MEASURING RECOVERY IN RCCS: CAN THE SURE TOOL HELP?

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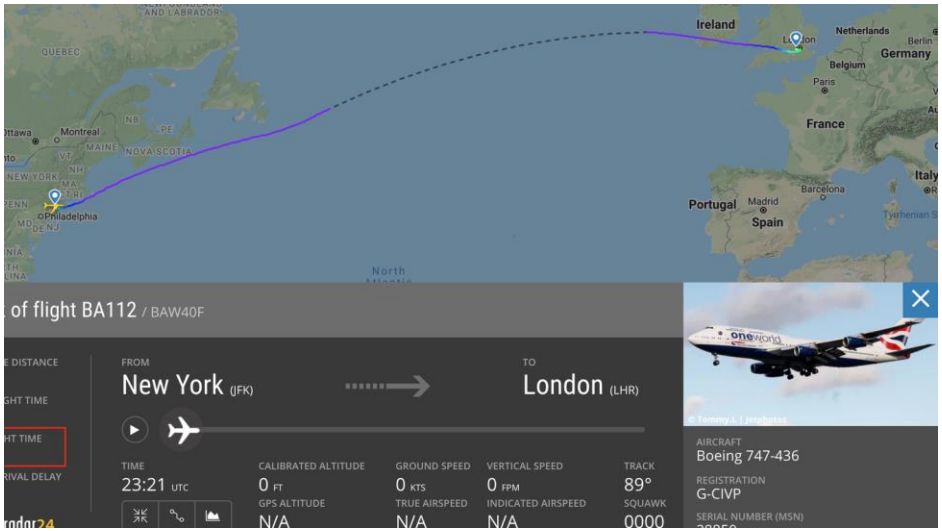
Recovery Community Center Webinar Series (NIDA R24): April 2021

Why are we meeting today?

- Because there is an interest in finding ways/ tools/ instruments to measure the success or ‘outcomes’ of RCCs

- **Aim:**
  1. **To talk to you about the SURE tool**
  2. **To consider whether SURE might be useful for measuring recovery in RCCs (or whether there are additional options)**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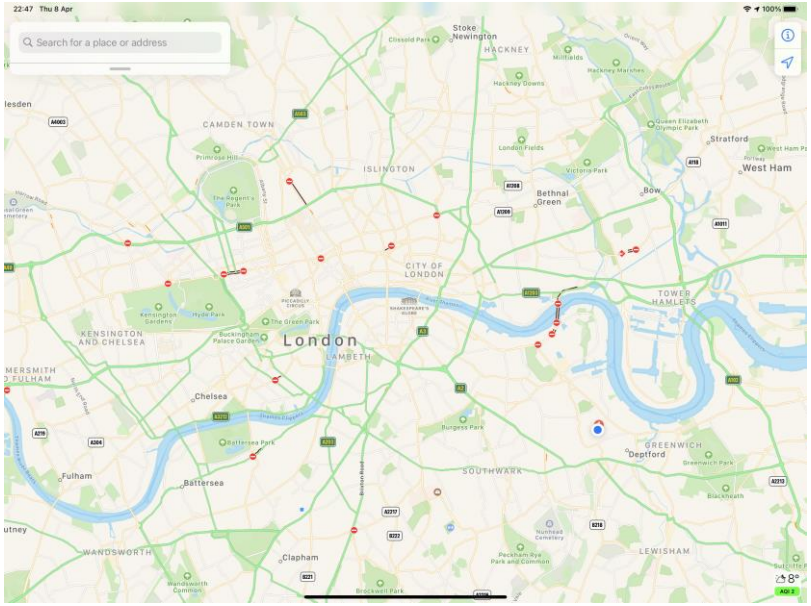
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LEWISHAM

WELCOME
To my home
DEPTford
Love
Little
Nan
xxx

Declarations & acknowledgements

- Jo Neale is part-funded by the National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health at South London and Maudsley NHS Foundation Trust and King's College London, UK. In the last 3 years, she has received honoraria and some expenses from the journal ‘Addiction’ in her role as Commissioning Editor and Senior Qualitative Editor. She has also received research funding from Mundipharma Research Ltd and Camurus AB and a speaker fee from Indivior (unrelated to the work presented).

