients
in development and implementation process

Van Daele et al. (2020)

25 recommendations to provide high quality e-mental health to clients

Psychotherapists

Acknowledge reluctance.

Exert caution with vulnerable clients.

Monitor progress and tailor treatment.

Assure personal guidance for self-help.

Avoid excessive burden.

Seek sufficient continuous education.

Opt for peer intervision & supervision.

Have protocols available for crises.

Be aware of applicable regulations.

Health services and regulatory agencies

Evaluate routine care effectiveness.

Create (inter)national guidelines.

Clarify who is to be held responsible.

Make intervention switching easy.

Provide reimbursement.

Set quality criteria for professionals.

Provide adequate working conditions.

Assure continuity of IT systems.

Developers

Develop multidisciplinary.

Tailor to the target population.

Comply with legal regulations.

Maintain ethical standards.

Involve end users.

Consider an evidence-based approach.

Provide robust evaluation evidence.

Account for adoption inequalities.

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recommendations for psychotherapists

Acknowledge reluctance

Acknowledge a strong reluctance towards digital mental health.

Potential **causes**

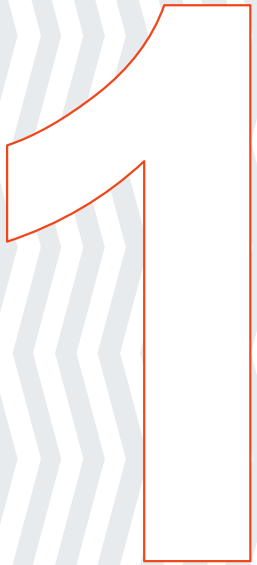
- Digital divide
  - ICT facilities, training, or social context (e.g., age or geographical location)
- Personal preference
- Specific target groups

Initial reluctance can turn around

Acknowledge reluctance

Potential **solutions**

- Providing information
  (e.g. digital mental health video)
- Digital mental health
  as complementary
- Tailoring & personalization
- Exploring non-technological alternatives



Exert caution with children & adolescents

Exert additional caution in children or other vulnerable client groups like older adults or people with intellectual disabilities.

Children & youth

- More need for therapist supervision
- Interactive virtual therapeutic space
- Approval of parents/guardians

Example – Calm Harm

About Calm Harm

The urge to self-harm is like a wave.
It feels the most powerful when you start wanting to do it.
Learn to ride the wave with the free Calm Harm app using these activities:
Comfort, Distract, Express Yourself, Release, Random and Breathe.
When you ride the wave, the urge to self-harm will fade.

Monitor progress

Monitor the progress of clients carefully and tailor treatment.

Self-report: Patient-reported outcome measures (PROMs)

- Standardized, validated questionnaires completed by clients to measure their health and well-being

Monitor progress

Monitor the progress of clients carefully and tailor treatment.

How to monitor

- Wearables
- Ecological momentary assessment (EMA)

Example – mPath

m-path.io

Include personal guidance

Self-administered digital mental health interventions should include personal guidance.

Associated with greater effectiveness

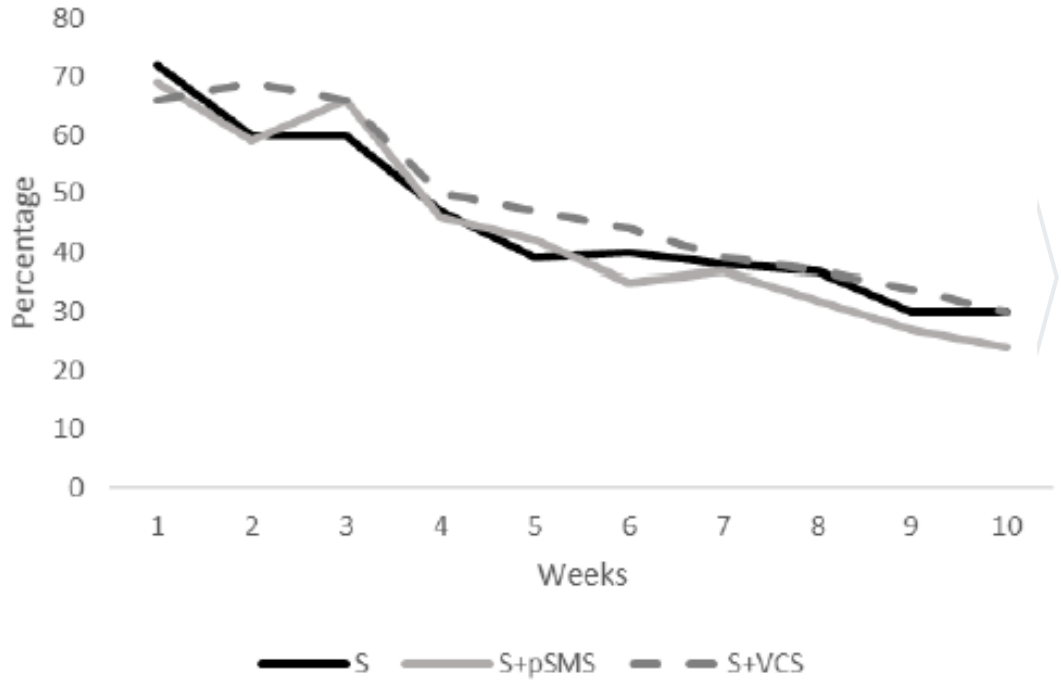
For example, weekly contacts via forum, email, or phone calls

Content & duration can vary depending on needs

- e.g. clarifying things, feedback

Include personal guidance

Figure 3. Percentage of participants who logged challenges over 10 weeks. S: standard—automated emails; S+pSMS: standard plus personalized SMS; S+VCS: standard plus videoconferencing support.



4

Online is challenging, even with support

Renfrew et al. (2020)

Include personal guidance

But what if no help is available?

We drop out en masse & that's OK.

Apps are not the only solution.

Especially 'doers' seem to benefit.

Include personal guidance

But what if no help is available?

Dare to experiment.

Anchor your use:
fixed moments, friends…

Make it a game,
but keep focussing on your goal

Include personal guidance

L "Sans ces conversations avec le chatbot Eliza, mon mari serait toujours là"

Devenu très éco-anxieux, un jeune Belge a trouvé refuge auprès d'Eliza, nom donné à un chatbot utilisant la technologie de ChatGPT. Au terme d'échanges intensifs de six semaines, il s'est donné la mort. Sa veuve nous livre un témoignage poignant et très interpellant sur l'éthique de ces nouveaux agents conversationnels "intelligents".

Pierre-François Lovens
Publié le 28-03-2023 à 06h35 - Mis à jour le 28-03-2023 à 07h06

Le chatbot Eliza utilisé par la victime recourt à la technologie ChatGPT développée par la société américaine OpenAI.
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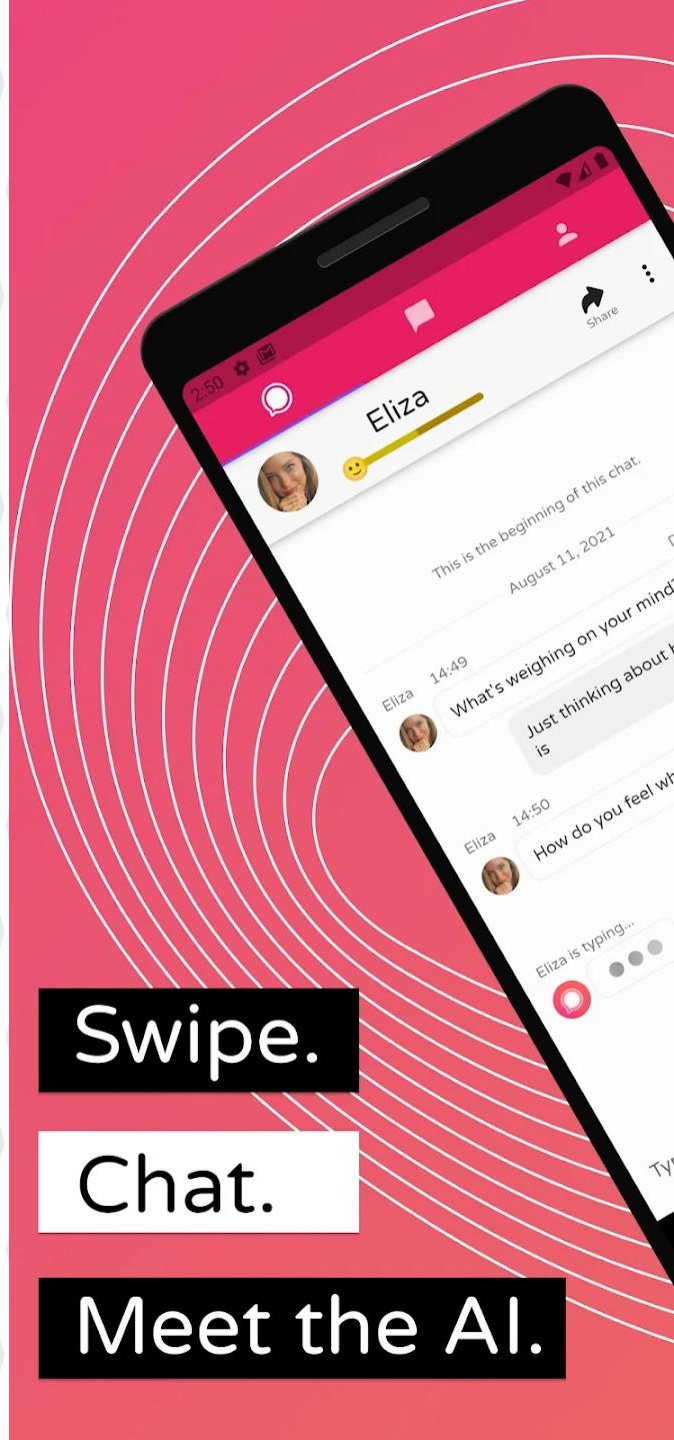


Do not overburden yourself or your patients

Digital mental health should not overburden therapists and their clients.

Digital mental health is not an easy low-effort alternative to traditional care.

Asynchronous communication

- Not immediate, but scattered over a longer period of time via email, internet, or automated messaging systems

Boundaries and availability should be discussed beforehand

Seek continuous education

Goal: guarantee highest possible client safety, desired quality of care, and sufficient evidence-base

Relates to technology, but also to theory, knowledge, and skills necessary for delivering adequate care that properly fits clients' needs

Seek continuous education

7893 participants - 6498 psychologists - 73 countries

6

Seek continuous education

Before outbreak
38% experience with online consultations

During outbreak
77% telephone & 84%
online consultations

Seek continuous education

Those not making use of online consultations (N=1281) quoted

lack of effectiveness (35%)
absence of client interest (22%)
lack of appropriate hard- or software (21%)

Seek continuous education

Those using online consultations (N = 6612) argued

necessity from a public health perspective (73%)

availablity for who could otherwise not attend (63%)

Seek continuous education

Differences concerning uptake between MHC professionals

More years of professional experience

Older

No difference in gender.

Seek continuous education

MHC professionals' characteristics & overall experience and telepresence

Previous experience slightly increases telepresence,

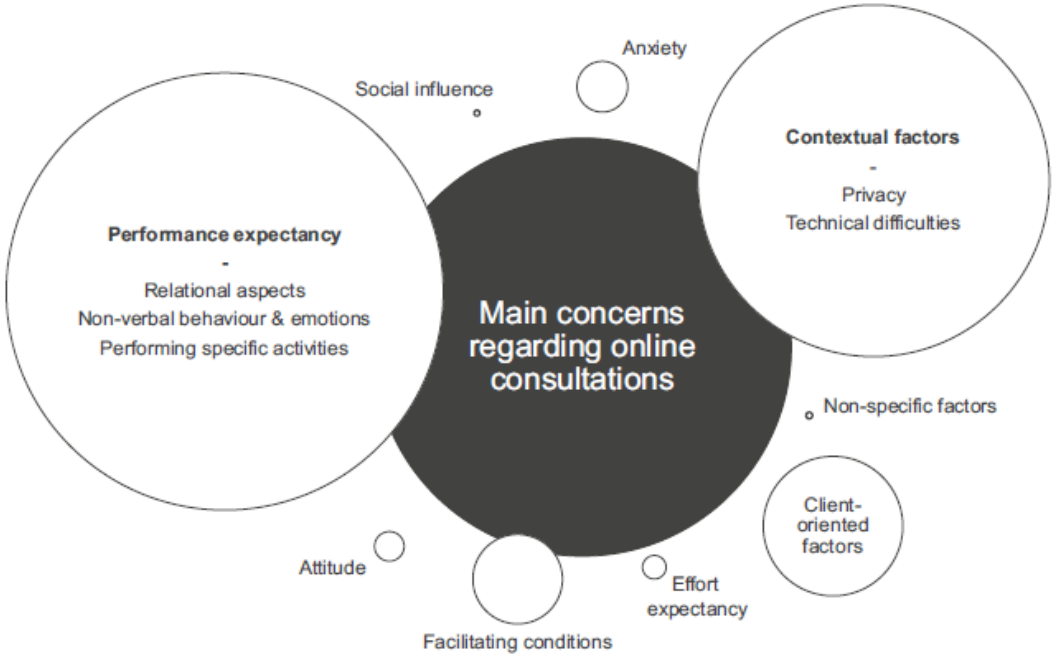
and results in a more positive overall experience.

Also, overall experience is positive.

M = 3.95 on a scale ranging from 1 'highly negative' to 5 'highly positive', with 6% reporting a 'highly negative', or 'somewhat negative' experience

Seek continuous education

Common concerns



9% **prior training**, half less than 4 hours

6

Seek continuous education

APA & APA

- APA Telepsychology 101
- App Evaluation Model

Massive Open Online Courses (MOOCs)

- e.g. edX, Coursera

Journals

- JMIR, Internet interventions (and ISRII/ESRII)…

Opt for peer intervision & supervision

In close collaboration with other (mental) healthcare professionals

7

Protocols for crises

Protocols for handling crises, before during, and after treatment, should be pre-planned and readily available.

Continuous assessment for active suicidal thoughts, at-risk behaviors (e.g., drug use)

Protocols for crises

Especially relevant
for autonomous interventions

Refer to (or alert) relevant
‘conventional’ local services

Follow applicable regulations

Follow applicable regulations regarding digital practice across borders.

Possibility to provide care
in different countries.

National legislations are sometimes complex,
lagging behind or restrictive

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recommendations for health services & regulatory agencies

Evaluate in routine care

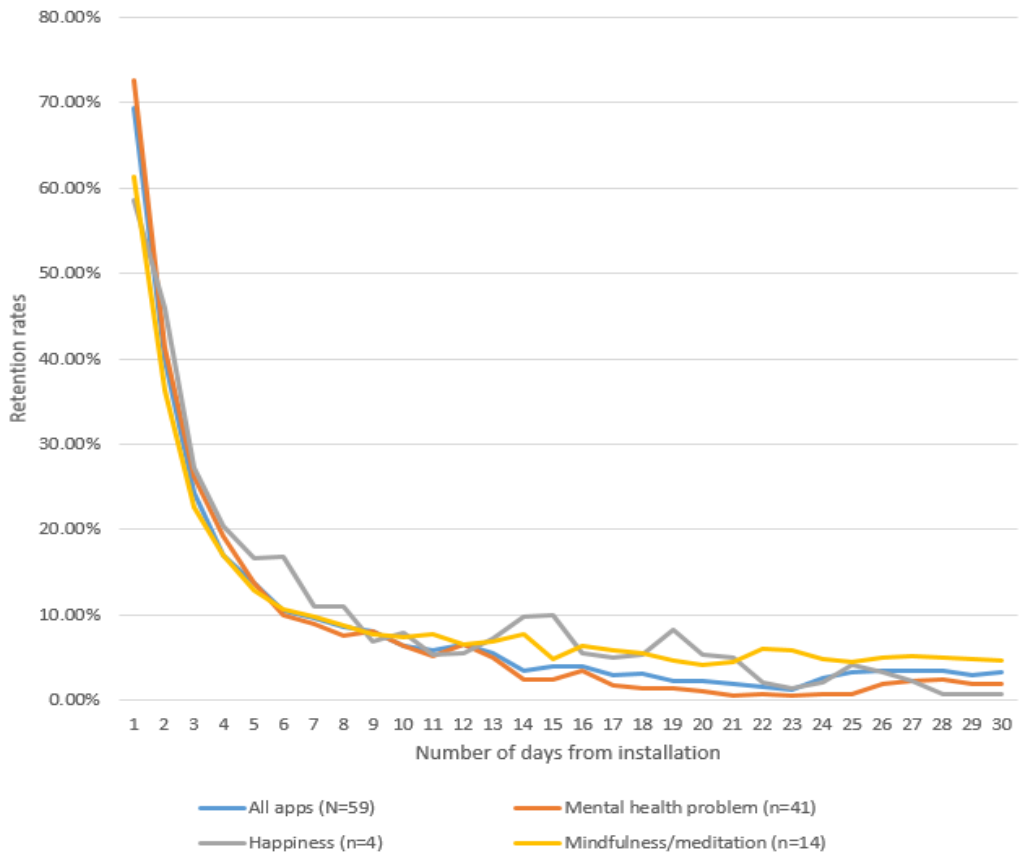
The efficacy and the effectiveness under routine care conditions needs to be evaluated.

Need to learn more about

- Adoption of digital mental health
- Effectiveness & potential harm

Evaluate in routine care

Adoption – general population



Evaluate in routine care

Adoption – clinical population

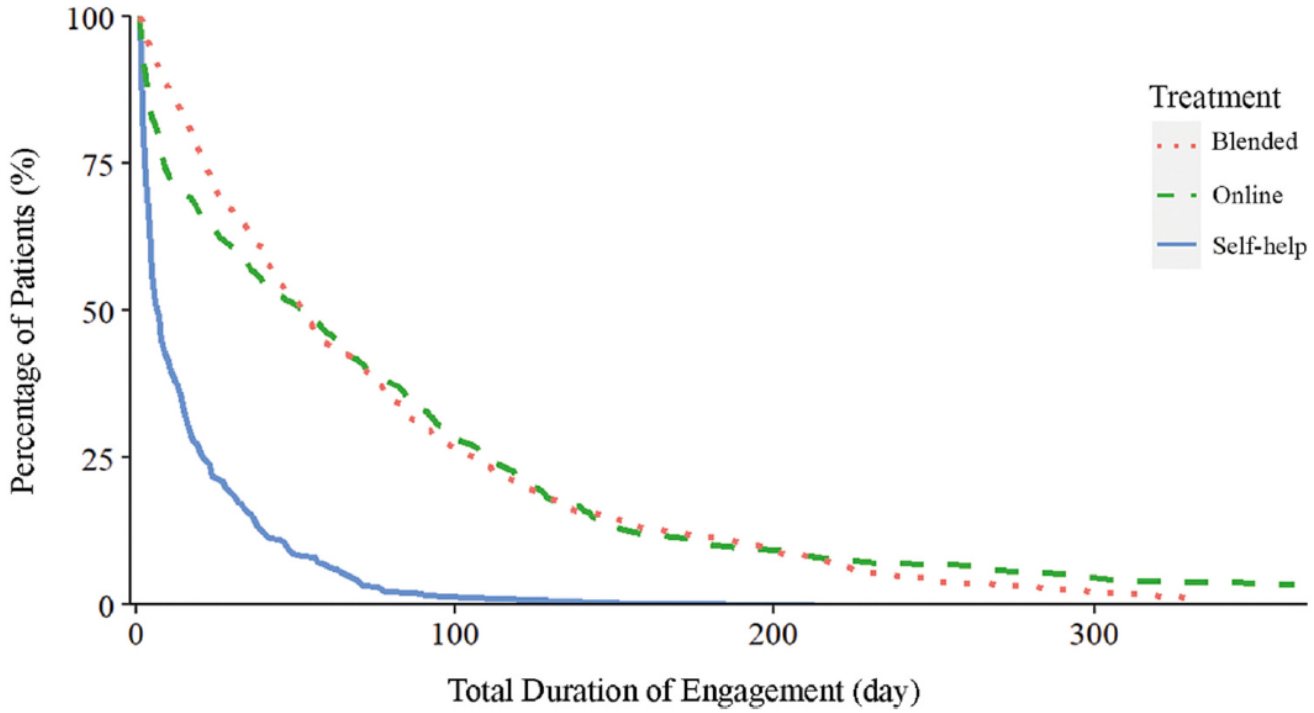


Fig. 1. Engagement with the platform across the three different treatment modalities.

