University of Saskatchewan

From 0 to 100 in Remote Dementia Research: A Practical Guide

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CCNA CCNV 15 Team équipe

Based on Working Paper

- O'Connell, McGilton, Vellani, O'Rourke, & Robertson

- True CCNA 'collision' collaboration

Moving Remote – Risk/Benefits

- Would participation involve undue stress/exposure?
- Does the use of a control group make some research untenable at this particular time given the risk benefit analysis?
- Does use of remote methods undermine your work? Would remote diagnosis meet research needs for a gold standard?

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Remote Measurement

- Standardized or quantified scales - you must first decide if you can translate these to remote administration **or** consider using alternative assessment methods

- Modifying standardized scales could change what they measure

- Burden of proof on researcher – convince others you are measuring a construct appropriately

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Remote Measurement

- Scales that have evidence for psychometric properties under the conditions of remote administration – use these

- Consult the literature for evidence of equivalence – level of evidence depends on modifications required for remote delivery

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Recommendations on Evidence Needed to Support Measurement Equivalence between Electronic and Paper-Based Patient-Reported Outcome (PRO) Measures: ISPOR ePRO Good Research Practices Task Force Report

Stephen Joel Coons, PhD,[1] Chad J. Gwaltney, PhD,[2] Ron D. Hays, PhD,[3] J. Jason Lundy, PhD,[4] Jeff A. Sloan, PhD,[5] Dennis A. Revicki, PhD,[6] William R. Lenderking, PhD,[7] David Cella, PhD,[8] Ethan Basch, MD, MSc,[9] on behalf of the ISPOR ePRO Task Force

Remote Measurement (Coons et al., 2009)

- Minor modification – e.g., a verbal response you record remotely vs in-person – cognitive debriefing is adequate

- Major modifications – e.g., wording changes or ways of responses changed, such as number of response options; psychomotor output to verbal output

= new test and psychometric properties must be established

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Remote Measurement (Coons et al., 2009)

- Moderate modifications – e.g., changing a visual response to a verbal response

- Moderate modifications could change interpretation in unknown ways or impact how a test taker approaches the task

- **NEED evidence of equivalency**

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Equivalency

- Groups randomly assigned to receive the test in-person vs remotely or a randomized crossover design – mean differences trivial in magnitude or less than an minimum important difference (Coons et al., 2009)

- Bland and Altman (1986) precision of measurement into confidence interval approaches around differences in means across modes of administration

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Equivalency

- We suggest differential item functioning (DIF) from item response theory
- Or measurement invariance (MI) of latent constructs with MG-CFA

- These methods constitute strong evidence for measurement equivalence when random assignment or cross-over designs are used
- Can also be applied to between-subjects designs

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Remote Measurement

- **Use of a scale that only has established psychometric properties for use in-person and modifying this for remote administration – is problematic if one blindly assumes it is equivalent to in-person administration** (Coons et al., 2009)

- Could have implications for the feasibility of translating your work from in-person to remote

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Moving Remote – Suitability for Participants

- Are they likely to have the ICT infrastructure?
- Are they likely have the knowledge to use this infrastructure without inducing undue stress?
- Are they likely to have sensory or cognitive impairments that make interaction with remote methods more challenging or even impossible?

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What is the ICT infrastructure required for your remote work

- List what equipment is needed
- Consider the likelihood of your participants having ready access to this equipment

- **Telephones are almost ubiquitous** - low burden method of communication. Our prior work detailed travel burden experienced by rural families in accessing Telehealth videoconferencing (O'Connell, 2014) so we use telephone for intake procedures now

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What is the ICT infrastructure required for your remote work

- List what equipment is needed & then consider the likelihood of your participants having ready access to this equipment

- Recommended 1024 kbps bandwidth for videoconferencing and newer smartphone/tablet/computer with speakers/headphones and microphone – **not ubiquitous**