- Jo wishes to acknowledge:
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  - All research participants, service providers & others who assisted with the research presented
  - Service User Research Group (SURG) & the Aurora Project
  - Action on Addiction
  - Mindwave Ventures
  - All co-investigators

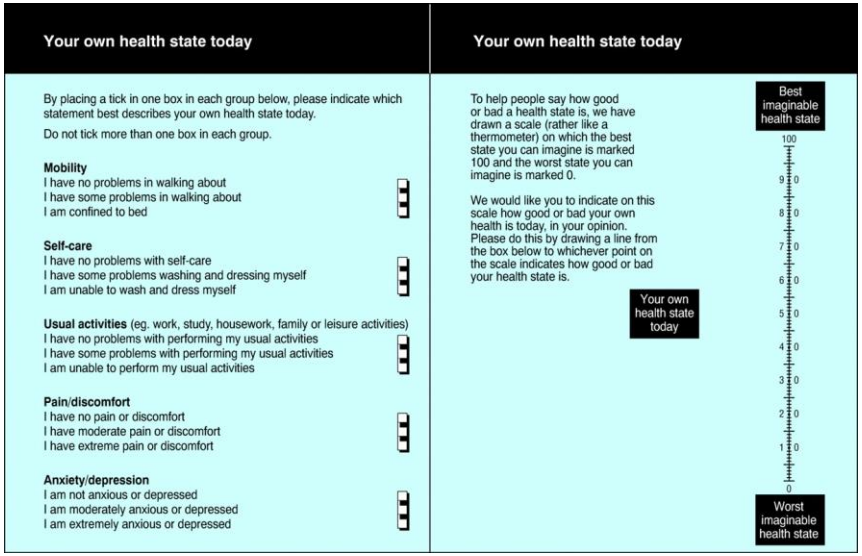
Webinar outline

- **Part 1:** What is SURE & how was it developed?
- **Part 2:** An opportunity to complete & discuss SURE
- **Part 3:** What has happened since we developed SURE?

PART 1: WHAT IS SURE & HOW WAS IT DEVELOPED?

What is a Patient Reported Outcome Measure (PROM)?

- Self-completed questionnaire/ assessment form/ rating scale
- Assesses health status or health-related quality of life, **focusing on the 'patient'/ 'service user'/ 'client' perspective**
- Development includes significant consultation with patients/ service users/ clients
- Once developed, PROMs are subject to rigorous psychometric testing



Your own health state today

By placing a tick in one box in each group below, please indicate which statement best describes your own health state today.

Do not tick more than one box in each group.

Mobility
I have no problems in walking about
I have some problems in walking about
I am confined to bed

Self-care
I have no problems with self-care
I have some problems washing and dressing myself
I am unable to wash and dress myself

Usual activities (eg. work, study, housework, family or leisure activities)
I have no problems with performing my usual activities
I have some problems with performing my usual activities
I am unable to perform my usual activities

Pain/discomfort
I have no pain or discomfort
I have moderate pain or discomfort
I have extreme pain or discomfort

Anxiety/depression
I am not anxious or depressed
I am moderately anxious or depressed
I am extremely anxious or depressed

Your own health state today

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is.

Your own health state today

Best imaginable health state

100
90
80
70
60
50
40
30
20
10
0

Worst imaginable health state

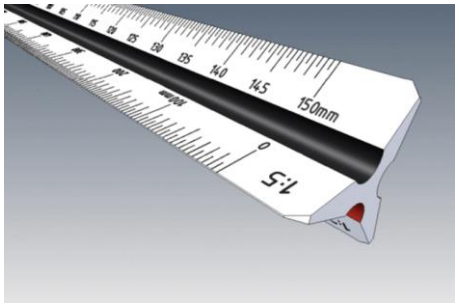
What is SURE?

- SURE stands for **S**ubstance **U**se **R**ecovery **E**valuator
- A quick & easy-to-complete PROM, developed in collaboration with people in recovery
- Measures recovery from dependence on alcohol and other drugs
- Has good face and content validity, acceptability, and usability for people in recovery
- Has been psychometrically tested
- Comprises 21 questions
- Can be used alongside, or instead of, existing outcome measures

Why was SURE developed?

UK 2013...

- The term ‘recovery’ was widely used, but…
- A poorly defined, contested & divisive concept
- Had been equated with abstinence from alcohol & other drug use
- Subsequently viewed as being broader than abstinence
- Uncertainty regarding what indicators of recovery mattered & to whom



How was SURE developed?