Evaluate in routine care

Adoption – clinical population

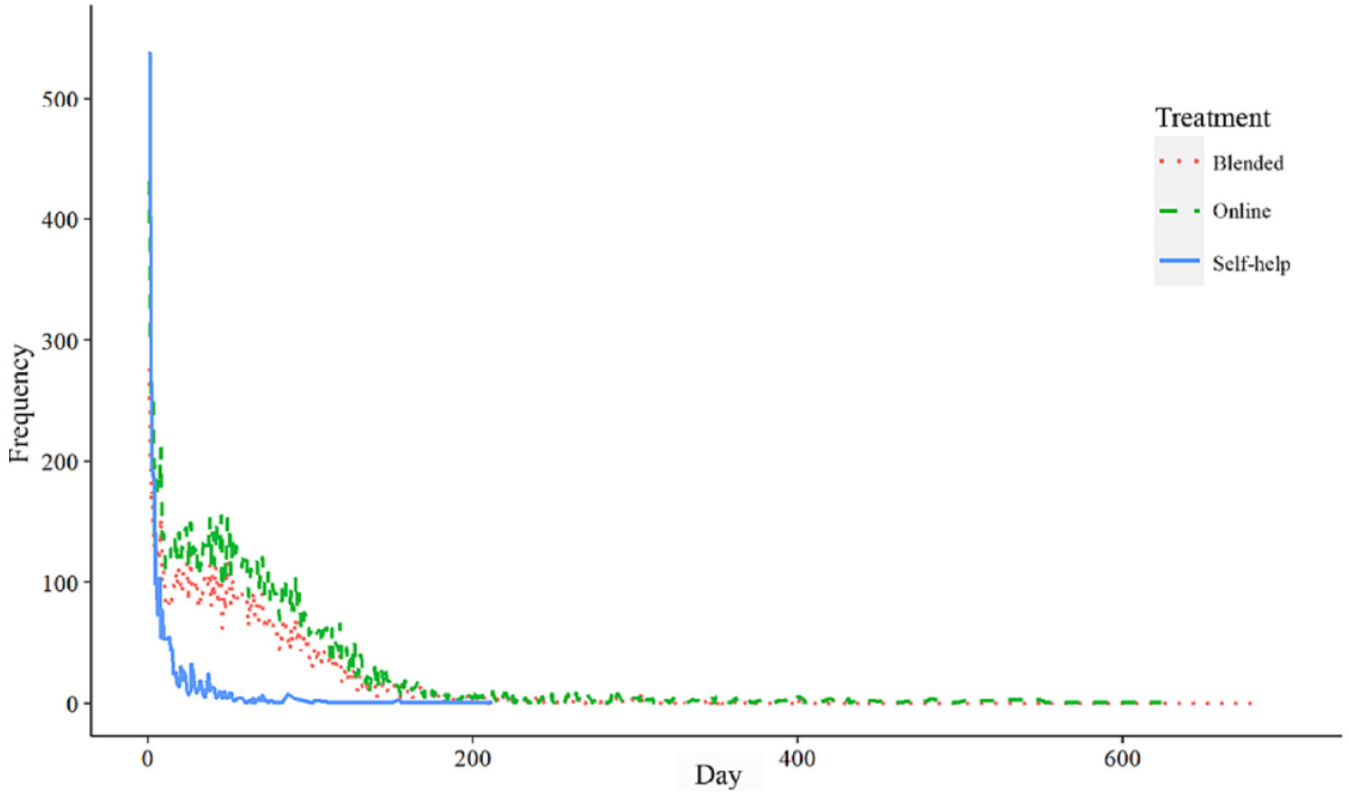


Fig. 2. Number of exercises in the trajectories over time in the three different treatment modalities.

Buelens et al. (2023)

Evaluate in routine care

Effectiveness - DMH

internet-delivered = conventional CBT

- for social anxiety disorder, panic disorder, depressive symptoms, body dissatisfaction, insomnia, tinnitus, male sexual dysfunction, spider phobia, snake phobia, and fibromyalgia

Tested in highly controlled RCTs

Some replications in routine care

Evaluate in routine care

Effectiveness - Blended

Variability in concepts & aims

- web-based programs with modules combining techniques, sometimes with email support.

Effects

- Documented effects in depression & anxiety
- Lower drop-out and/or higher abstinence in substance abuse
- Time & cost-effective (when implemented well)
  - Saves 50% to 86 % of clinician time without reducing therapeutic outcome

Erbe et al. (2017)

Evaluate in routine care

The efficacy and the effectiveness under routine care conditions needs to be evaluated.

Need to learn more about

- Adoption of digital mental health
- Effectiveness & potential harm
- How it works
- Cost-effectiveness

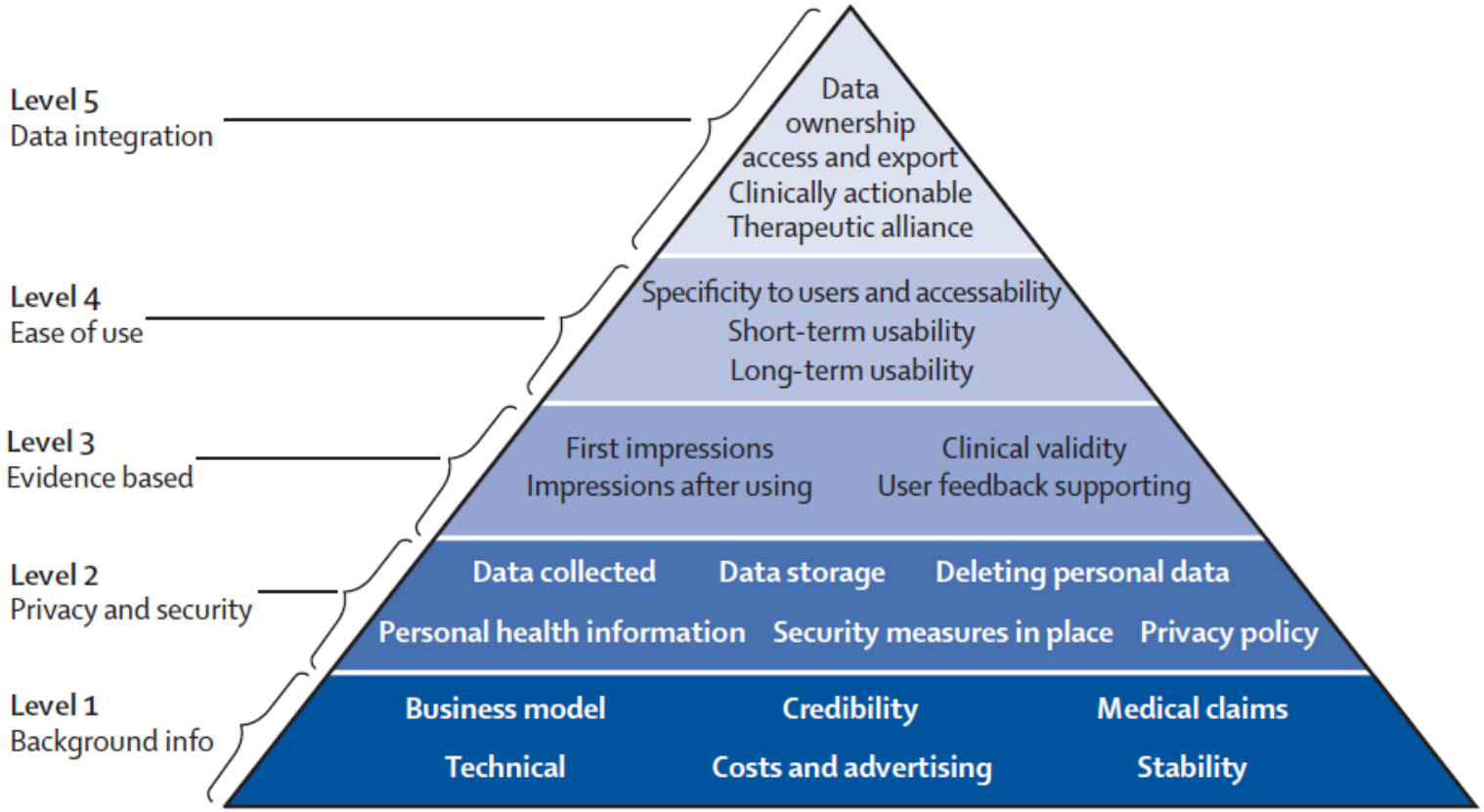
Guidelines & standards

Need for (inter)national guidelines and reporting standards for digital mental health.

Difficult to evaluate digital mental health interventions and provide this information to users.

Guidelines & standards

Hands-on: finding your own way



2

Guidelines & standards

Hands-on: finding your own way

Step 1: Gather Background Information

The first step of the model is to help ensure that as much useful background information about the app is known **before you evaluate it**. This information helps create a useful context in which you can consider using the app and provides a framework for your decision making. The questions below are to help you decide whether to proceed with the app evaluation. You do not need to have an answer for each question in order to proceed with evaluating an app.

- What is the business model? If the app is free, then how does it support its own development?
- Who is the developer?
- Does it claim to be medical?
- What is the cost? Does it require in-app purchases to unlock certain features? Is it free?
- Does it integrate advertising into its usability?
- On which platforms does it work (e.g., iOS, Android)?
- When was it last updated? How many updates have there been? What were the reasons for the updates (i.e., security updates; software glitches or bugs; improved functionality or added services)?

Guidelines & standards

Hands-on: finding your own way

Step 2: Risk/Privacy & Security

While nearly any measurement or intervention contains some risk (e.g., physical, psychological, legal, social, and economic), apps present some unique risks that may often be overlooked. Risks may include data costs associated with app use (i.e., depending on your data plan with your wireless provider), profiling, loss of benefits or insurability — all of which are associated with privacy and security. Digital privacy and security are not often high level risk factors when prescribing a medication or conducting in-person therapy when deciding to use an app, however, they are extremely important and should be the first area evaluated.

The questions below are intended to help you and your patient consider many aspects of app security and privacy. Note that they are not all-inclusive, as there is currently no "gold standard" for rating apps' privacy and security. Many of your answers to these questions should be found in the app's privacy policy. If there is no privacy policy then that is a very good reason to be concerned about that app.

For certain questions, like what security measures are in place, it is necessary to take the app's description at face value at this time. There is no cut-off or score for this level of the model; instead you and the patient will need to decide if—based on the answers to these questions—you feel the app meets your standards. **However, if you cannot find answers to many of these questions, or again there is no privacy policy, that is a good indication that you may want to avoid this app.** The ultimate goal of this level is to ensure an app will not cause harm by violating patient safety, security, and privacy.

- Is there a privacy policy?
- What data are collected?
- Are personal data de-identified?
- Can you opt-out of data collection?
- Can you delete data?
- Are cookies placed on your device?
- Who are data shared with/What data are shared?
- Are data maintained on the device or the web (i.e., "the cloud")? Both?
- What security measures are in place? Are data encrypted on the device and server?
- Does it purport HIPAA compliance? / Does it need to be HIPAA-compliant?

Guidelines & standards

Hands-on: finding your own way

Step 3: Evidence

App developers often make many claims even though there is currently little clinical evidence to support such. This does not mean that apps don't work, but rather that there is much we still do not know. If you decide that an app has sufficient privacy and security at Level 2, then your task at Level 3 is **to evaluate any evidence for potential benefits**.

While some apps' benefits have been documented in clinical studies, many — if not most — have not. In that case, we recommend that you download and try the app to see what it is actually doing and if the content and information it offers appear at least reasonable and not harmful (i.e., evidence of "face validity"). Again, few apps will have a gold standard, randomized double blinded placebo controlled study to suggest they are effective, so the questions presented below are designed to help you think of other ways you can make the best informed decision about an app's evidence base.

- What does it claim to do vs. what does it actually do?
- Is there peer-reviewed, published evidence about tool or science behind it?
- Is there any feedback from users to support claims (App store, website, review sites, etc.)?
- Does the content appear of at least reasonable value?

Guidelines & standards

Hands-on: finding your own way

Step 4: Ease of Use

To recap, if an app has satisfied criteria in Steps One and Two, then you may assume that:

1. It offers minimal risk in terms of digital safety and privacy
2. It appears to have some benefit.

Thus, Step 4 helps evaluate ease of us because an app is only as useful as you and your patients find it to actually use. Ease of use is a more subjective category and so different people will have very different ideas about what ease of use means to them. The questions below are, again, designed to help you think about the app's interface and overall functionality and then make an informed decision about how usable an app will be for the case and patient at hand.

- Is it easy to access for the patient at hand (i.e., based on patient diagnosis or other factors)?
- Would it be easy to use on a long-term basis?
- Is the app or are features of the app customizable?
- Does it need an active connection to the Internet to work?
- What platforms does it work on?
- Is it accessible for those with impaired vision or other disabilities?
- Is it culturally relevant?

Scoring the App

- 1: advise user not to proceed (bad)
- 2: advise user to proceed with caution (some concern)
- 3: advise user to proceed (appears ok)

Guidelines & standards

App information & evaluation

General evaluation vs.
personal assessment of fit

Future perspective:
self-certification program
interaction developer - user

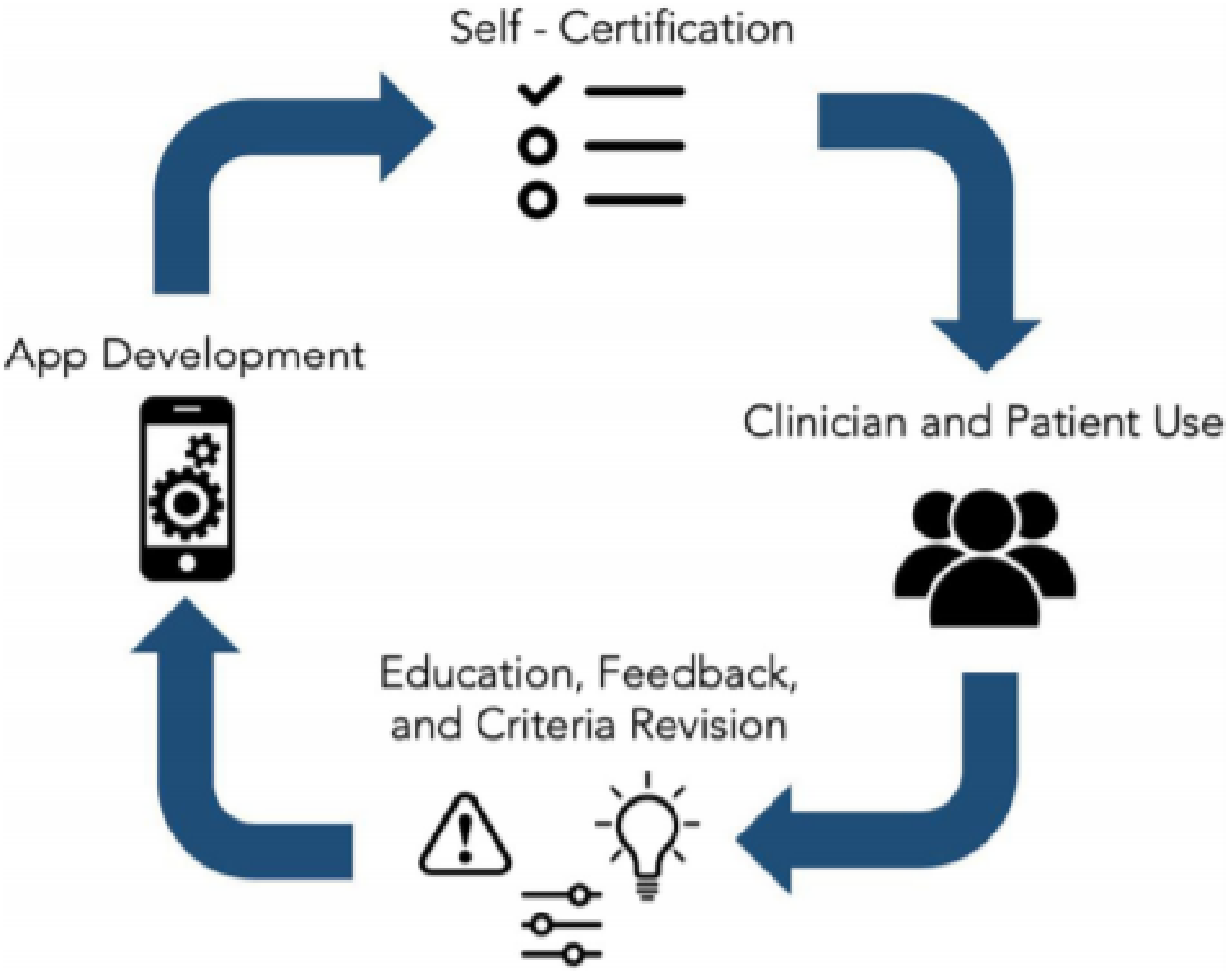


Fig. 1 A schematic of the self-certification system towards improving transparency and empowering patients, clinicians, and technology developers to take an active role in regulating digital health tools

Guidelines & standards

App information & evaluation

Characteristics of interventions
to be reported

- background and credibility of content creators
- detailed overview of specific intervention features
- adherence to data protection and privacy regulation
- current evidence-base for efficacy & effectiveness
- costs
- conditions for use (e.g., level of support required)

Guidelines & standards

App information & evaluation

Websites that offer app overviews

- The division of digital psychiatry at BIDMC
  - https://apps.digitalpsych.org/
- NHS health & wellbeing apps library
  - https://www.nhs.uk/apps-library/
- Apps with CE/FDA approval:
  - https://apps.healthskouts.com/
- Appstore for mental health in Flanders:
  - www.onlinehulp-apps.be
- ORCHA (but requires membership)

online help apps

your guide to apps and websites forwelfare andmental health

Find the app or website you need:

Type to search...

– All themes

TO SEARCH

Featured: Volunteers Matter! Also in welfare work.

Well

Children and young people can go to listening line Awel for a listening ear about everything that concerns them.

Click here for it →

Give a Day

Give a Day matches requests for help and offers. Neighborhoods, municipalities, organizations and associations can launch their offer for volunteers there. And as a citizen you can look for volunteer work that suits you.

Click here for it →

helper

Helpper connects people seeking help with day-to-day tasks with helpful helpers nearby.

Click here for it →


onlinehulp-apps
Find apps
Submit an app yourself
Frequently Asked Questions
About
CONTACT
online help apps
your guide to wellness and mental health apps
Home / Apps overview
RESET ALL FILTERS
Type to search...
from a to Z
Show by 12
Available via
Target audience
Theme
Contact with professional
Language
Cost price
140 search results
10,000 steps
10,000 steps is an online diary in which you can register your steps and movement every day.
Click here for it
123 DiGiT
123 DiGiT offers free teaching materials to become digitally wiser yourself or to organize training courses about this as a supervisor of digitally vulnerable people
Click here for it
1712
This website offers information and/or personal advice on violence, abuse and child abuse.
Click here for it
Aphasia Therapy
Aphasia therapy was created for speech therapists to enable people with aphasia to practice more intensively and more often in practice or at home.
Click here for it
Alcohol help
All about cancer

Guidelines & standards

App information & evaluation

Websites that digs through privacy policies

- Mozilla Foundation's *Privacy Not Included
  - also specifically for mental health apps https://foundation.mozilla.org/en/privacynotincluded/categories/mental-health-apps/

* Privacy Not Included

moz://a

Sort by

- Creepiness: Least – Most
- Creepiness: Most – Least
- Alphabetical

Headspace

Headspace, Inc

Wi-Fi

Review date: April 25, 2023 | Mozilla researched 16 hours | Mozilla says | People voted: Somewhat creepy

Headspace says their mission is to improve the health and happiness of the world. Founded by a former monk who also seems to have a love for the circus, Headspace offers guided meditation and mindfulness tips as well music from John Legend to help you fall asleep. This popular app -- the company claims over 70 million members in 190 countries around the world -- says it wants to be 'your mind's best friend," which sure does sound nice. Seems your mind's best friend also might like to collect and share your data with places like Facebook and Google though so maybe hold off on that BFF label for now.