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Videoconferencing

- Videoconferencing for remote contact is the closest analogue to in-person (Tuerk & Shore, 2015)
- Some non-verbal cues are available, visual mouth cues can help with those who have hearing loss, and rapport can be easily established when used for dementia care (Morgan et al., 2011)
- Nevertheless, videoconferencing misses many non-verbal cues (O'Connell et al., 2014)

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Considerations for Persons with Cognitive Impairments

- Neuropsychological deficits in interact with technology use and learning of new technology

- We recommend leveraging ICT methods with which the participants have prior exposure if there are cognitive impairments (O'Connell et al., 2003)

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Considerations for Persons with Sensory Impairments

- **Sensory impairments could contraindicate remote methods**, but this is highly individualized
- For those with some hearing deficit, headphones may enhance the communication, as they can help with the amplification of the researcher's voice which is not available in face-to-face settings (Tuerk & Shore, 2015)
- Severe auditory impairments can be mitigated with use of closed captioning during videoconferencing

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Assessment of ICT Infrastructure With **Each** Participant

- Assessment of ICT infrastructure is not straightforward – NONE of our participants can detail their internet bandwidth

- Lack of historical access to ICT impacts attitudes and use of ICT – double-digital divide

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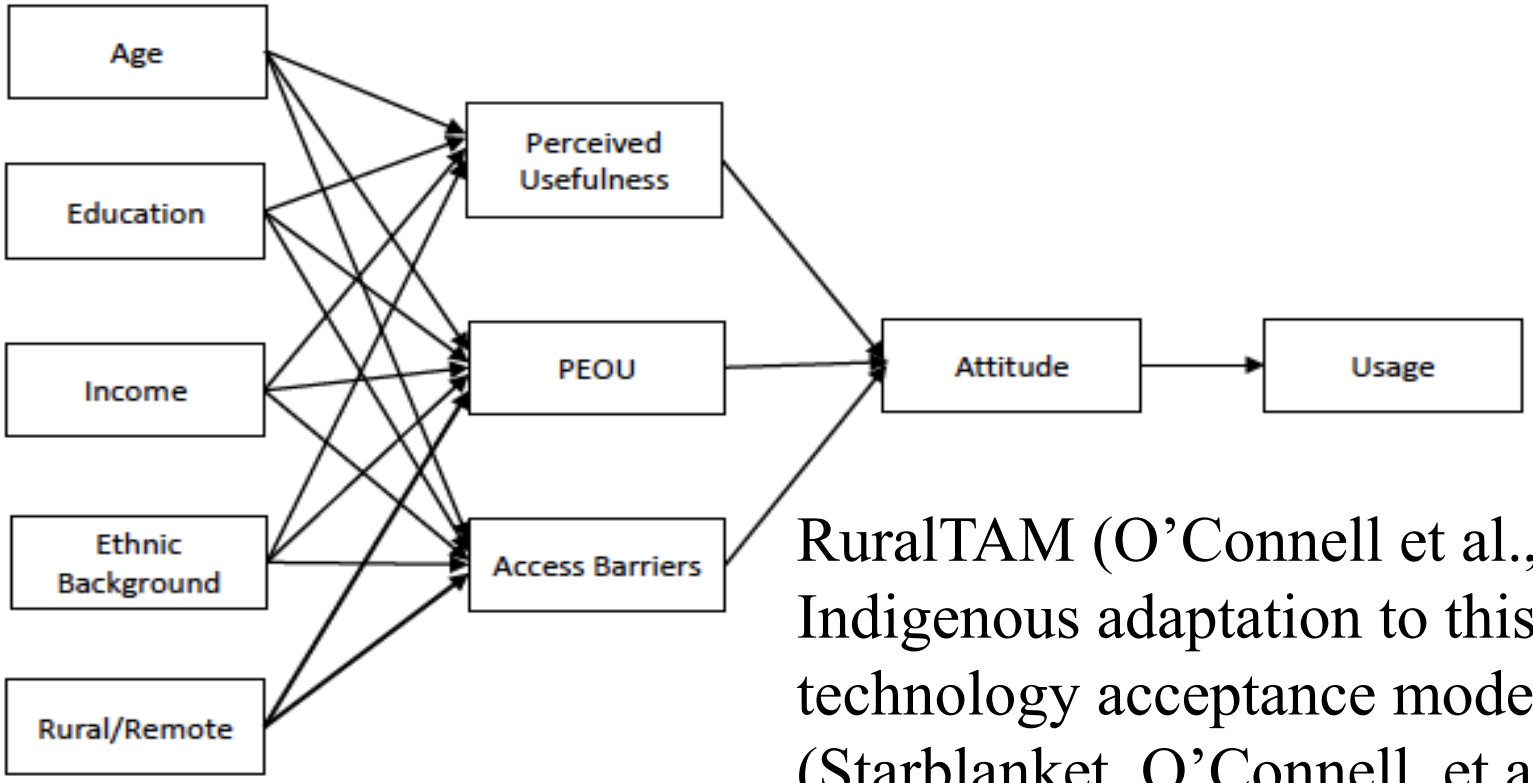
ICT for remote work