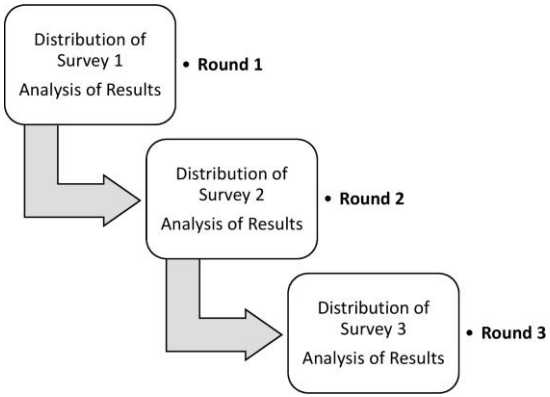
- **Researchers:** Neale, J., Finch, E., Marsden, J., Mitcheson, L., Panebianco, D., Rose, D., Strang, J., Vitoratou, V., & Wykes, T.
- **Partners:** KCL Addiction Service User Research Group (SURG) & the Aurora Project, Lambeth, London
- **Funder:** NIHR Maudsley Biomedical Research Centre for Mental Health, Institute of Psychiatry, Psychology & Neuroscience, King's College London
- **Dates**: 2013 - 2016
- **Study aim:** To produce and undertake psychometric testing of a new PROM for recovery (includes recovery from *dependence on alcohol and other drugs*)

Multi-stage mixed methods study

1. Delphi groups
2. Focus groups
3. Expert panels
4. Cognitive interviews
5. Acceptability + usability study
6. Validation study

Stage 1: Delphi groups

- **Aim:** To identify service providers' views on defining and measuring recovery
- **Methods**: Online Delphi groups with addiction psychiatrists, senior residential rehabilitation staff & senior inpatient detoxification staff (n=25)
- **Findings:**
  - 76 indicators of recovery that comprised 15 broad domains
  - Domains were very consistent across the 3 service provider groups
  - Disagreement on the importance of specific indicators



Service provider indicators of recovery

1. **Substance use** (reduced drug use; practising harm reduction; achieving abstinence; engaging with relapse prevention)
2. **Treatment/support** (accessing peer support or self-help groups; engaging in private therapy)
3. **Psychological health** (improved general mental health, confidence, coping, control, self-belief, self-worth, trust, self-esteem, self-efficacy, self-autonomy, emotional balance, stress management, self-acceptance; reduced anxiety; dealing with past trauma; accepting responsibility; managing feelings)
4. **Physical health** (improved general physical health, physical activity, appearance, self-care, nutrition)
5. **Use of time** (more daily structure, leisure pursuits, meaningful use of time; reduced boredom)
6. **Education/training/employment** (more education, training, voluntary work; securing employment)
7. **Income** (more income stability, decreasing debts; better financial management)
8. **Housing** (increased housing stability; living independently)
9. **Relationships** (improved relationships with family, including partners and children, non-users, peers in recovery; more social support; independence; moving away from negative relationships; choosing relationships; reciprocal helping; improved honesty with others)
10. **Social functioning** (more community involvement/ social integration; better self-management; reduced social problems; better quality of life for others; more life skills; realizing change is constant; 'living right')
11. **Offending/anti-social behavior** (reduced offending; no offending; less contact with the criminal justice system)
12. **Wellbeing** (decreased feelings of shame & guilt; having a positive outlook; talking openly without stigma, prejudice or shame)
13. **Identity/self-awareness** (changed identity focusing on non-addict status; greater self-awareness; increased sense of identity)
14. **Goals/aspirations** (adopting a purposeful life; setting realistic goals; making hopeful & achievable plans)
15. **Spirituality** (improved spiritual well-being; attainment of hope)

Stage 2: Focus groups

- **Aim:** To explore whether & how service users' views of measuring recovery differed from those of service providers
- **Methods:** 5 focus groups with service users (n=44)
- **Findings:**
  - Service users identified multiple problems with the 76 indicators generated from the service provider Delphi groups
  - Difficulties included:
    1. Expecting the impossible of service users
    2. Not recognizing the dangers of positive outcomes
    3. Using outcomes that negate the agency in recovery
    4. Having contradictory measures
    5. Not recognizing individual differences
    6. Not appreciating entrenched vulnerabilities
    7. Misattributing feelings & behaviours
    8. Using inappropriate language

Stage 3: Expert panels

- The research team combined the findings from the Delphi groups & focus groups
- Many of the 76 Delphi group indicators had to be rejected & others were reworded
- A revised list of 33 possible recovery indicators resulted
- Two expert panels of current & ex users were asked to debate & rank the list of 33 recovery indicators in terms of wording, acceptability & importance
- 30/33 indicators seemed largely acceptable & important to service users