*Privacy Not Included

moz://a

Sort by

- Creepiness: Least – Most
- Creepiness: Most – Least
- Alphabetical

⚠ What could happen if something goes wrong?

Believe us when we say this: Nissan's privacy policy is probably the most mind boggling creepy, scary, sad, messed up privacy policy we have ever read. And we here at *Privacy Not Included read a LOT of privacy policies. Please people, if you care even a little about privacy, please stay as far away from Nissan's cars, apps, and connected services as you possibly can.

Here's why: They come right out and say they can collect and share your **sexual activity, health diagnosis data, and genetic information** and other sensitive personal information for targeted marketing purposes. We absolutely aren't making that up. It says so in their Nissan USA privacy notice. And that's not all! They also say they can share and **even sell** "Inferences drawn from any Personal Data collected to create a profile about a consumer reflecting the consumer's preferences, characteristics, **psychological trends, predispositions, behavior, attitudes, intelligence, abilities, and aptitudes**" to others for targeted marketing purposes. Yes, Nissan says they can infer things like how smart you are, if you have a predisposition to drink, if you are acting depressed, and if you are any good at chess

Who to hold responsible

Clients should know which psychotherapist and/or organization can be held responsible.

Psychotherapists should

- Let clients know who is behind the screen
- Share their credentials, licensure, theoretical and therapeutic approach and experiences

Who to hold responsible

Clients should know which psychotherapist and/or organization can be held responsible.

Systems should

- Use content from theory-driven, evidence-based psychotherapeutic approaches
- Use **Persuasive theory**: human communication that is designed to influence others by modifying their beliefs, values, or attitudes

Who to hold responsible

Persuasive Theory

How to promote a sense of system credibility in clients

- Trustworthiness
  providing truthful, fair, and unbiased information
- Expertise
  demonstrating knowledge, experience, and competence
- Surface credibility
  sense of credibility upon first inspection

Who to hold responsible

Persuasive Theory

How to promote a sense of system credibility in clients

- Real-world feel
  ability to communicate with the people behind it
- Authority
  materials from/evaluated by an acknowledged authority

Who to hold responsible

Persuasive Theory

How to promote a sense of system credibility in clients

- Third-party endorsements
  support from reliable sources (e.g., university)

- Verifiability
  accuracy of content can be checked via outside sources (e.g., peer-reviewed research articles)

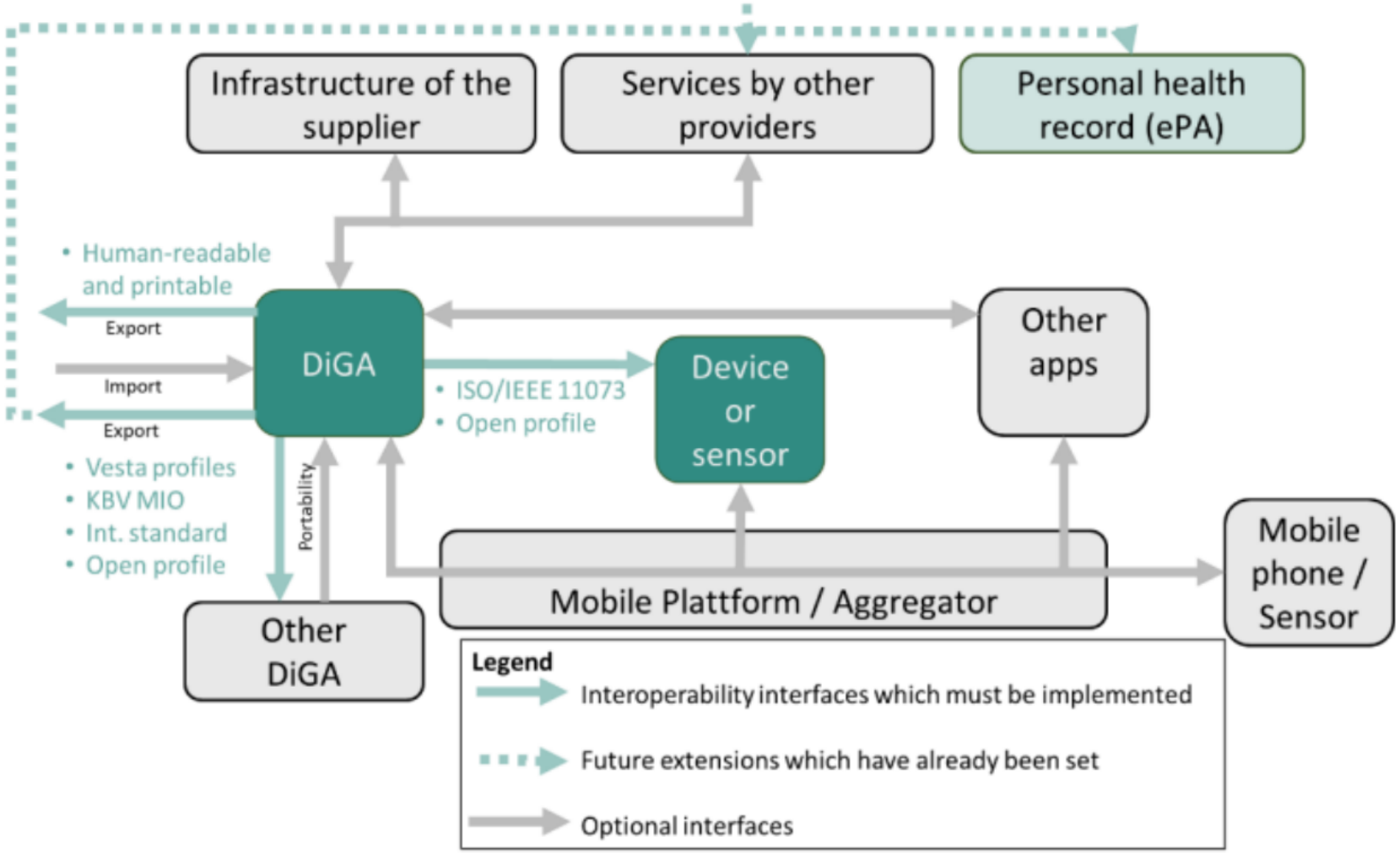
Easy switching

Switching to another intervention should be made easy for the client.

Interventions do not always work or can be harmful, so switching should be possible

Need for ‘interoperable systems’: systems than can communicate and transfer data

Digitale Gesundheitsanwendung - DiGA



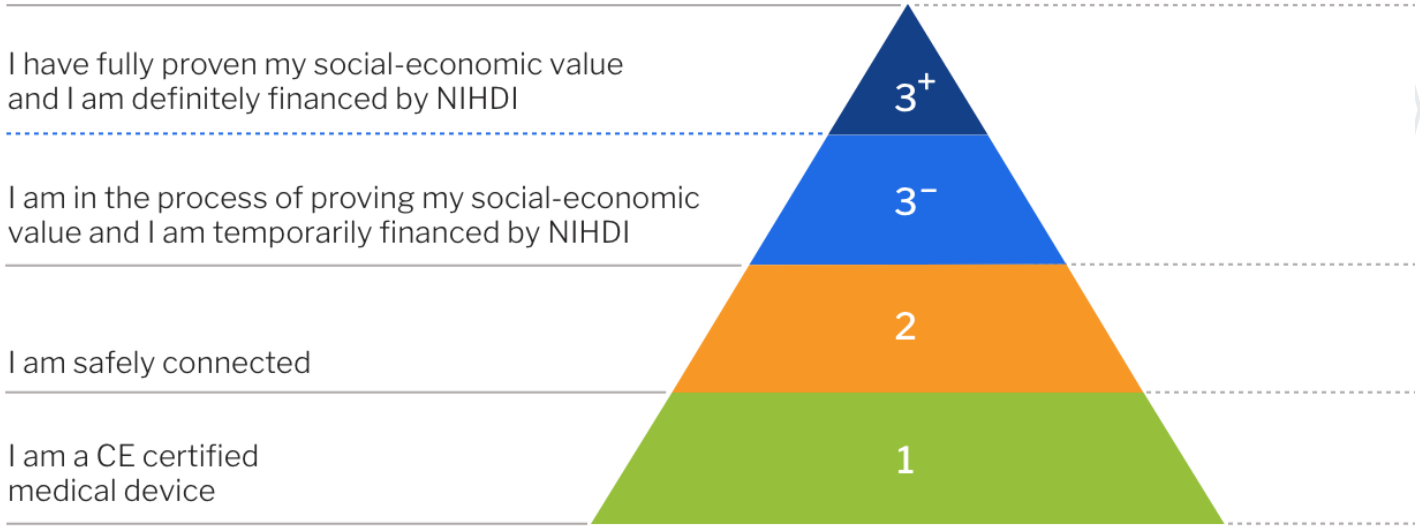
Reimbursement

Reimbursement by healthcare systems is a prerequisite for sustainability of digital mental health.

Criteria should be set on existing evidence base (e.g., guided vs. unguided)

Reimbursement

Belgium: validation pyramid



5

Reimbursement

The case of Deprexis

Germany
DiGA fast track

France
Early access programme specific for innovative Medical Devices

Reimbursement

The case of Deprexis, in Germany

Accepted for permanent reimbursement under DiGA framework

- on the basis of mainly 2 RCTs on 163 and 1013 patients
- showing significant improvement on the Patient Health Questionnaire 9
- compared to the control group receiving usual care.

Reimbursement

The case of Deprexis, in France

Not accepted for reimbursement under early access programme for innovative medical devices.

- for this programme, demonstration of clinical effectiveness alone ≠ sufficient
- also significant improvement of sufficient magnitude in health state
- studies on Deprexis showed mild to moderate improvement, criterion ≠ fulfilled

Quality criteria for professionals

Given that specific standard trainings are often lacking, quality criteria for professionals should be determined.

Need for adequate background
& sufficient continuous education
for use of e-mental health interventions.

Digital (mental) health is rarely in curricula.

6

Adequate conditions

Health services should assure adequate conditions for optimal use of digital mental health, both for psychotherapists and clients.

Professional needs suitable location, equipment & time

Client also needs sufficient facilities, knowledge, & skills

Requires public funding

7

Continuity

Services should guarantee continuity of IT systems for healthcare.

High-quality, interoperable platforms & records:

- improved care
- client empowerment
- decreased documentation burden

Updating for cybersecurity

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recommendations for developers

Multidisciplinarity

Development of digital mental health should always be a theory- and best-practices-driven, multidisciplinary endeavor.

Absolutely necessary

- Psychological theory & evidence
- Technological theory & design principles
  - Good interface & goal-oriented approach (e.g., gamification, narratives, avatars) can lead to increased motivation, self-efficacy, and even effectiveness

Multidisciplinarity

Deepfake therapy

Pathological mourning

vs

Perpetrator confrontation

Multidisciplinarity

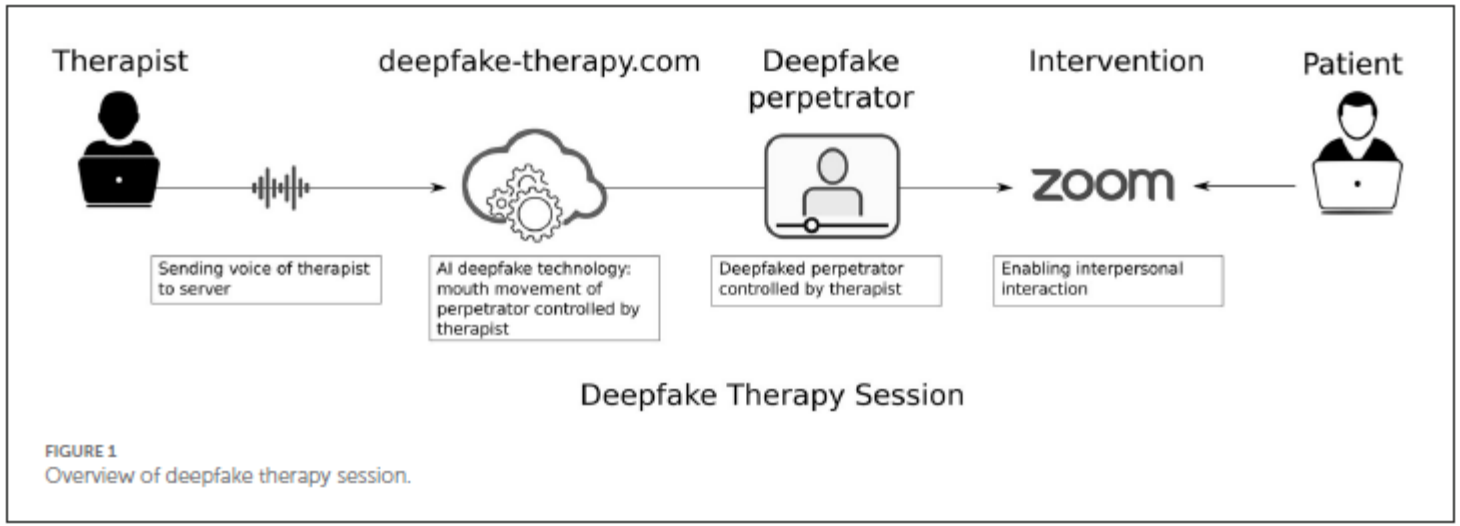
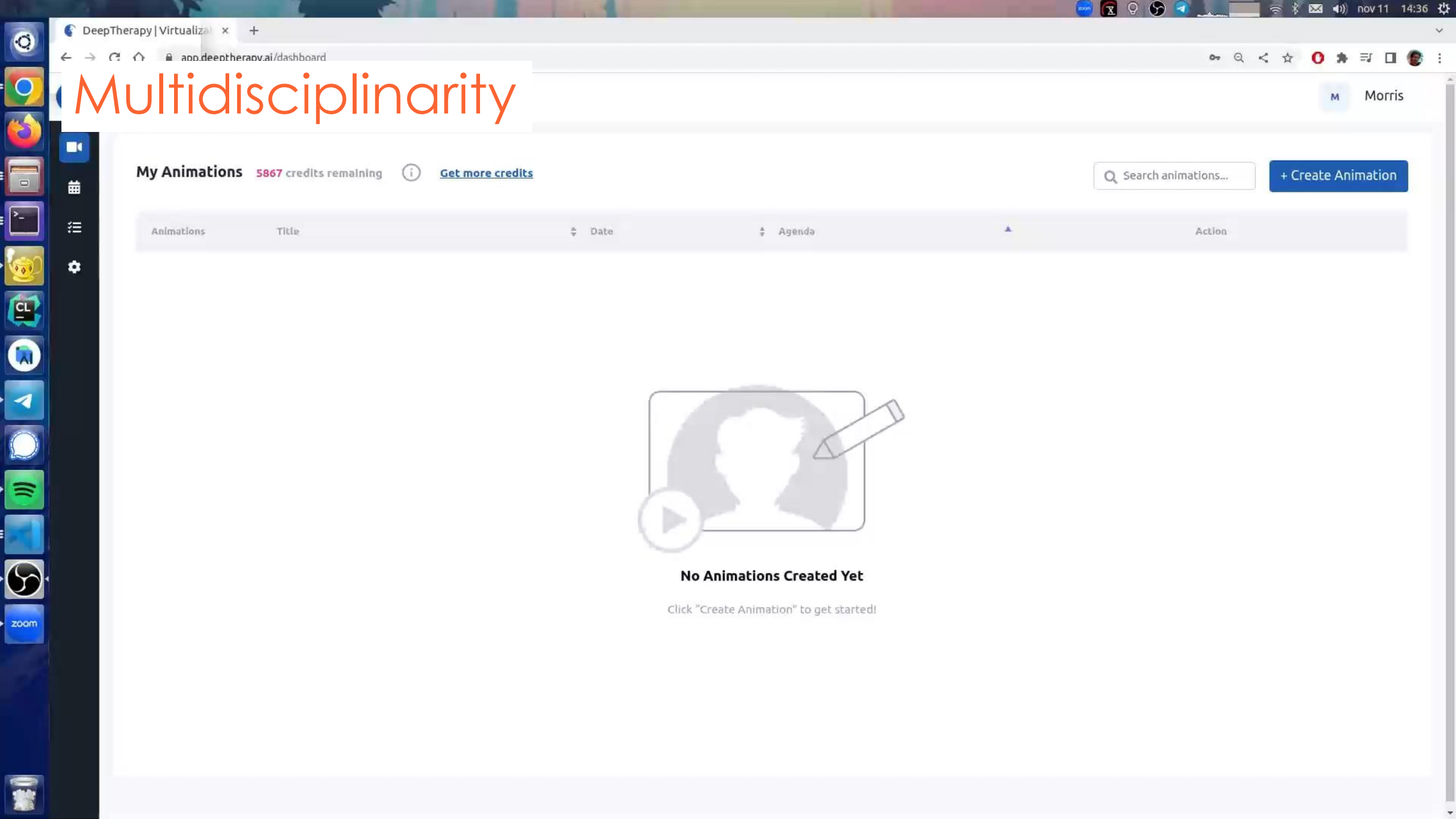


FIGURE 1
Overview of deepfake therapy session.

1

Multidisciplinarity



Multidisciplinarity

Deepfake therapy

1

Tailor to target population

Digital mental health needs to be adapted to the proposed target population and its context.

Keep in mind: cultural factors, comorbidities and severity of different mental disorders.

Severe depressive symptoms
→ new online intervention?

Tailor to target population

Severe symptoms are often a contra-indication.