RuralTAM (O'Connell et al., 2018) Indigenous adaptation to this technology acceptance model (Starblanket, O'Connell, et al., 2019)

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ICT Infrastructure Assessment

- A screening question we have found useful is – do you have a computer, tablet, or smartphone that you use to connect with others?
- If yes, do you connect with others using video? If yes, does this video freeze and make it hard to communicate?
- If no, do you watch movies or videos on your computer/tablet/smartphone?

Will not inform about upload speeds but will give a hint and also tell you if the **system has speakers**

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ICT Infrastructure Assessment

- Details about type of ICT they have; including if it is a MacOS or PC
  - Could recruiting ICT infrastructure from a friend or a neighbor put them at risk of exposure?
- Do they have access to an in-home technology helper
  - Could recruiting a helper put them at risk of exposure? Use of home care staff?
- For videoconferencing, **do they have a microphone**?

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ICT Infrastructure Assessment

- For videoconferencing, can the camera be moved
  - ensure adequate exposure to the researchers/clinicians' mouth-based cues which can also mitigate hearing loss, provided, of course, the visual and auditory feed are synchronous

- If they have headphones (are they charged if they are wireless), these can help a lot with minimizing extra noise and focus the sound

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ICT Infrastructure Assessment

- How do they use technology? Do they use apps (do they know what this is?)?

- Do not assume e-mail is accessible on the device they wish to use for videoconferencing

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Assessment = Appropriate for Remote Contact

- **Now** you can consider the method to use for this remote contact
- Ideally, researcher adapts their ICT for remote research to the participant and their wishes

In other words, we recommend that the participant does not have to adapt to you, you have to adapt to them

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Why Adapt Your Tech to Participants?

- mitigates anxiety for participants
- maximize the probability of success for the remote interaction
- leverages prior learning for those with memory impairments
- minimize new learning required because you will need to plan to train each participant in the use of the technology platform required for your remote contact

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You Can Only Adapt To Participants Wishes So Far

- Issues of access
- HIPA, PHIPA, or PIPEDA compatible if needed
  - Zoom Healthcare
  - WebEX
  - Noustalk
  - Doxy.me
  - Pexip
- Do you need 1:1 or group – limits options

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Be Prepared to Spend Time and Effort on Training

- **ALWAYS** have a telephone number back up in case of technical failure
- Prior to your first research data collection – you will need to spend time getting your participant comfortable with the technology **to do this use the telephone**
- We have been doing this – **it can be done**. Make all activities explicit – avoid jargon

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Be Prepared to Spend Time and Effort on Training

- Create a step by step guide – verbal or visually-based
- Send a step by step guide by e-mail
- www.techcoaches.ca
- Have screenshots of common problems sourced from the multitude of helpful YouTube videos
- Make a video yourself – particularly if you have a good idea about where technologically naïve people will struggle

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TECHCOACHES TOOLBOX

HOW TO JOIN A ZOOM MEETING VIA E-MAIL INVITATION

1

Visit your inbox and open the email invitation sent from the meeting host.