Stage 4: Cognitive interviews
Stage 5: Acceptability + usability study

- Face-to-face cognitive interviews with 8 service users
- 40 service users participated in a small acceptability & usability study to:
  - rate themselves on the proposed recovery indicators
  - comment on the appropriateness & usefulness of the proposed recovery indicators
- Several indicators were again reworded or modified

- Outcome = draft PROM
  - 30 indicators

Stage 6: Validation study

A. 461 individuals completed the draft PROM and basic demographic, drug use and recovery questions (in person). Of whom….
   - 111 also completed 2 other validated measures &
   - 50 completed all questions again 2-7 days later

B. 114 individuals completed the draft PROM and basic demographic, drug use and recovery questions (online)

- Outcome = SURE
- 5 dimensions of recovery; 21 indicators of recovery
- Items scored 1-3
- Total score range = 21-63

Dimensions & indicators

A. SUBSTANCE USE

1. Not drinking too much
2. Not using street drugs
3. Not experiencing cravings
4. Coping with problems without turning to drugs or alcohol
5. Managing pains & ill-health without misusing drugs or alcohol
6. Spending free time on hobbies & interests that do not involve drinking or drug use

B. SELF-CARE

7. Taking care of mental health
8. Taking care of physical health
9. Eating a good diet
10. Sleeping well
11. Having a good daily routine

C. RELATIONSHIPS

12. Getting on well with people
13. Feeling supported by people
14. Being treated with respect & consideration by other people
15. Treating others with respect & consideration

D. MATERIAL RESOURCES

16. Having secure housing
17. Having a regular income (from benefits, work, or other legal sources)
18. Managing money well

E. OUTLOOK ON LIFE

19. Feeling happy with overall quality of life
20. Feeling positive
21. Having realistic hopes & goals for oneself

Thinking about the last week, ***please rate yourself on each of the following statements***

DRINKING AND DRUG USE (Part 1) – *Thinking about the last week*

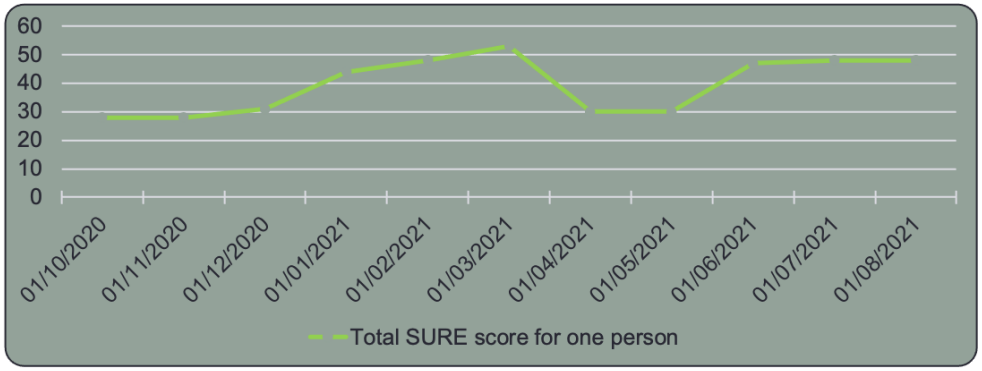
1. I have drunk too much				
Never	On 1 or 2 days	On 3 or 4 days	On 5 or 6 days	Every day
O	O	O	O	O

2. I have used street drugs				
Never	On 1 or 2 days	On 3 or 4 days	On 5 or 6 days	Every day
O	O	O	O	O

3. I have experienced cravings				
Never	On 1 or 2 days	On 3 or 4 days	On 5 or 6 days	Every day
O	O	O	O	O

How to use SURE

- SURE is completed by the person in recovery
- A professional can help someone to complete SURE – for example by reading out the questions – but must never complete it on behalf of someone else
- Ideally SURE should be completed regularly – every week, two weeks or month in order to see how the recovery journey is progressing
- Completing SURE is very simple.