But chat can also offer help in acute distress

- Suicide prevention
  - Lifeline crisis chat (USA)
  - Zelfmoordlijn (Belgium)

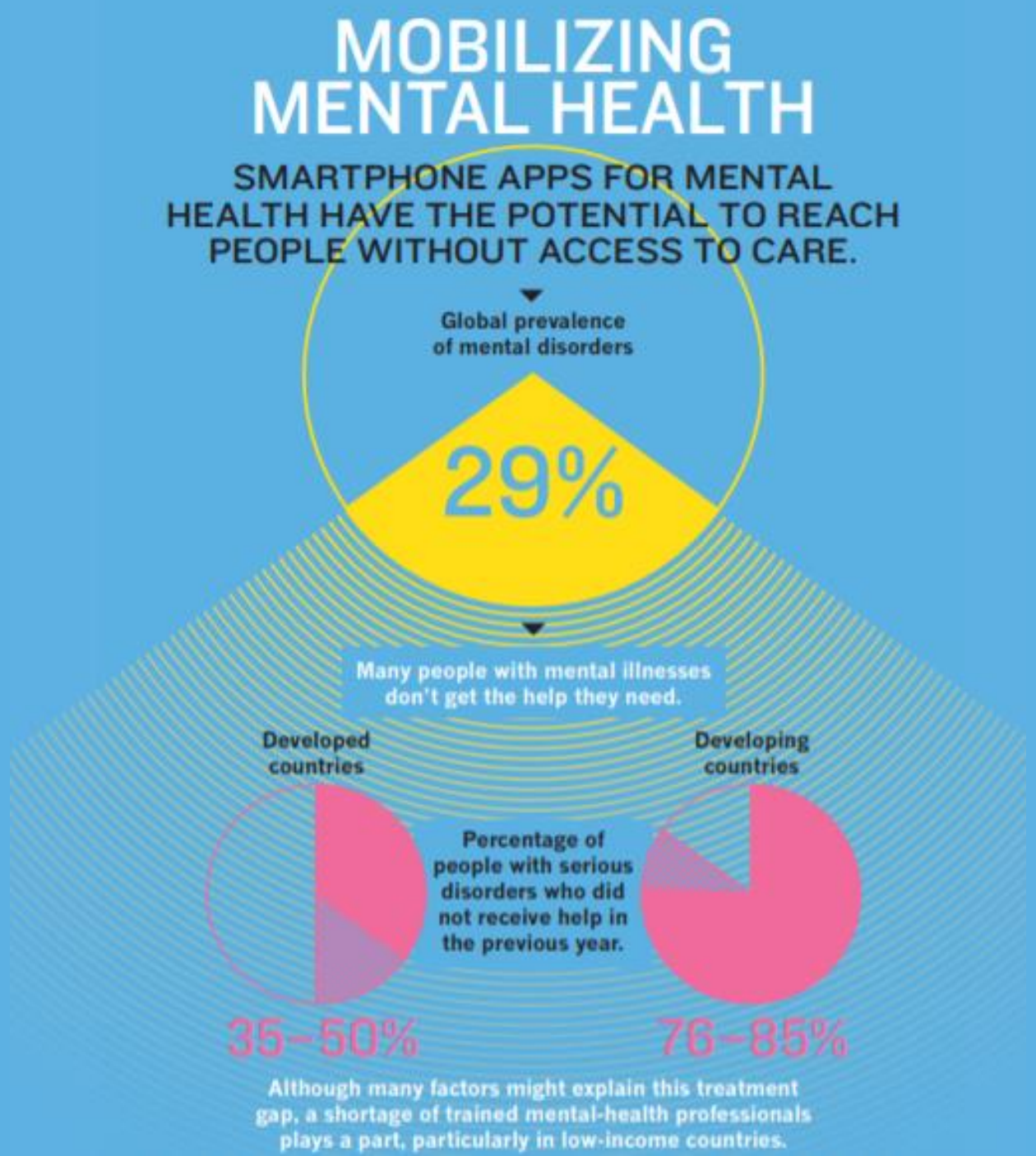
- General mental health problems
  Mental health commission (Australia)

Tailor to target population

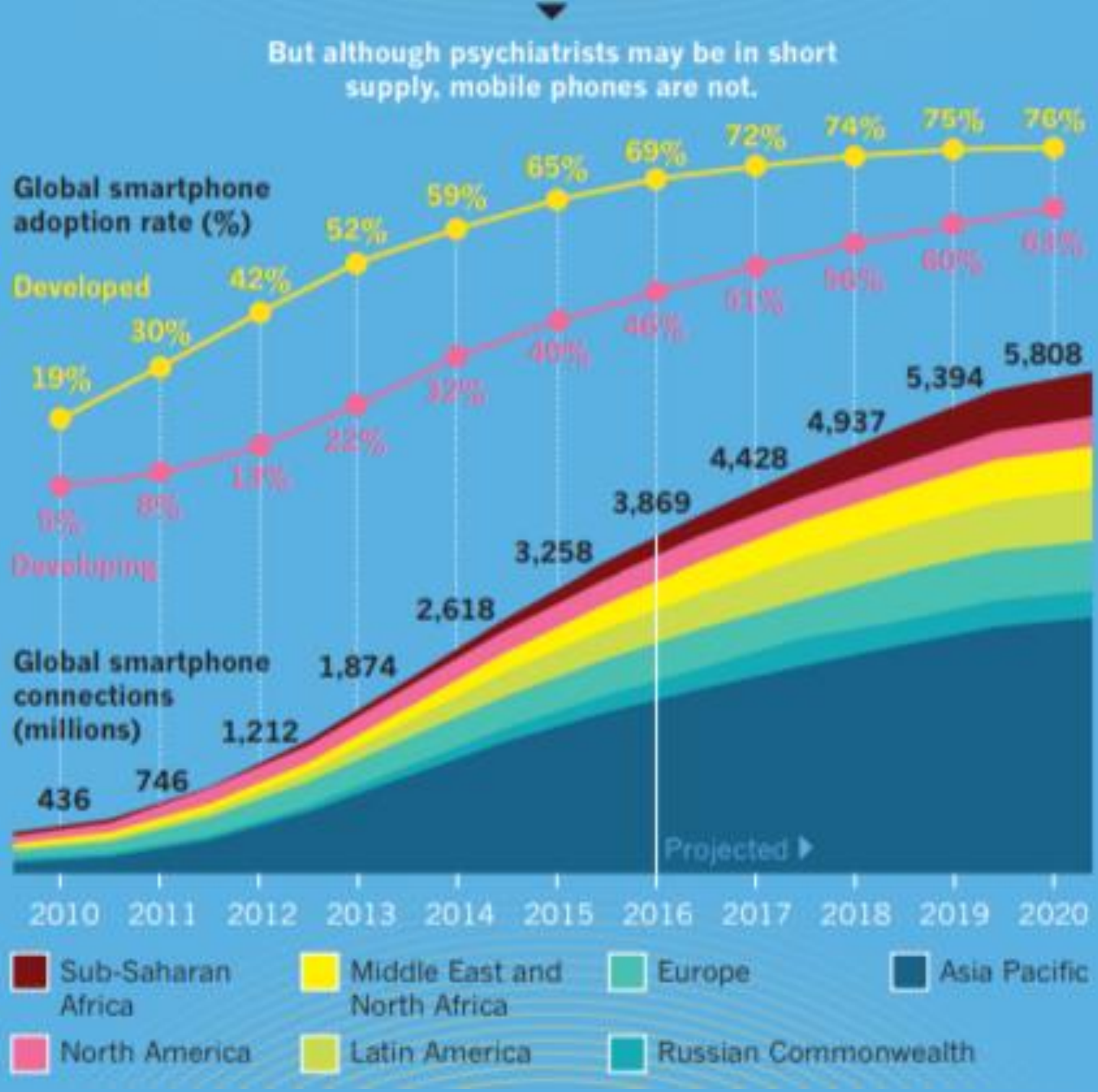
Keep in mind: cultural factors, comorbidities & severity of different mental disorders.

Severe depressive symptoms
→ new online intervention?

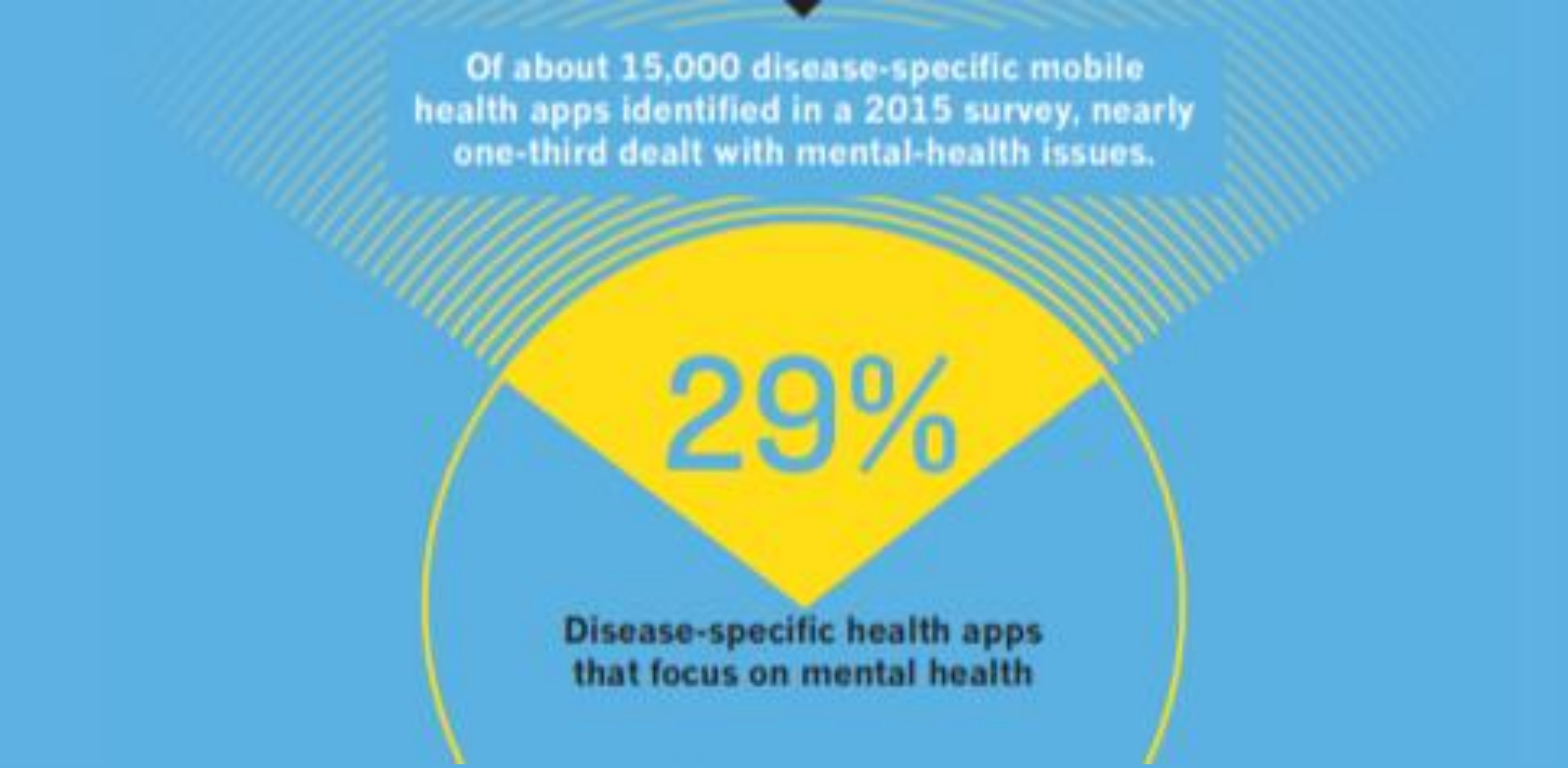
Reach: large accessibility of smartphones & continuum of mental health



Anthes et al. (2016)



Anthes et al. (2016)



Anthes et al. (2016)

Tailor to target population

Keep in mind: cultural factors, comorbidities & severity of different mental disorders.

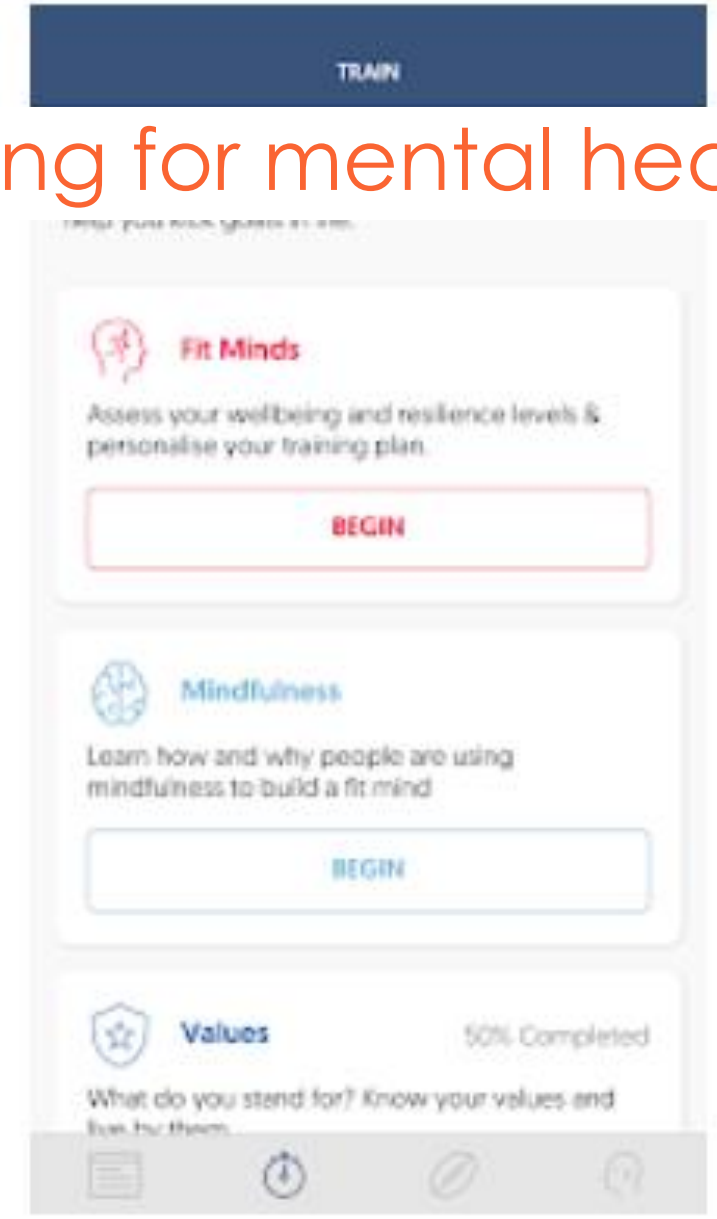
Severe depressive symptoms
→ new online intervention?

Reach: large accessibility of smartphones & continuum of mental health

Tailoring can occur based on theoretical, behavioral, or demographic information

Lower help seeking for mental health in men

Mindmax app



Comply with legal regulations

Digital mental health needs to comply with legal regulations and assure a safe service.

Regulatory frameworks taking shape

Many applications not properly regulated by the FDA

- solely claim to target symptoms (not diagnose or treat disorders)
- estimated to have low potential for harm.

Comply with legal regulations

The case of Vastaamo

Ethical standards

Maintaining ethical standards should be an overarching goal.

Pay attention to

- Process
- Contact details of psychotherapists
- Risks (e.g., likelihood of technical difficulties)
- Confidentiality and privacy

Transparent reporting

Involve users

Involve end users, clients & professionals, in the design process.

To maximize potential use, digital mental health should be based on needs

Surveys, focus groups, interviews or hands-on experience with wireframes and prototypes.

Involve users

Successful User Participation Examples and Recommendations in Digital Mental Health

https://www.interregnorthsea.eu/super

Evidence-based approach

Developers should consider an evidence-based approach.

Commercial apps often not based on theory.

Currently mostly CBT-based, but other approaches also possible

Also persuasive theory

Evaluation evidence

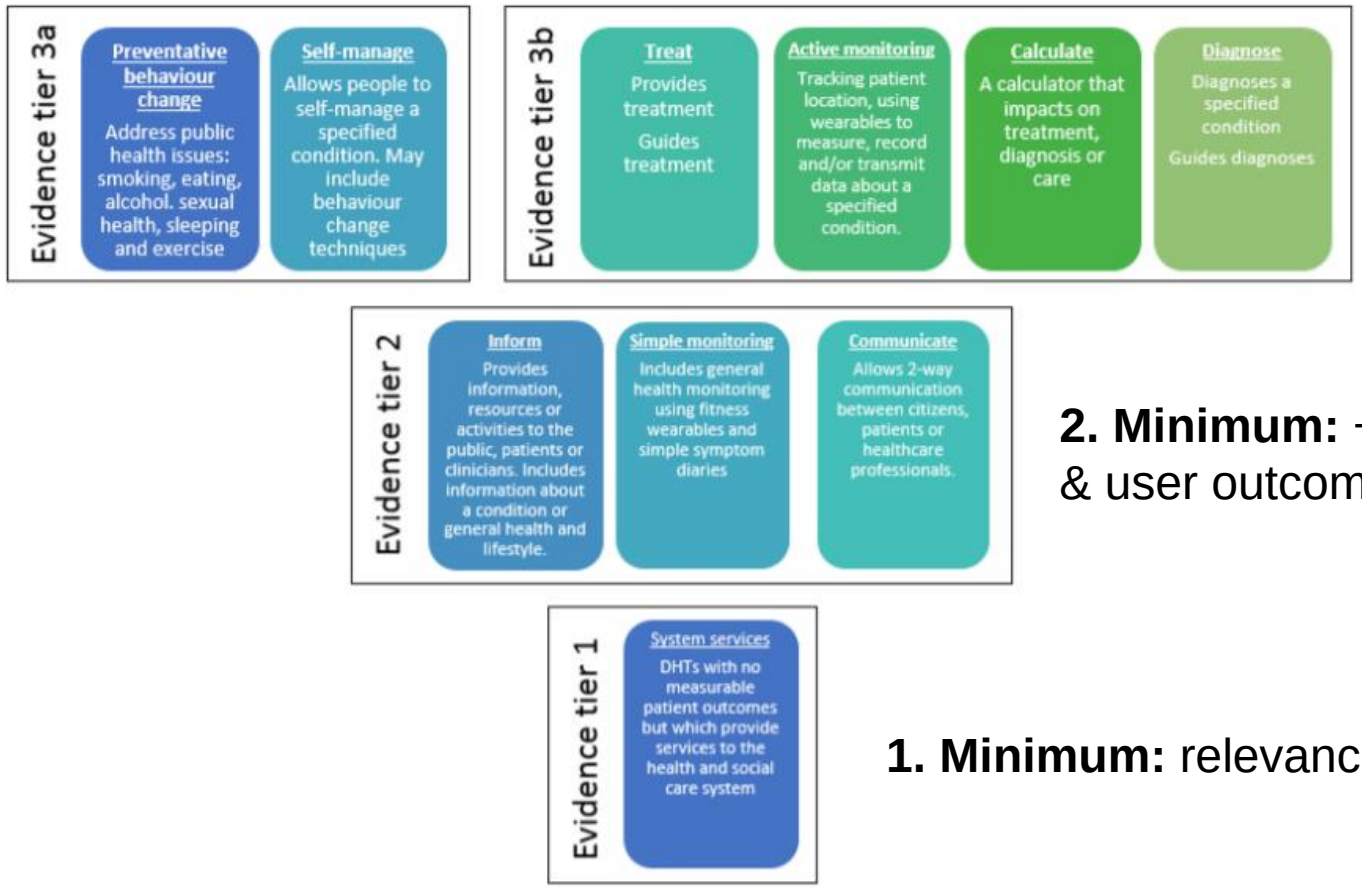
Developers should consider an evidence-based approach.

Randomized Controlled Trials (RCTs)

Different applications, different risks, different evaluation needed.

Evidence-standards framework (NICE)

Figure 1 DHTs classified by function and stratified into evidence tiers



3a Minimum: high quality observational or quasi-experimental studies

3b Minimum: High quality intervention study

2. Minimum: + data collection on usage & user outcome & satisfaction

1. Minimum: relevance, accuracy & technical, pilot

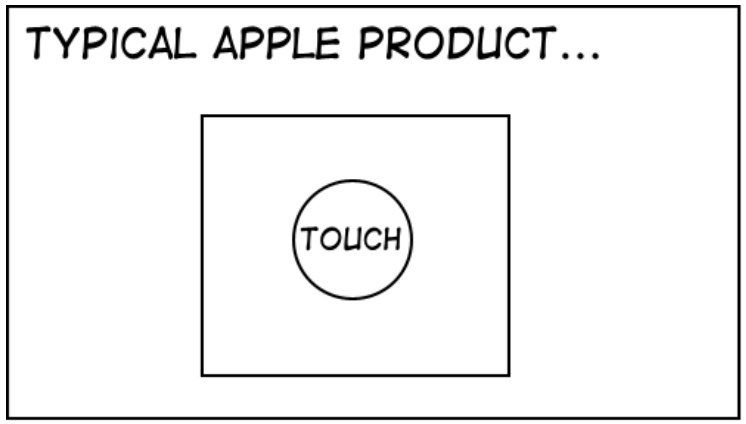
Adoption

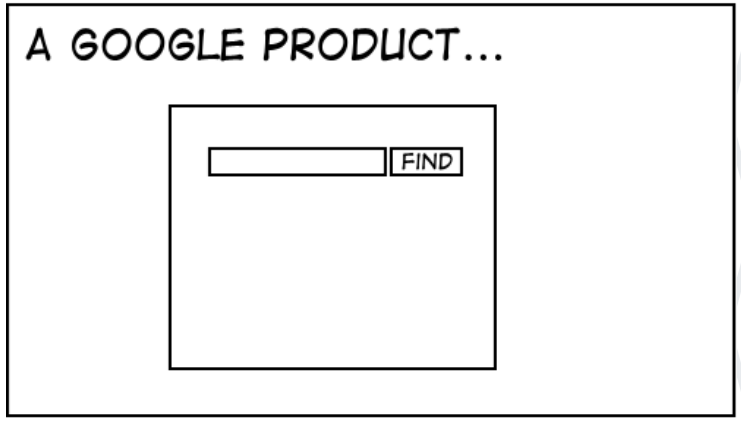
Developers should, account for factors that contribute to adoption.