2

While viewing the message, look for and click/tap on the hyperlink provided under **Join Zoom Meeting.**

3

On a computer, a new page will open automatically. You may be prompted to open the Zoom app, click **Allow.**

Task Analysis

- 1) To host meetings
- -Put phone on speakerphone so you can have it in front of you
- -Unlock phone
- -Locate app store
- -open app store
- -search for zoom in the search bar
- -Download it: second entry; tap “get”
- -Tap install
- -enter apple username and password
- -go back to home screen and find the app (may be on a second page)
- -open zoom
- -hit sign up in bottom left
-

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Be Prepared to Spend Time and Effort on Training

- Have a practice session – walk them through this – repeat until they feel comfortable and confident
- Zoom must be downloaded for use on iPhone or iPad – do they have their AppleID password?
- Manage frustrations by being prepared to troubleshoot
- Keep calm and carry on – **anxiety is contagious**

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Be Prepared to Spend Time and Effort on Troubleshooting

- **ALWAYS** have a telephone number back up in case of technical failure
- If you are holding a focus group – recruit trouble shooting back-up
- Keep calm and carry on – **anxiety is contagious**

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Be Prepared to Spend Time and Effort on Troubleshooting

- Use screenshare (if you have the same platform)
- Have the participant's platform information handy – if you use Mac have pictures of the PC interface handy, etc
- I have back up technology at my fingertips – pre-navigated resources

- Keep calm and carry on – **anxiety is contagious**

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Remote Consent

- Many ethical issues remain the same for remote service delivery as for in-person
- Obtaining proxy consent when it is required in cases with diminished capacity could become more complicated under conditions of remote work
  - Might require multiple remote contacts
- Imminent risk to self or others
  - Ensure you know how to access services in the location for your participant – if they are rural 911 might not work

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How to Obtain Consent for Remote Research?

- **If your remote contact is verbal** – over the phone or videoconferencing – **we argue consent processes should be verbal**
- Expecting the participants to download, sign, and return the consent form to the research team may "be unrealistic" (Salmons et al., 2016)
- REBs need to understand undue burden associated with return address mailing procedures and appreciate this could increase risk of exposure to SARS-CoV-2

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Ready to Collect Data?

- Spend time setting the scene – camera angle, seat placement, etc
- You and your participant should agree on a remote contact time that is to be distraction free
  - Few people in the space
  - Pick a space where they are not likely to be interrupted
  - Be **explicit about multitasking** – you can reschedule
  - Turn of telephone ringer – discuss use of phone in case of disconnection

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Ready to Collect Data?

- We recommend you **spend more time** than you might need to spend during an in-person visit building rapport

- At the Rural and Remote Memory Clinic-interventions we find we need to spend more time building rapport for phone contacts than for videoconferenced remote contacts

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Remote Research

- Remote approach must be conducted with clear purpose and is well considered

- We hope it is clear that remote approaches take a lot more time investment from the researcher

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Research Advantages with Remote Videoconferenced Work

- Recording capabilities are integrated in many platforms
  - Facilitating examination of intervention fidelity
  - Supervision of research assistants or trainees
  - Capturing audio for transcription
- CC or use of headphones might help those with mild to moderate hearing loss
- Reduced travel burden for participants
- For many project, the only way to proceed in the era of COVID-19