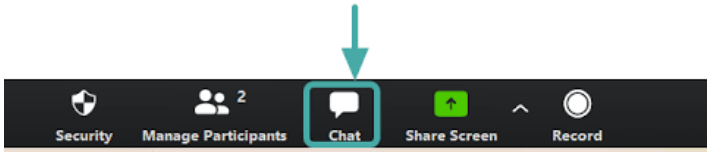
Self-help Tutorial on YouTube

https://www.youtube.com/watch?v=CTuqHqHU41Y&t=46s

PART 2: AN OPPORTUNITY TO COMPLETE & DISCUSS SURE

Activities for the next 5-10 minutes

1. Review and/or complete SURE either by using the PDF file or by following the link, both posted in the chat: http://54.77.56.51/sure/
2. Post any comments or questions you have about SURE in the chat box
3. Raise your hand to ask a question or make a comment about SURE so we can start our discussion whilst you try it out



PART 3: WHAT HAS HAPPENED SINCE WE DEVELOPED SURE?

Anticipated uses of SURE

- **By people in recovery**
  - To monitor & reflect on their own recovery
- **By clinicians & workers**
  - To facilitate discussions about recovery & related issues
- **By researchers**
  - To assess patient & service level outcomes
  - To use as an outcome measure when designing & implementing treatment & recovery-focused interventions

Actual uses of SURE

- National & international interest
- Adoption by ICHOM
- Integration within routine treatment & monitoring systems
- International translations & validation exercises
- Use by other researchers (including within RCTs of psycho-social & pharmacological interventions)

Used in clinical and research settings in:

- UK
- Norway
- Italy
- Japan
- Canada
- South Africa
- Brazil
- Spain
- Denmark
- Pakistan
- Portugal
- Australia
- US
- Philippines

Translated into:

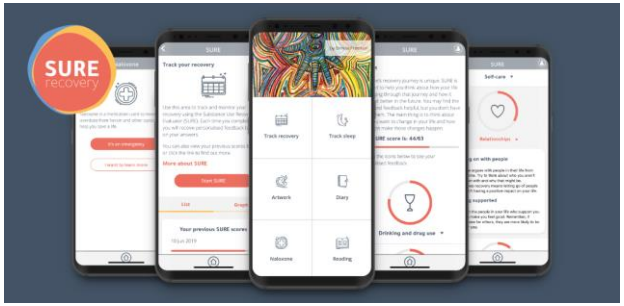
- Norwegian
- Italian
- Spanish
- Danish
- Filipino
- Argentinian Spanish
- French

Translations in progress to:

- Turkish
- Brazilian Portugese
- Australian (cultural adaptation)

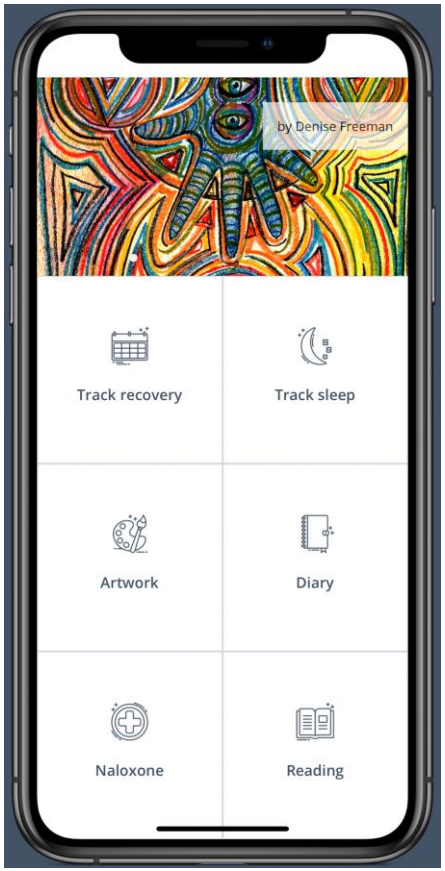
Requests for a SURE Recovery App

- Co-produced with people using substances, in treatment and in recovery to enable people to:
  - Track & monitor their own recovery journeys
  - Recognise when they might need help
  - Identify sources of support
  - Find inspiration from others in recovery
- And to generate new data to help us better understand substance use & recovery



Content

- Six main features:
  1. Recovery tracker (SURE)
  2. Sleep tracker
  3. Diary
  4. Artwork
  5. Naloxone
  6. Reading
- Plus optional participation in research



Accessing the SURE App

Search for **‘SURE Recovery’** on the App Store or Google Play

SURE Recovery is FREE to download

Other resources

1. Website: http://tiny.cc/surerecovery
2. Twitter: @SURE_Recovery
3. Facebook: @surerecoveryapp
4. Instagram: @sure_recovery
5. YouTube: SURE Recovery
6. Email: surerecoveryapp@gmail.com
7. New SURE App network (looking for local champions)

References

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Thank you for participating!

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