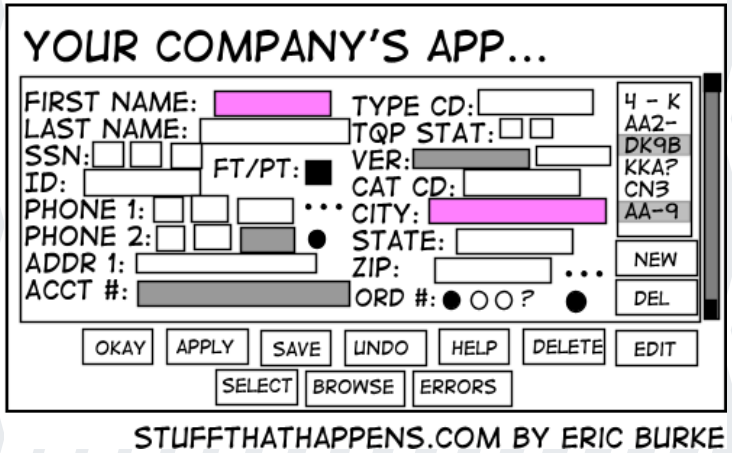
Developers should

1) assess users' digital literacy
2) aim for simplicity
3) aim for flexible use
   (e.g., smartphones, tablets, computers)
4) plan for technical assistance availability
   and easy video tutorials

Adoption







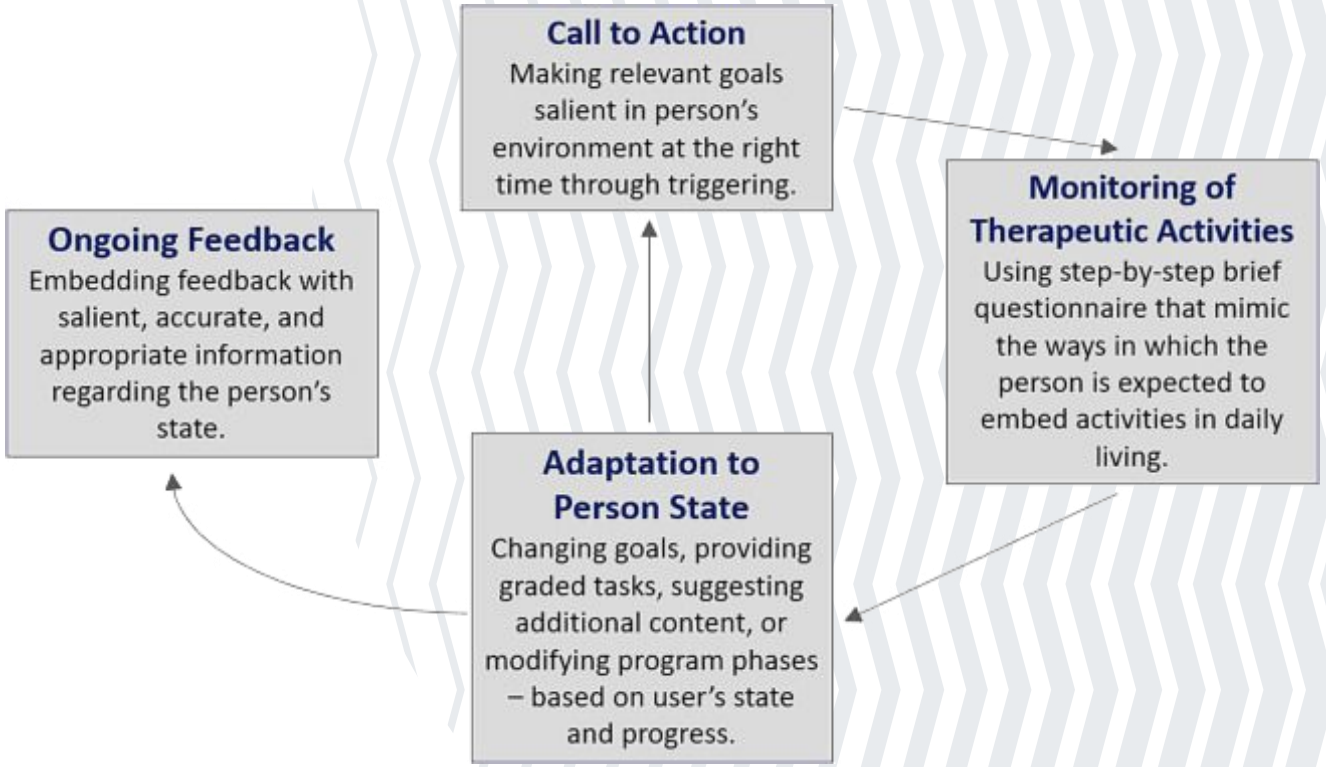
STUFFTHATHAPPENS.COM BY ERIC BURKE

Adoption

Product design matters.

Completion rates

- Standard eLearning platforms: 28%
- unguided digital parent training program: 69%



Baumel et al. (2023)

Adoption

Developers should account for factors that contribute to adoption.

“There are few examples of implementing a combination of different design requirements in real world products”

Aryana et al. (2019)

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Telepsychology: EFPA recommendations for ethical practice

Background

Growth in digital services

Solely online,
as well as blended

EFPA guidelines to update ethics codes to consider impact of technological innovations.

Ethical challenges

Impoverished communication

Security considerations

Competencies & evidence

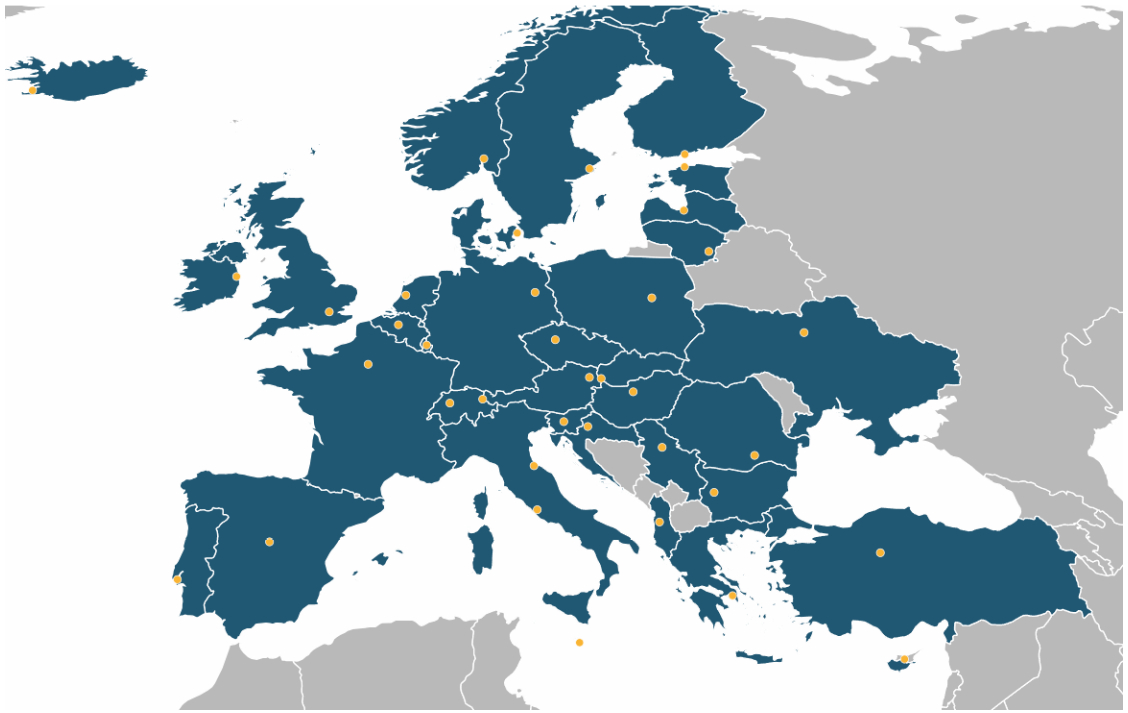
Cross-national issues

Recommendations & general principles

Each organization should produce a statement.

Ethical dimensions are nonetheless always the same.

Different mediums and communication settings may pose specific challenges.



Specific guidance

Security

Identity of the psychologist

Psychologists can make use of internet & social media to establish online presence.

Should be easily identified as such.

Any AI provision should be made clear.

"I could "simply" enter my patient's names and their contact information on their special marketing platform, and it would contact my patients with a request for reviews for me."

Lucas (2023)

Security

Identity of client / users

Should normally be required.

If anonymity is preferred,
additional caution should be exerted.

Security

Protection

Best practices around data security (e.g. MFA) & encryption.

Training in cybersecurity

Clear protocol in case of breaches.

Confidentiality

Recognition of limits

Communicate clearly
on relevant legislation
and limits to confidentiality
(e.g. subpoena of records)

Confidentiality

Maintenance of records

Keep appropriate back-ups.

Clarity regarding (mutual) registration and storage.

Presence of ‘third parties’.

Appropriateness

Explore tech, but with caution
if evidence base is limited.

Be aware of varying affordances.

Practice within range of competences.

Avoid exaggerated claims
on success of service.

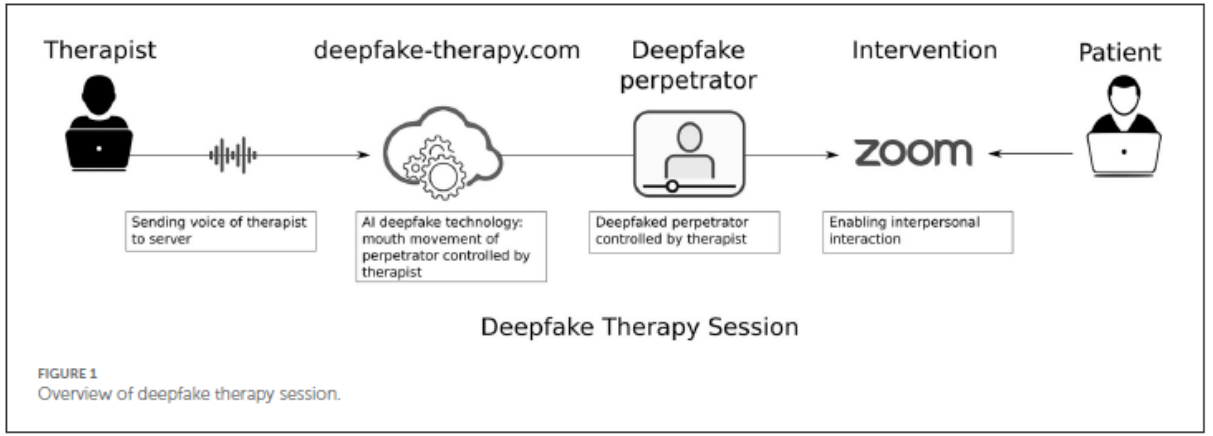


FIGURE 1
Overview of deepfake therapy session.

Special characteristics of services via the internet

Mode of delivery & turnaround time

Role of AI

Geographical location and implications

Need for training & CE

Need for suitable working environments

Special characteristics of services via the internet

Psychological assessment

User support

Separating private and professional data

Exploring optimal ‘dosage’ of tech

Conclusion

Rapidly evolving field requiring monitoring of practice & frequent reviewing of ethical codes.

Online presence of national associations.

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Data life cycle & eHealth

Overview

Open Science

Research data management

Data management plan

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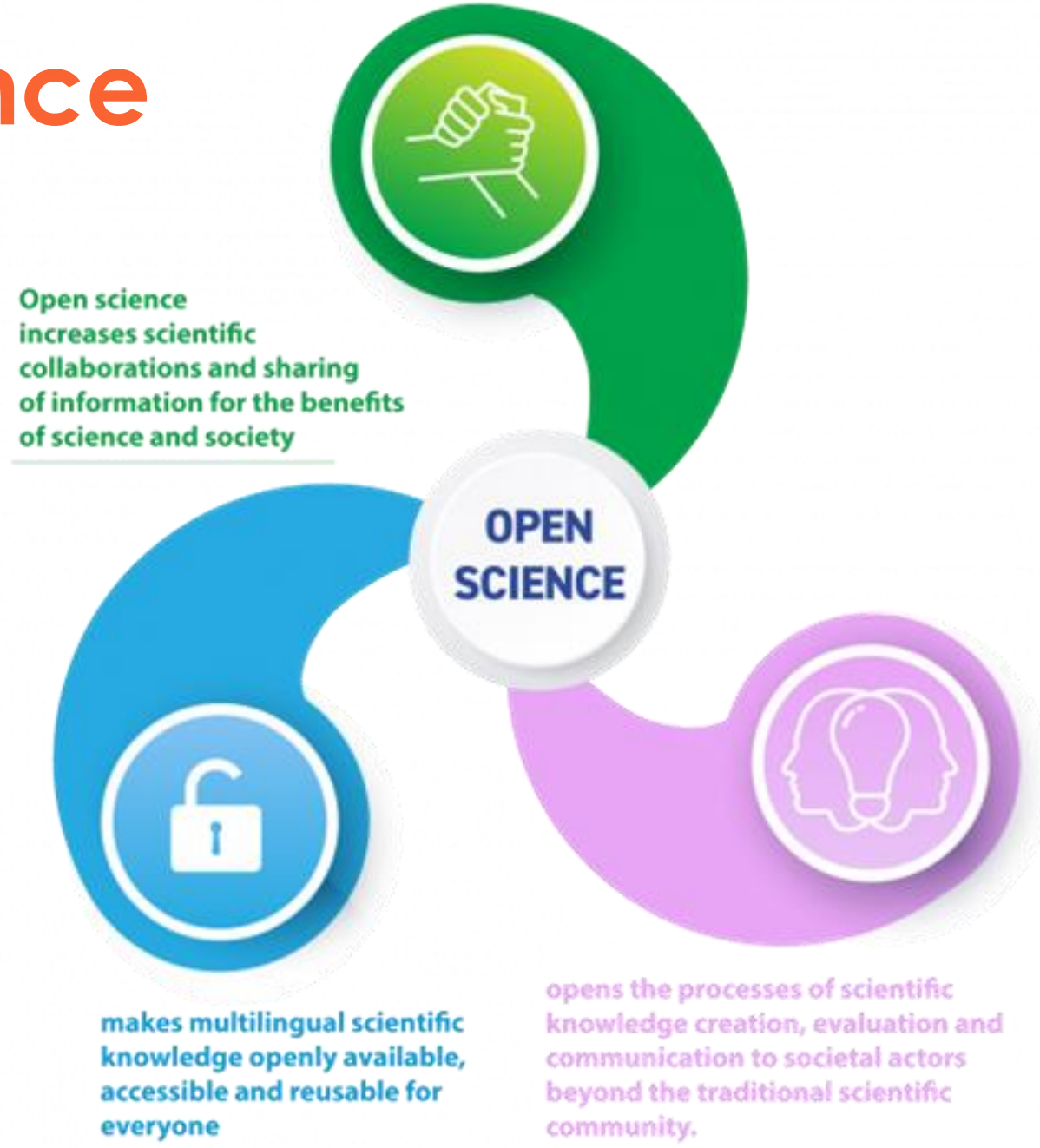
Open Science

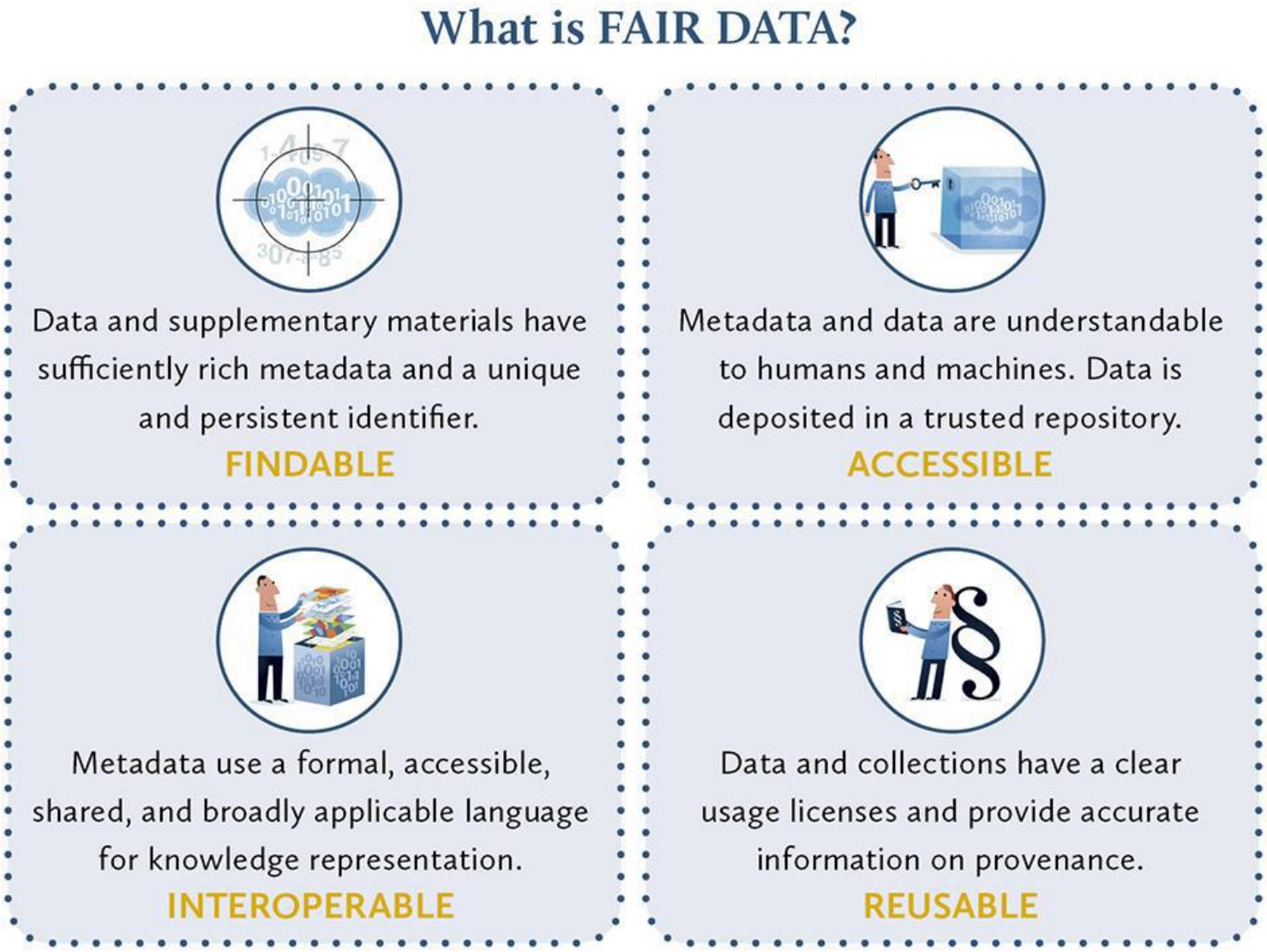
Open Science



Open Science

CC-BY Danny Kingsley & Sarah Brown

Open Science



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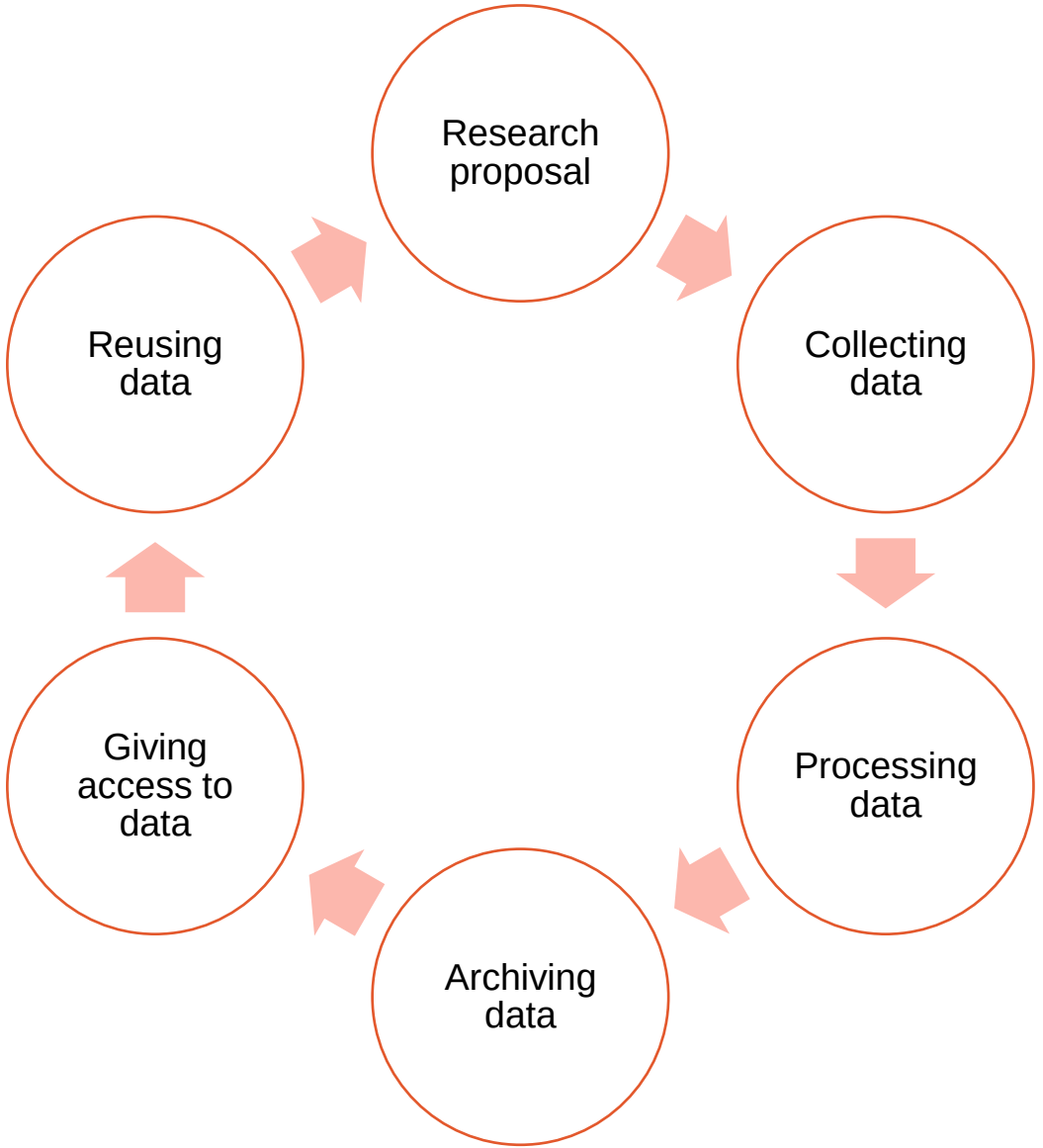
Research data management