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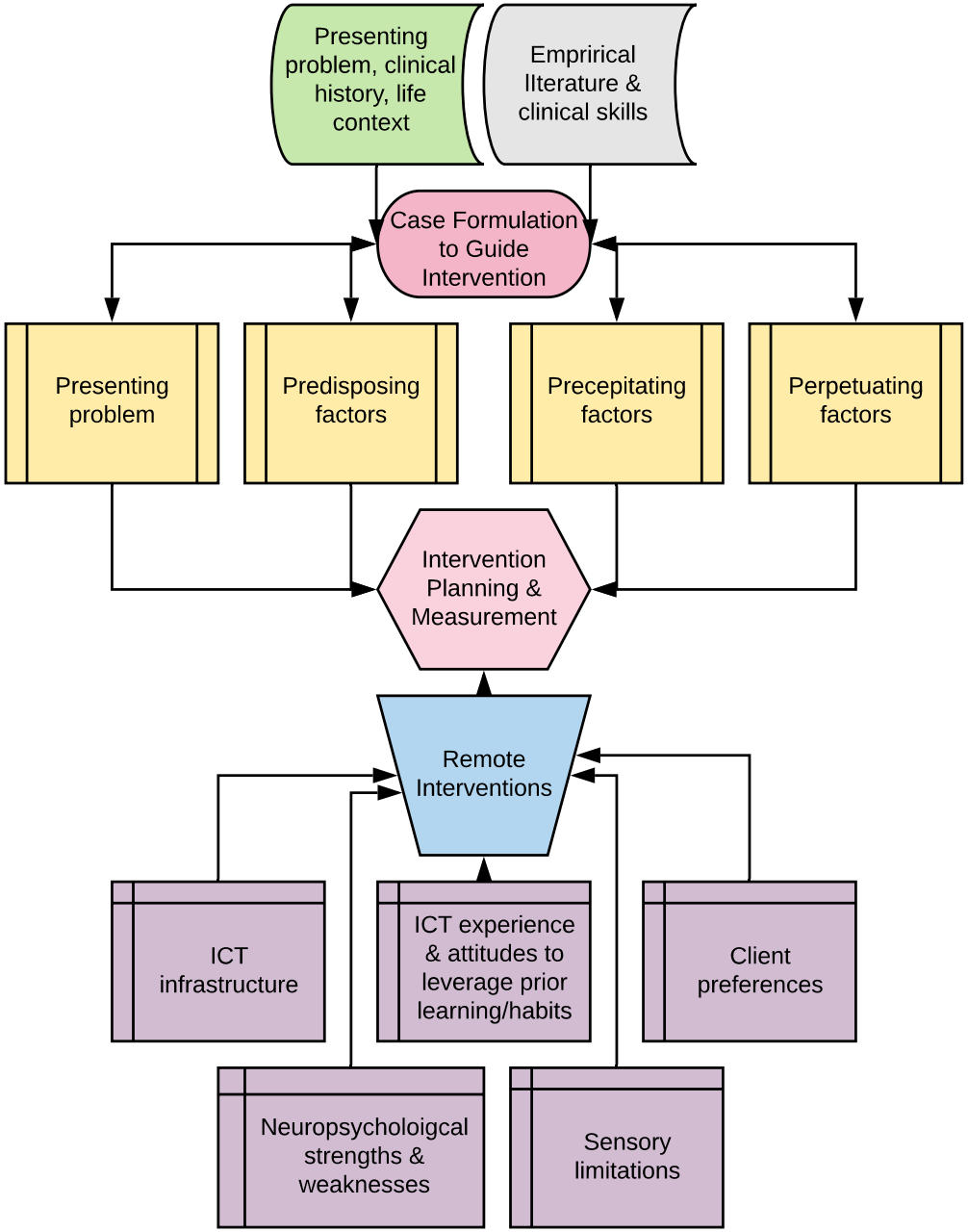
Presenting problem, clinical history, life context
Emprirical literature & clinical skills
Case Formulation to Guide Intervention
Presenting problem
Predisposing factors
Precepitating factors
Perpetuating factors
Intervention Planning & Measurement
Remote Interventions
ICT infrastructure
ICT experience & attitudes to leverage prior learning/habits
Client preferences
Neuropsycholoigcal strengths & weaknesses
Sensory limitations


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Canadian Consortium on Neurodegeneration in Aging
CCNV
Consortium canadien en neurodégénérescence associée au vieillissement
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