Based on Noppe, Vanvelk, & Ninotsjka (2023)

Research data management

Managing, storing and sharing data at every stage of the research process

Integral part of research planning



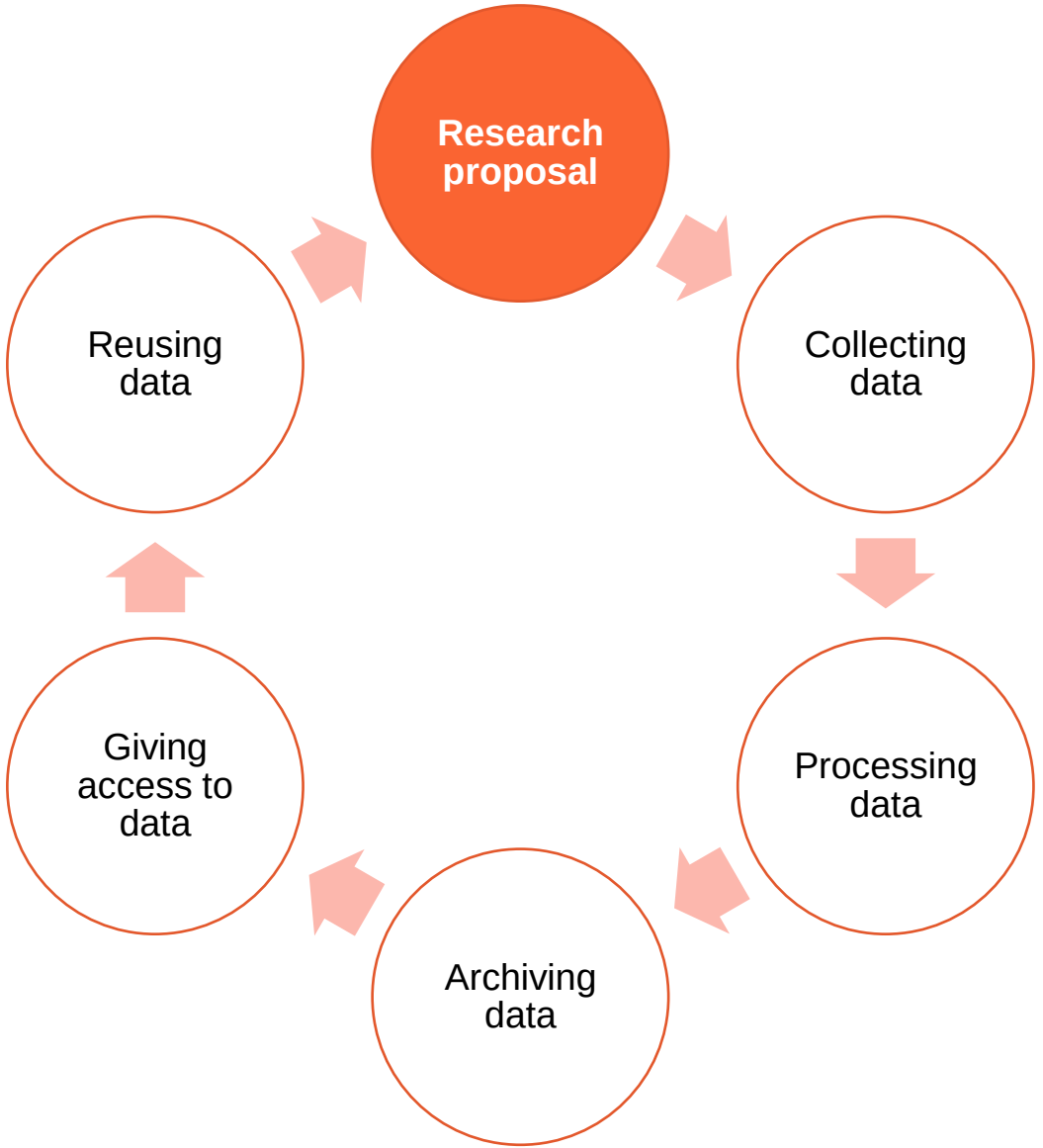
Research data management

Data management plan

Ethics

Intellectual property rights

Related infrastructure



Research data management

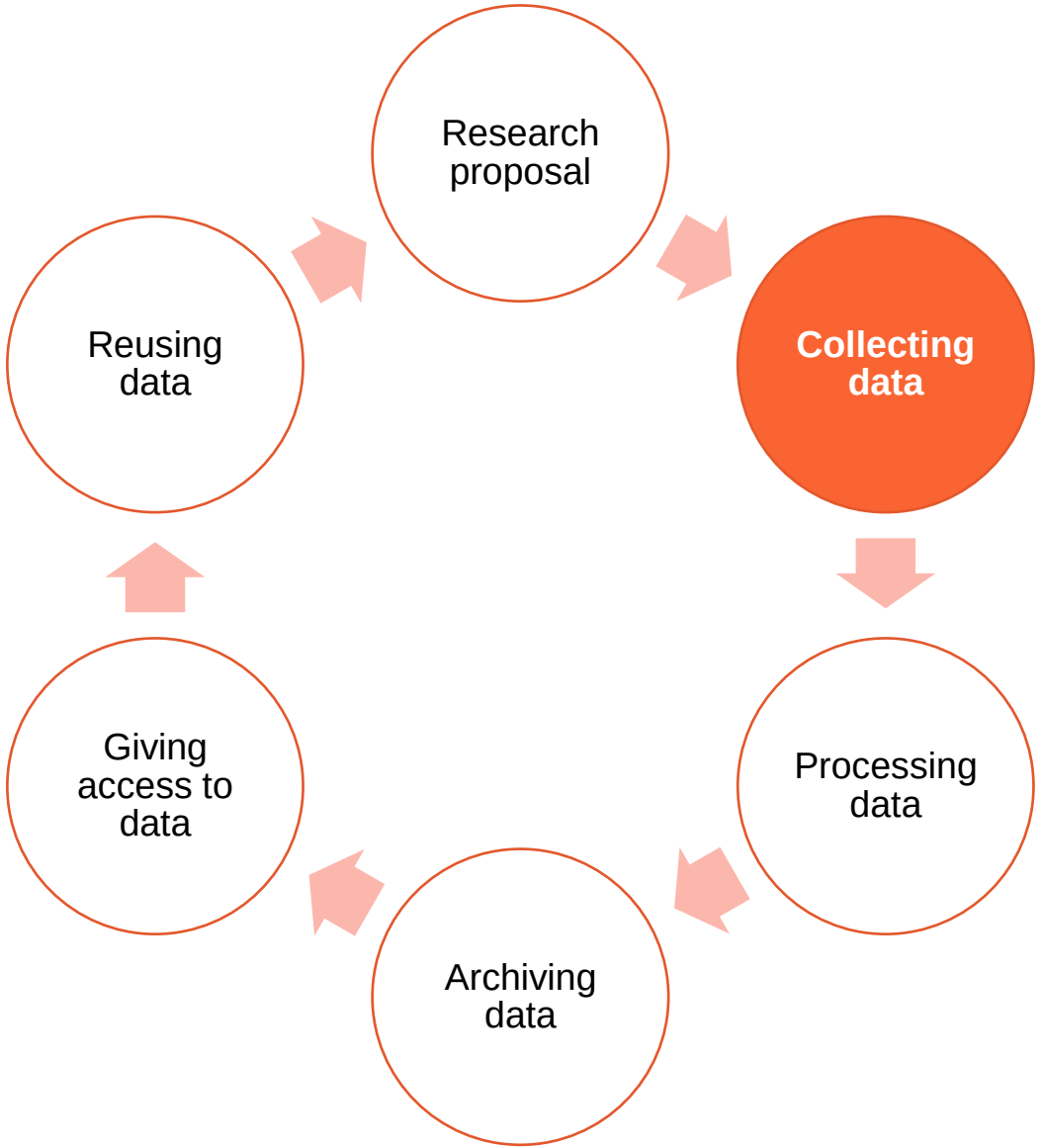
Types and formats of data

Naming and organising files

Storage and backup

Metadata and documentation

Related infrastructure



Research data management

Data anonymisation

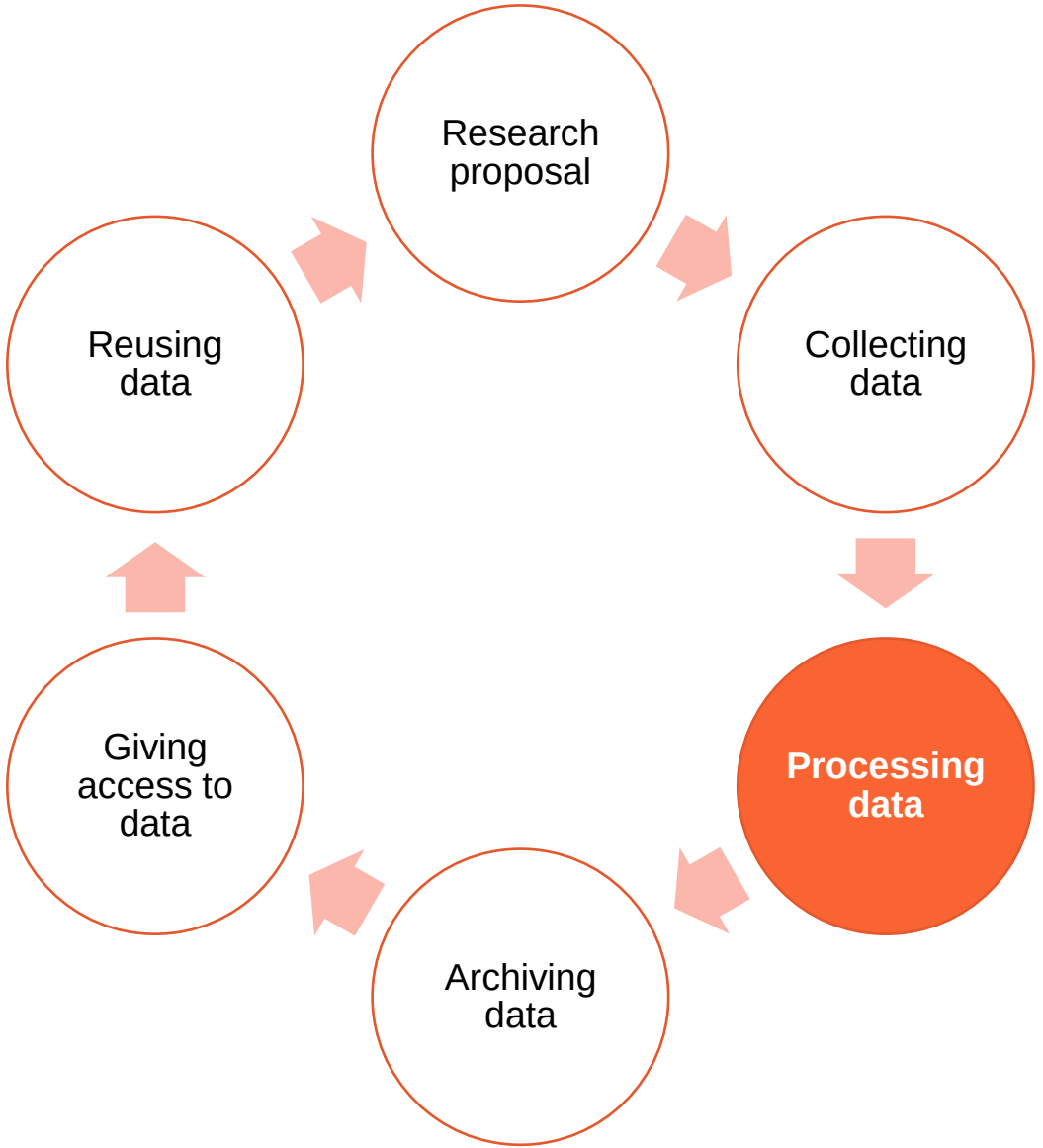
Types and formats of data

Naming and organising files

Storage and backup

Metadata and documentation

Related infrastructure



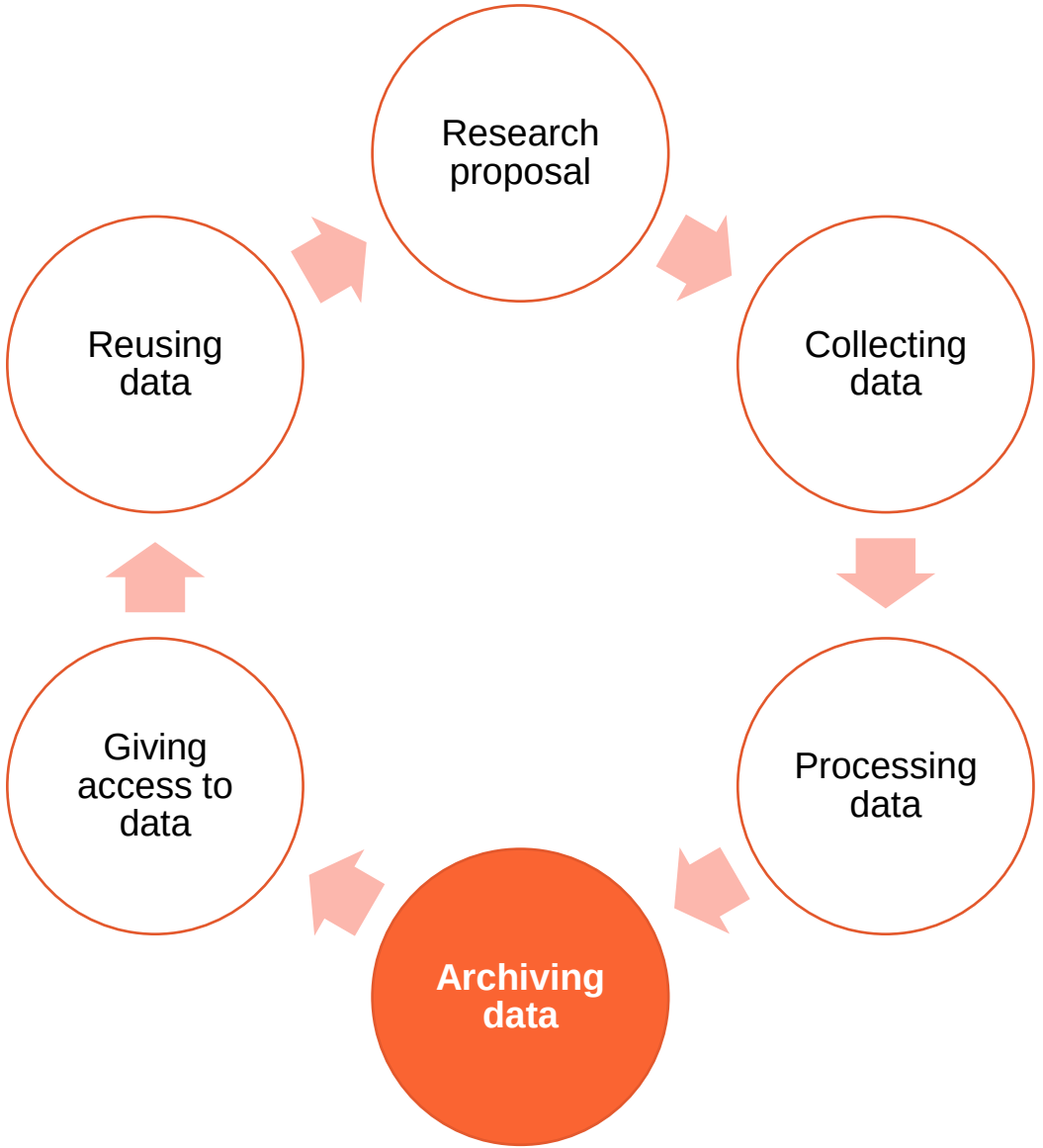
Research data management

Data selection

Data preservation

Data repositories

Related infrastructure

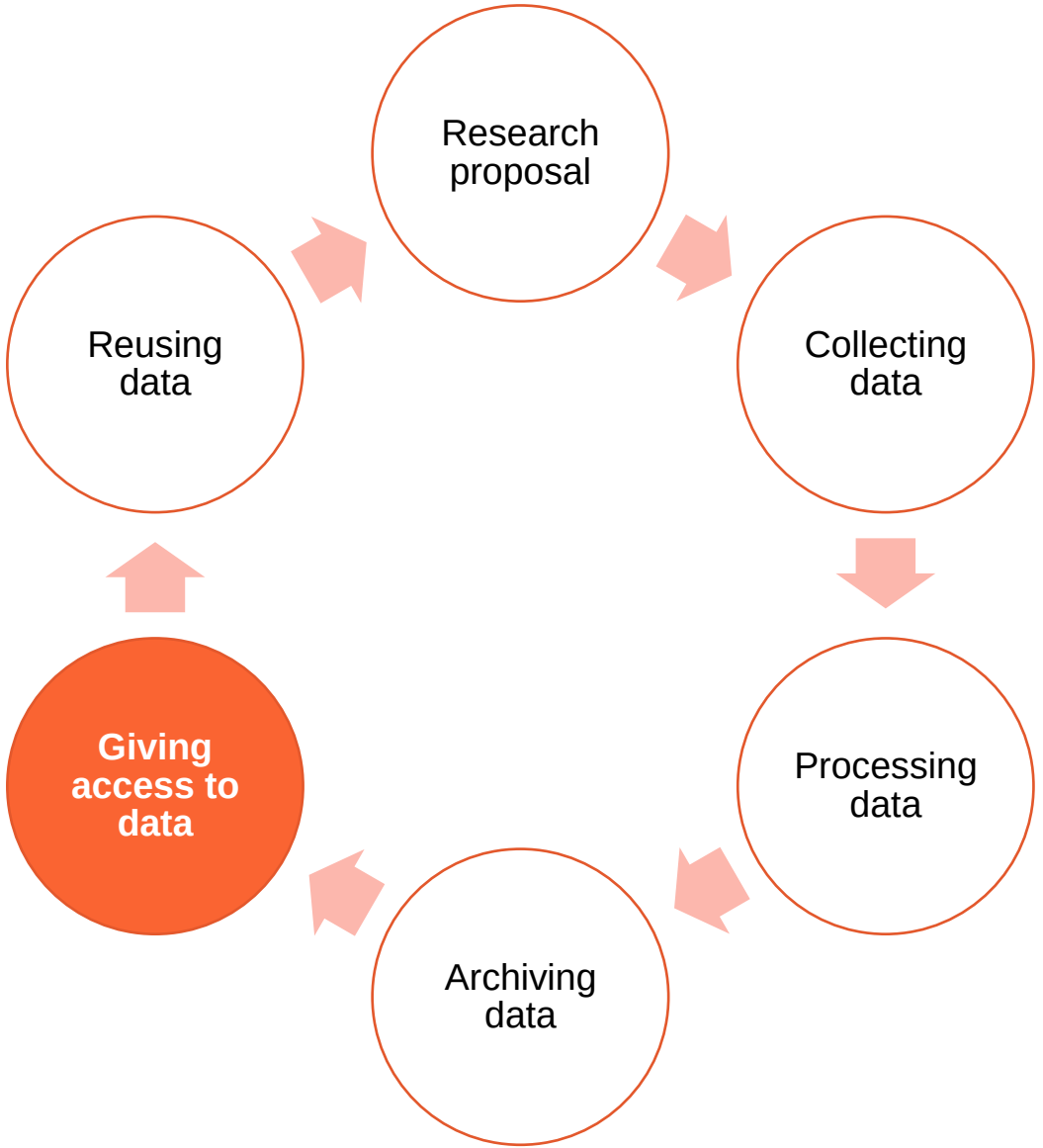


Research data management

Data publishing

Data sharing

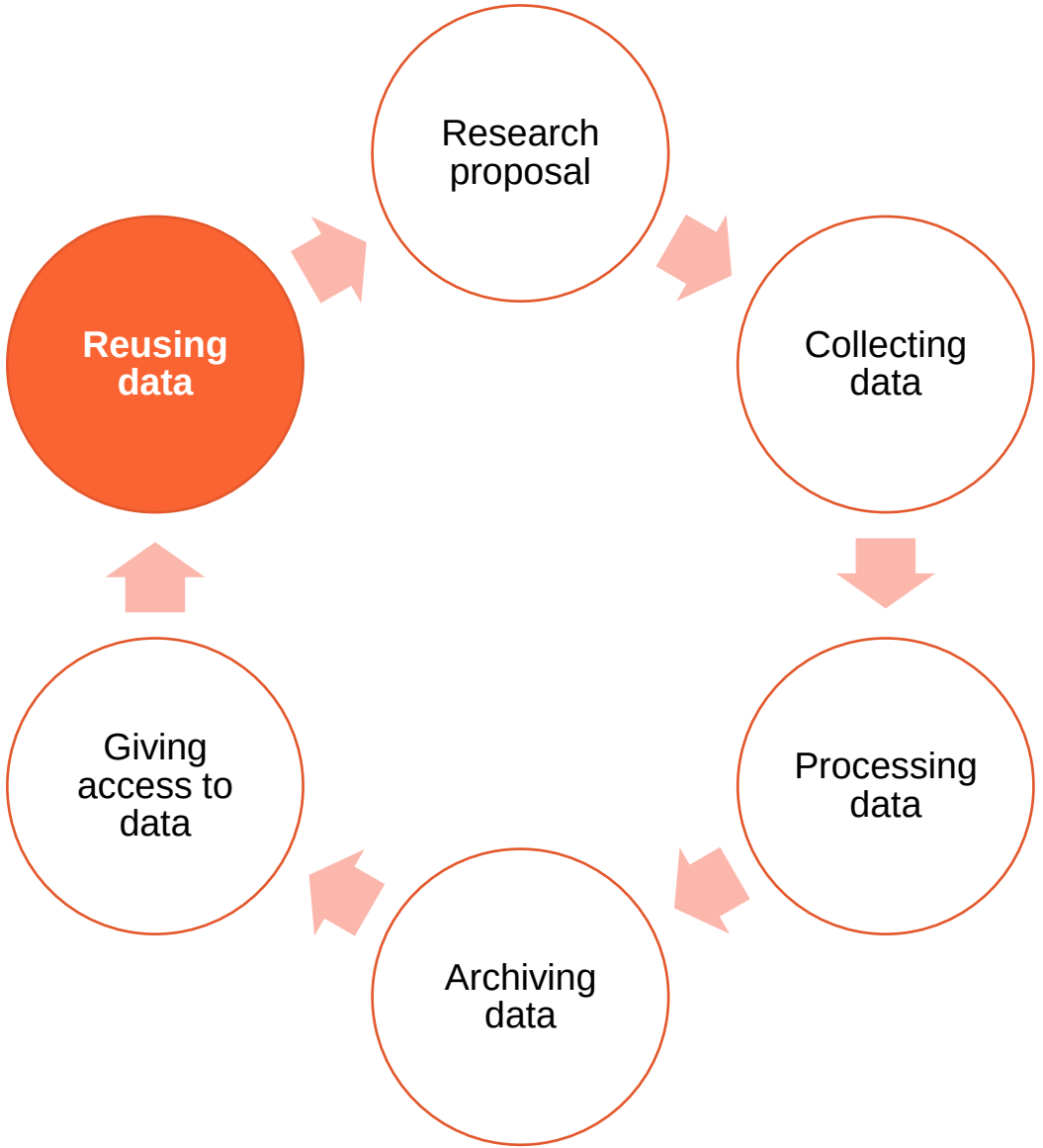
Related infrastructure



Research data management

Data citation

Related infrastructure



ORCID iD

What

- Global, unique digital identifier for anyone doing research

Why

- Increases transparancy
- Helps researchers to distinghuis themselves
- Reduces administration (e.g., ORCID iD-logins)

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Data management plan

Why?

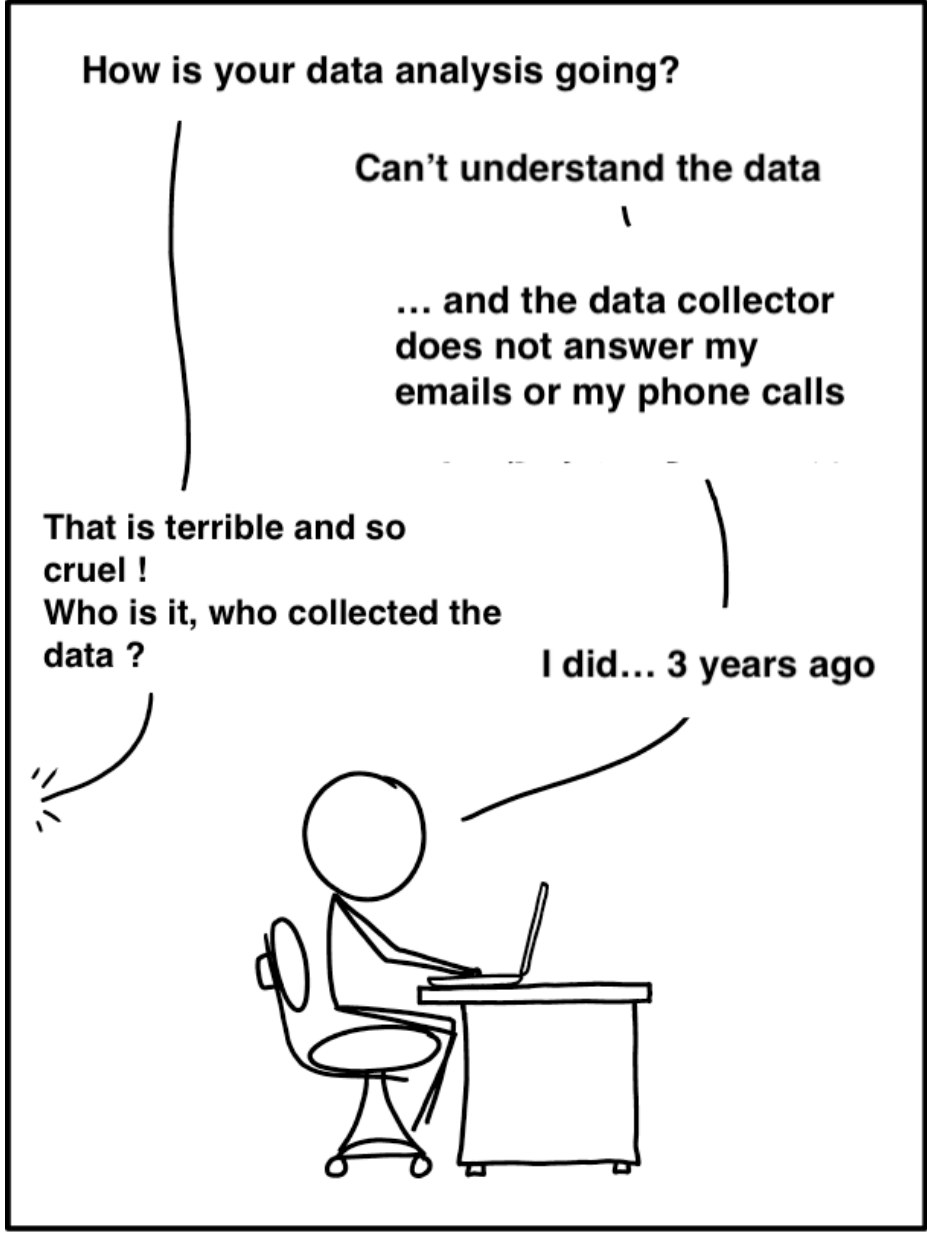
A DMP

- is essential for **proper and efficient management of** research **data**
- helps to meet all **legal and ethical obligations**
- is an important step towards **Open Science**
- helps to increase the **visibility and impact** of your research

Why?

The primary purpose remains
to support yourself.

A DMP documents intentions.
Data management practices will probably evolve & improve throughout your research
→ you can keep updating your DMP



Your first collaborators
are your future selves,
be nice to them !

your future self, by Julien Colomb, CC-BY-NC, derived from .NORM Normal File Format, CC-BY-NC, by Randall Munroe

How?

- Keep it short and simple
- Use lists
- Not everything can or needs be decided right now
- If you can’t answer a DMP question just yet, show in your reply that you’re aware of potential issues and describe how you will solve them (for example, by consulting experts at your institution).
- Write only what you understand
- Write for yourself

Parts of a DMP

0. Info

- General project info

1. Data summary

- Kind of generated data
- Ethical issues
- Personal data

2. Documentation

- Data documentation
- Metadata

3. Data storage

- How are data stored
- Backup-system
- Safety measures
- Expected costs

4. Preservation

- How will the data be archived
- Expected costs

5. Data sharing

- How will the data be shared
- Sharing restrictions
- Usage licenses

6. Responsibility

- Who will manage data storage, preservation,…
- Additional resources

Flemish Standard Data Management Plan as one example.

0. General Project Information

Name grant holder + ORCID iD

Contributor name(s) + ORCID iD + roles

Affiliation(s)

Internal Project number and title

Funder(s) GrantID

Short project description (abstract)

Versioning of the DMP (Application, **Initial**, Updated, **Final**)

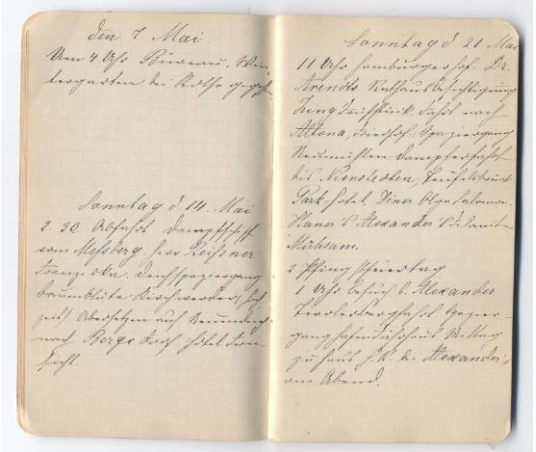
1. Data summary

Which data are you going to collect or generate?

- Create a full overview for yourself of all research data
- Primary as well as secondary data
- Consider technical aspects, formats, implications etc.
- in eHealth, predominantly digital data,
  but sometimes also physical data!

The more specific, the better.

1. Data summary



```
%% settings
t_start=1; %Start year of simulation (1)
t_end=100; %End year of simulation (100)
dx = 50; %resolution of raster cells (in m)
dt = 24*3600; % number of seconds in one timestep
outflow= [35,367]; % row and column coordinate of catchment outlet
runoff_velocity_land = 0.3; % velocity of runoff overland (m/s)
velocity_river = 0.3; % velocity of water in the river (m/s)
```

1. Data summary

Dataset Name	Description	New or reused	Digital or Physical	Digital Data Type	Digital Data format	Digital data volume (MB/GB/TB)
Expert pool feedback	Documents containing feedback on guidelines or other documents	Generate new Data	Digital	Compiled	.docx, .xlsx	<100MB
Tandem Pilots	Qualitative data on usability of two apps	Generate new Data	Digital	Observational	.xlsx	<100MB
Pilot focus groups recordings	Recording of focus groups with stakeholders	Generate new Data	Digital	Observational: focus group recordings	.mp4	<100MB
Pilot focus group transcriptions	Transcription of focus group Recordings	Generate new Data	Digital	Observational: transcriptions of focus group recordings	.docx	<100MB
Guidelines	Document containing guidelines on how to involve stakeholders in the development of digital mental health tools	Generate new data	Digital	Compiled data	.docx, .pdf	<100MB

1. Data summary

Observational
Experimental
Compiled
Simulation
Software
Other

Textual
Tabular
Image
Audio
Video

1 GB
10 GB
100 GB
1 TB
10 TB

Dataset Name	Description	New or reused	Digital or Physical	Digital Data Type	Digital Data format	Digital data volume (MB/GB/TB)
Expert pool feedback	Documents containing feedback on guidelines or other documents	Generate new Data	Digital	Compiled	.docx, .xlsx	<100MB
Tandem Pilots	Qualitative data on usability of two apps	Generate new Data	Digital	Observational	.xlsx	<100MB
Pilot focus groups recordings	Recording of focus groups with stakeholders	Generate new Data	Digital	Observational: focus group recordings	.mp4	<100MB
Pilot focus group transcriptions	Transcription of focus group Recordings	Generate new Data	Digital	Observational: transcriptions of focus group recordings	.docx	<100MB
Guidelines	Document containing guidelines on how to involve stakeholders in the development of digital mental health tools	Generate new data	Digital	Compiled data	.docx, .pdf	<100MB

1. Data summary

Which file formats are right for my data?

- Quick overview of recommended formats for different materials (UK Data Service)
- Concise overview of the properties of various file formats (Data Archiving and Networked Services)
- Extremely in depth analysis of various file formats (Library of Congress)

1. Data summary

Optionally: how is your **data created**?

- The software you use
- Methods or protocols
- Procedures to ensure consistency and quality (e.g. standardized interviews)

1. Data summary

Optionally: how is your **data created**?

DOING IT WRONG —

Botched Excel import may have caused loss of 15,841 UK COVID-19 cases

Agency reportedly lost data after exceeding maximum rows for a spreadsheet.

Lee & Timothy (2020)

1. Data summary

Do you aim to repurpose existing data?

- Primary data: generated over the course of your project
- **Secondary data**: datasets from previous research, from companies etc.
- Important to mention sources
- Copyright/license: under which conditions can you repurpose data? What about future perspectives?

1. Data summary

Ethical issues

- Refer to an (optional, but recommended) ethical committee application
- Consider potential implications

Using **personal data**?

- Refere to an (optional, but recommended) ethical committee application
- Consider potential implications
  - Anonimising, pseudonimising
  - Secure storage with access control
  - What to do with data at the end of your project?

1. Data summary

Anonymization

First Name	Name	DOB	E-mail	City	Score
Theodor	Gravey	05/08/1994	happyt0@fotki.com	Longguang	51.27
Addison	Bricham	18/03/1951	abricham1@thetimes.co.uk	Timoulilt	41.1
Keelia	Wildsmith	14/10/1999	kwildsmith2@buzzfeed.com	Pawili	71.3
Karrie	Picken	13/06/1998	kpicken3@quantcast.com	Shitan	71.64
Sosanna	Capnor	19/08/2003	scapnor4@walmart.com	Nanterre	11.86

1. Data summary

Anonymization – deleting non-essentials

Record	Score
P1	51.27
P2	41.1
P3	71.3
P4	71.64
P5	11.86

1. Data summary

Anonymization – masking

First Name	Name	DOB	E-mail	City	Score
heod****	*****avey	05/08/1994	**********	Longguang	51.27
Addis****	*****cham	18/03/1951	**********	Timoulilt	41.1
Keeli****	*****mith	14/10/1999	**********	Pawili	71.3
Karri****	*****cken	13/06/1998	**********	Shitan	71.64
Sosan****	*****pnor	19/08/2003	**********	Nanterre	11.86

1. Data summary

Anonymization – swapping

First Name	Name	DOB	E-mail	City	Score
Bricham	Addison	05/08/1994	happyt0@fotki.com	Longguang	71.64
Picken	Karrie	18/03/1951	abricham1@thetimes.co.uk	Timoulilt	11.86
Wildsmith	Keelia	14/10/1999	kwildsmith2@buzzfeed.com	Pawili	71.3
Capnor	Sosanna	13/06/1998	kpicken3@quantcast.com	Shitan	51.27
Gravey	Theodor	19/08/2003	scapnor4@walmart.com	Nanterre	41.1

1. Data summary

Anonymization – generalisation

Record	Age	City	Score
P1	20-30	Longguang	51.27
P2	70-80	Timoulilt	41.1
P3	20-30	Pawili	71.3
P4	20-30	Shitan	71.64
P5	10-20	Nanterre	11.86

1. Data summary

Anonymization – data perturbation (rounding up, adding noise)

Record	Age_pertur	City	Score_perturb
P1	27	Longguang	51.47
P2	72	Timoulilt	40.99
P3	21	Pawili	70.42
P4	24	Shitan	70.87
P5	18	Nanterre	12.14

1. Data summary

Pseudonymization

First Name	Name	DOB	E-mail	City	Score
Theodor	Gravey	05/08/1994	happyt0@fotki.com	Longguang	51.27
Addison	Bricham	18/03/1951	abricham1@thetimes.co.uk	Timoulilt	41.1
Keelia	Wildsmith	14/10/1999	kwildsmith2@buzzfeed.com	Pawili	71.3
Karrie	Picken	13/06/1998	kpicken3@quantcast.com	Shitan	71.64
Sosanna	Capnor	19/08/2003	scapnor4@walmart.com	Nanterre	11.86

1. Data summary

Pseudonymization

P - Unique	P - Determ	First Name	Name	DOB	E-mail	City	Score
1	1	Theodor	Gravey	05/08/1994	happyt0@fotki.com	Longguang	51.27
2	2	Addison	Bricham	18/03/1951	abricham1@thetimes.co.uk	Timoulilt	41.1
3	3	Keelia	Wildsmith	14/10/1999	kwildsmith2@buzzfeed.com	Pawili	71.3
4	4	Karrie	Picken	13/06/1998	kpicken3@quantcast.com	Shitan	71.64
5	5	Sosanna	Capnor	19/08/2003	scapnor4@walmart.com	Nanterre	11.86

1. Data summary

Pseudonymization

P - Random	First Name	Name	DOB	E-mail	City	Score
1545	Theodor	Gravey	05/08/1994	happyt0@fotki.com	Longguang	51.27
6735	Addison	Bricham	18/03/1951	abricham1@thetimes.co.uk	Timoulilt	41.1
8755	Keelia	Wildsmith	14/10/1999	kwildsmith2@buzzfeed.com	Pawili	71.3
8478	Karrie	Picken	13/06/1998	kpicken3@quantcast.com	Shitan	71.64
3250	Sosanna	Capnor	19/08/2003	scapnor4@walmart.com	Nanterre	11.86

1. Data summary

Pseudonymization

P – Unique	P - Determ	First Name	Name	DOB	E-mail	City	Score
6	1	Theodor	Gravey	05/08/1994	happyt0@fotki.com	Longguang	87.34

1. Data summary

Pseudonymization – Spreadsheet Cell Conceal

First Name	Name	DOB	E-mail	City	Score
EIVCnGiH7GHQaujq mQsEEzaLNdNkP5aq Ms6m3twKxqM==\	Gravey	05/08/1994	happyt0@fotki.com	Longguang	51.27
1IQQJN0Zl+eI26rzVgz pjeRxKf729XBcmXZZ wk1yreI==\	Bricham	18/03/1951	abricham1@thetimes.co.uk	Timoulilt	41.1
7UJF1ufE1R3iRUSB5 wCTAdbwZnJAVVF12 atE2ZxHp3M==\	Wildsmith	14/10/1999	kwildsmith2@buzzfeed.com	Pawili	71.3
4fUNIASoOMNgWmll WDVFIhHbfdoUkZsgA nieQTWm59Q==\	Picken	13/06/1998	kpicken3@quantcast.com	Shitan	71.64
fh/WtHMCPLzhgcpm5 NZyZLm6br45uFnU8v SrrYGoT7s==\	Capnor	19/08/2003	scapnor4@walmart.com	Nanterre	11.86

1. Data summary

Is there potential for **commercial valorisation**?

- Who will own the data?

Agreements with **third parties**?

- Secondary data
- Respondents, study participants

Other **legal** issues?

- Contractual agreements with partners
- Agreements concerning intellectual property rights

2. Documentation and Metadata

Documentation

- Information making your data accessible to others
- What you need to know to understand and reuse data
- 5 Ws: Who did what, when, why, in which way?

2. Documentation and Metadata

Documentation examples

- **Readme file**
  - For interviews: setting, subject, instructions given to respondents …
  - For surveys: questionaires, number of respondents, time of survey …
  - For Excel files: protocolls, materials, units, measurements …
  - To be saved in the same location as the dataset

- **Comments in code** or model script

2. Documentation and Metadata

ReadMe-file

	A
1	21 February 2017
2	Claire Treat
3	cctreat@gmail.com
4	
5	This dataset describes locations, ages, and other descriptions of buried peat sediments found globally.
6	Buried peat was defined as organic-rich sediments overlain by mineral sediments with some indication of deposition in a wet environment.
7	Radiocarbon ages were calibrated using Calib 7.0/IntCal13
8	
9	Dataset is the supplement to the manuscript "Widespread peatland establishment and persistence for the past 130,000 years" by Treat et al., in prep for Nature Geosciences.
10	
11	

Dataset

	D	E	F	G	H	I	J	K	L	M
1	**Data Table 1. Site list and references for buried peats**									
2	**Author**	**Year**	**Title**	**Journal**	**Site Name**	**Profile/ CoreName**	**Surface Description**	**Location**	**Latitude (°N)**	**Longitude (°E)**
3	**North America**									
4	Anderson	1993	A 35,000 Year veg	Quat. Res. 40, 35	Potato Lake	1	pond	Arizona, USA	34.5	-111.5
5	Bigelow et al.	2014	Tundra and boreal	Veget Hist Archae	KY-11	2001 section	silt	Interior Alaska, AK	66.58	-152.23
6	Bigelow et al.	2014	Tundra and boreal	Veget Hist Archae	KY-11	2001 section	silt	Interior Alaska, AK	66.58	-152.23
7	Bigelow et al.	2014	Tundra and boreal	Veget Hist Archae	Birch Creek	BC-1	Loess	Interior Alaska, AK	65.92	-144.45
8	Brown and Sellma	1966	Radiocarbon Datin	Science	Barrow spit	PEAT	bench gravel	AK, USA	71.349	-156.57
9	Clague et al.	1983	Sedimentary enviro	Can J. Earth Sci.	Pitt Meadows Airport			British Columbia, Canada	49	-123
10	Clarke and Carver	1992	Late Holocene Tec	Science	Humbolt Bay	Clam Beach Pr	Modern Soil	CA, USA	40.994244	-124.114568
11	Darienzo et al.	1994	Stratigraphic Evide	Journal of Coasta	Northern coastal Or	Necarium, Nest	buried peat	Oregon, USA	45.15	-123.9666667
12	Delorme et al.	1977	Freshwater shelled	Can. J. Earth Sci.	14: 2029-2046	1	alpine tundra	Mackenzie river delta, Canada	67.26666667	-135.2333333
13	Delorme et al.	1977	Freshwater shelled	Can. J. Earth Sci.	14: 2029-2046	2	alpine tundra	Mackenzie river delta, Canada	66.03333333	-135.1

2. Documentation and Metadata

Comment in a code
is also documentation

```
%% settings
t_start=1; %Start year of simulation (1)
t_end=100; %End year of simulation (100)
dx = 50; %resolution of raster cells (in m)
dt = 24*3600; % number of seconds in one timestep
outflow= [35,367]; % row and column coordinate of catchment outlet
runoff_velocity_land = 0.3; % velocity of runoff overland (m/s)
velocity_river = 0.3; % velocity of water in the river (m/s)

%% calibration parameters
CROPFcal = 2.925; % CROPF-calibration parameter
Ccal = 0.1567; %Soilflow calibration parameter
AWcal = 3.8666e-4; % Groundwater-flow calibration parameter
WHOLDNcal = 1; %Water holding capacity calibration parameter: default=1 [>0]
MELTcal = 10; %Snowmelt calibration parameter: default=10 [>0]

%% load GIS raster data
% This model code works with Topotoolbox. A freely available set of
% GIS-toolboxes, written in Matlab-code. Topotoolbox is available from
% www.https://topotoolbox.wordpress.com/

[DEM] = GRIDobj('dem.txt'); % dem
[MASK] = GRIDobj('mask.txt'); % watershed mask map
```

2. Documentation and Metadata

2. **Metadata**: structured info on data, can be read out by machines
   - Often generated by instruments, e.g., cameras, scanners
   - Also survey software (e.g., QuestionPro, Qualtrics) can generate metadata
   - Discipline specific metadata-standards
     - Basic info (author, keywords, year of publication…)
     - Management of data (licences, versions,….)
     - Structure of data (list of variables, units, etc)

Identifier	Definition
Title	A name given to the resource.
Creator	An entity primarily responsible for making the content of the resource.
Subject	The topic of the content of the resource.
Description	An account of the content of the resource.
Publisher	An entity responsible for making the resource available.
Contributor	An entity responsible for making contributions to the content of the resource.
Date	A date associated with an event in the life cycle of the resource.
Type	The nature or genre of the content of the resource.
Format	The physical or digital manifestation of the resource.
Identifier	An unambiguous reference to the resource within a given context.
Source	A reference to a resource from which the present resource is derived.
Language	A language of the intellectual content of the resource.
Relation	A reference to a related resource.
Coverage	The extent or scope of the content of the resource.
Rights	Information about rights held in and over the resource.

2. Documentation and Metadata

Metadata in DMP

- Discipline-specific, to choose a relevant one within your domain.
- In case not using a metdata standard, indicate how you are going to allocate metadata
  - Throug a simple Excel or Word-file
  - Including author, project, location, date etc.

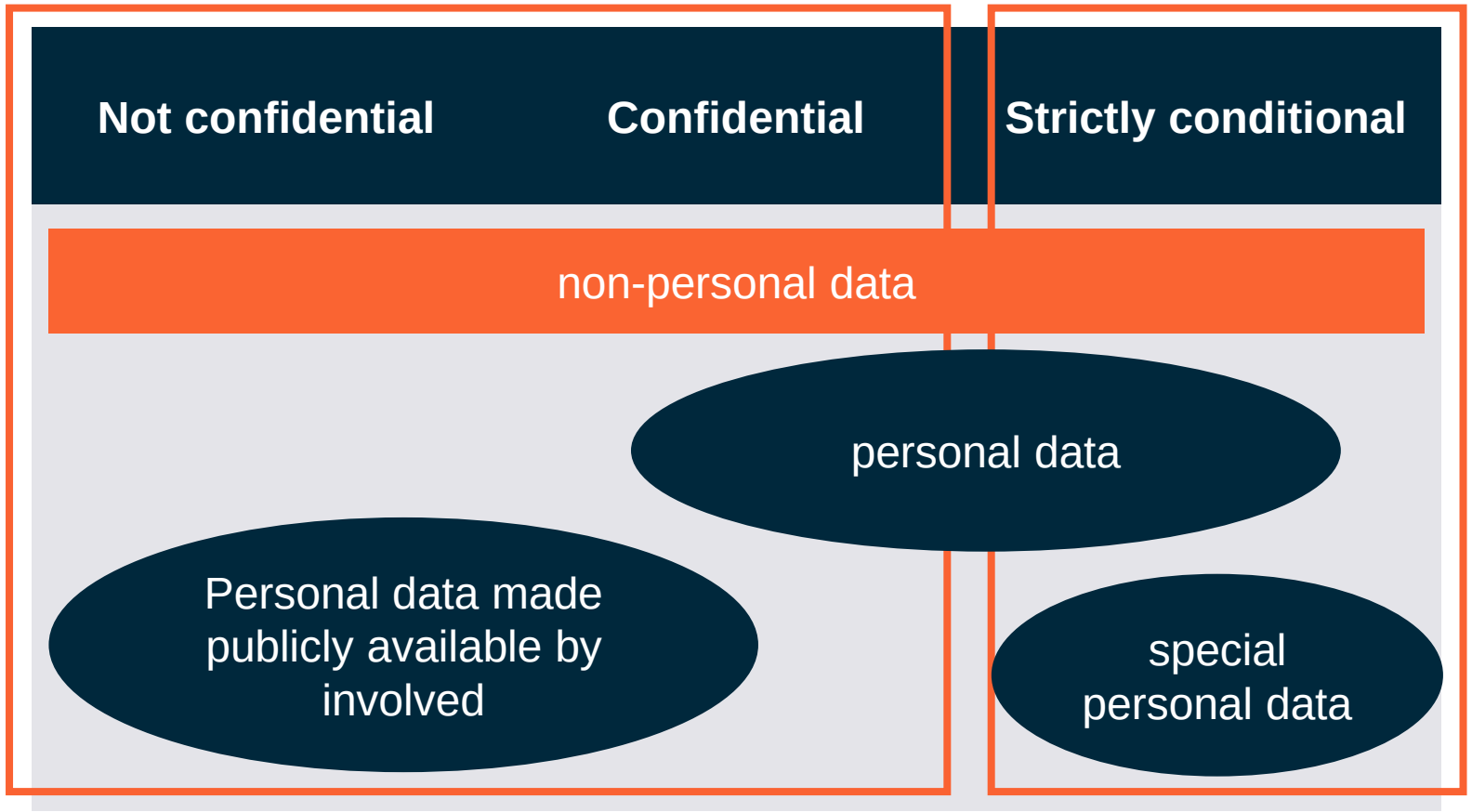
3. Data storage & back-up

Where are data stored?

- Best option = Cloud services, e.g.,
  - Microsoft Azure (including MS 365, e.g., Teams, OneDrive, SharePoint) is
  - Amazon AWS
  - Exoscale
  - OVHCloud
- Special attention for personal data
  - Pseudonymisation and anonymisation
  - Additional encryption on top of the standard encryption of the supplier
  - Multifactor authentication
  - Strict management of dataset access rights

3. Data storage & back-up

Cloud data storage



in the cloud

in the cloud with additional precautions

3. Data storage & back-up during the project

Data security

- Data storage in cloud services is sufficient for non-confidential, as well as confidential data
- Consider additional measures for strictly confidential data
  - Pseudonymisation and anonymisation
  - Extra encryption on top of the standard encryption of the supplier
  - Multifactor authentication
  - Strict management of access rights to datasets

Costs

3. Secure data storage

Storage of research data

- Often cloud services, agreements with organisations in place
  - Safe, reliable and durable
  - Automatic back-up function

3. Secure data storage

Storage on own PC	→	Dedicated cloud services
External HDD or USB-stick	→	Dedicated cloud services
Dropbox or Google Drive	→	Dedicated cloud services

Additional offline backup in a secure location?
Never hurted anyone, but labour-intensive

5. Data sharing and reuse

Do you intend to make your data available for reuse, during/after the project?

- Best effort: at least the data required for verification and replication
- But closed, in case of legislation, privacy, ethical concerns, potential for valorisation…
- Restrictions are possible. Data sharing ≠ open data !
- Keeping in mind the FAIR principles

5. Data sharing and reuse

You can **anticipate data sharing challenges**

- **Anonymization** or **Pseudonymization**
- Asking participants for consent
- Embargo periods

In case of **restrictions**: who gets access under which conditions?

- Solely for research, non-commercial activities
- Following the signing of a data sharing agreement

5. Data sharing and reuse

When will you make your data available?

- Following publication of results
  (alongside your report, article, advice etc).

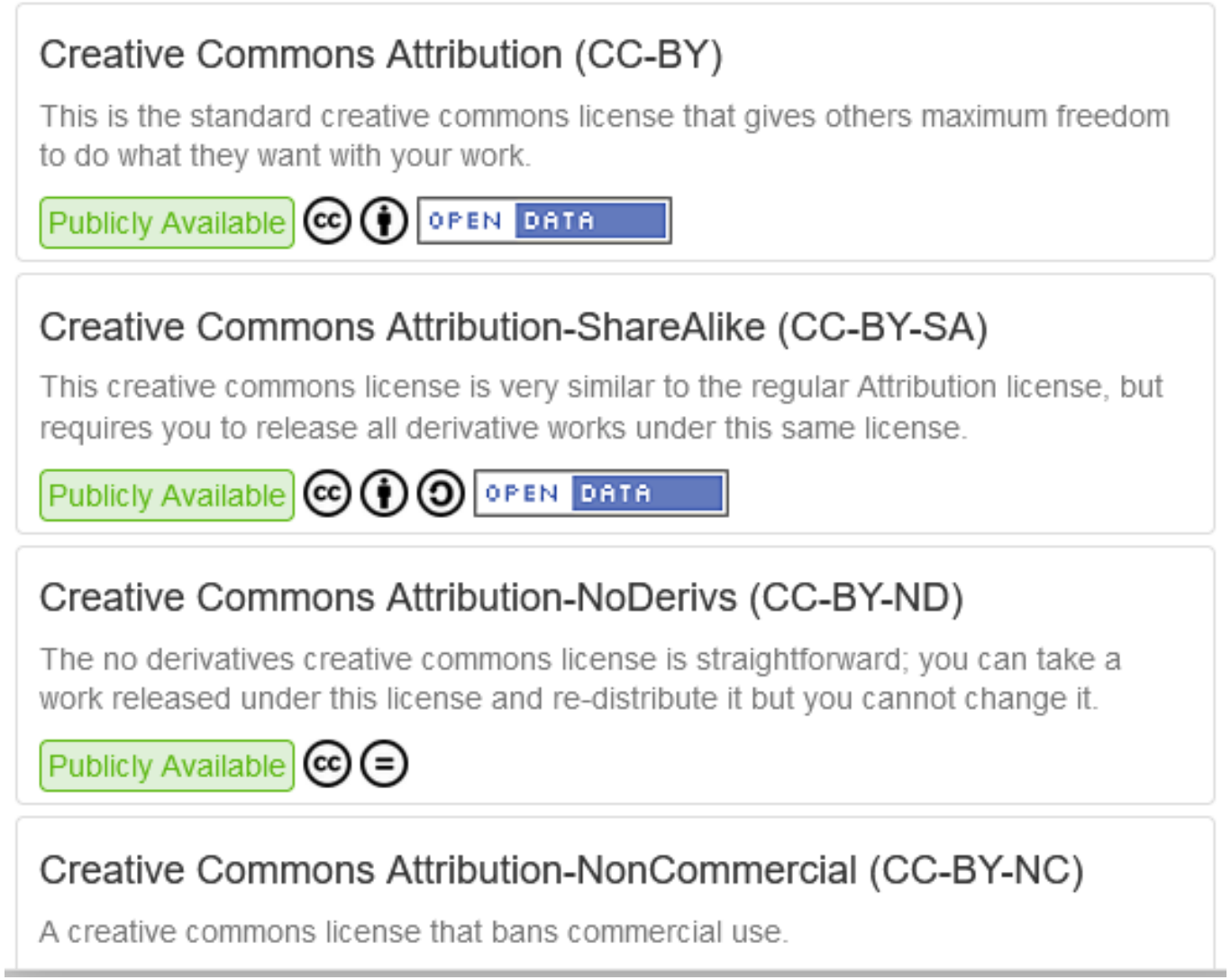
- At project completion

5. Data sharing and reuse

Which data usage licenses?

- Taking into account the potential for valorisation

- Data License Selector Tool
- No restrictions: CC-BY
- No commercialisation: CC-BY-NC



5. Data sharing and reuse

PID/DOI/accession number

- Automatically alloated in repositories, data papers, etc.
- If you do not intend to share your data through repositories: no PID/DOI

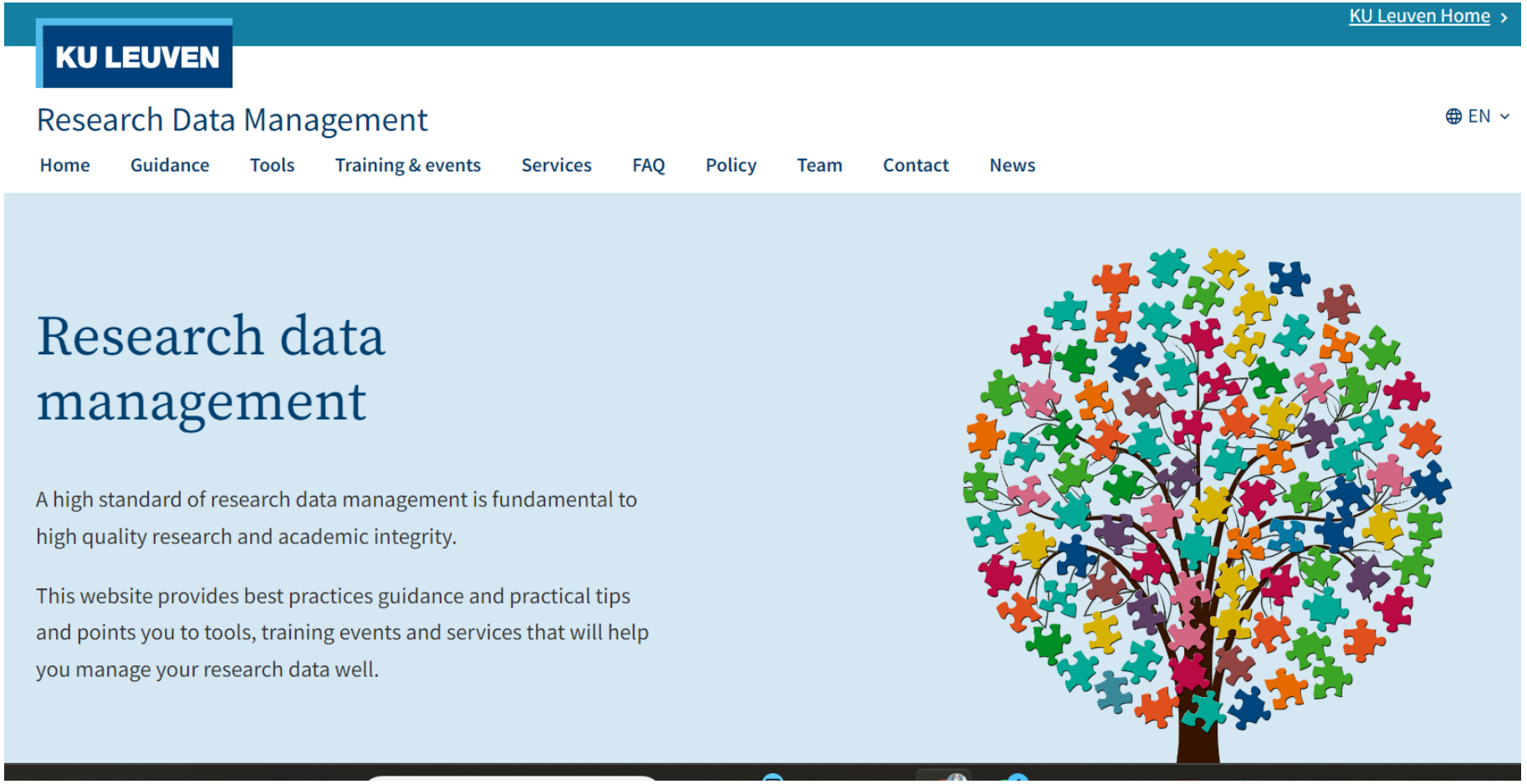
Most of the time **no costs involved**
when sharing data through data repositories.

6. Responsabilities

1 → 4 Responsabilities

- Often multiple people
  - Contributions by **project collaborators**,
  - eindverantwoordelijkheid bij **projectleider** of bij **onderzoeksmanager**
- Stel verantwoordelijke aan bij elke partner

Want to learn more?



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In conclusion

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