"If we start with lived-experience evidence in rural mental health – where does it take us?"

Professor Sarah Skerratt

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Leading the way in Agriculture and Rural Research, Education and Consulting

Presentation outline:

1. **Why** start with lived experience data?
2. **What** do we find out if/when we do?
3. What can **happen**?
4. On-going need to be **vigilant**:

1. **Why**?

1. **Respect** for multiple world views and voices:
   – Insider's view from insider's perspective
   – World views

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2. **Legitimacy** of those voices:
   - Social justice
   - No matter location

3. Info formation

what i think   what i say

FREEDOM TRUST JUSTICE LOVE RULE OF LAW PEACE PROSPERITY DIGNITY EQUALITY

1. **Why?**

1. **Respect** for multiple world views and voices:
   – Insider's view from insider's perspective
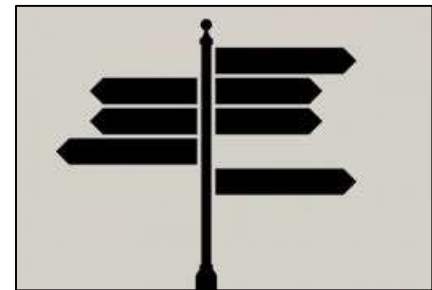   – World views

2. **Legitimacy** of those voices:
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3. Informing **policy** formation/implementation:
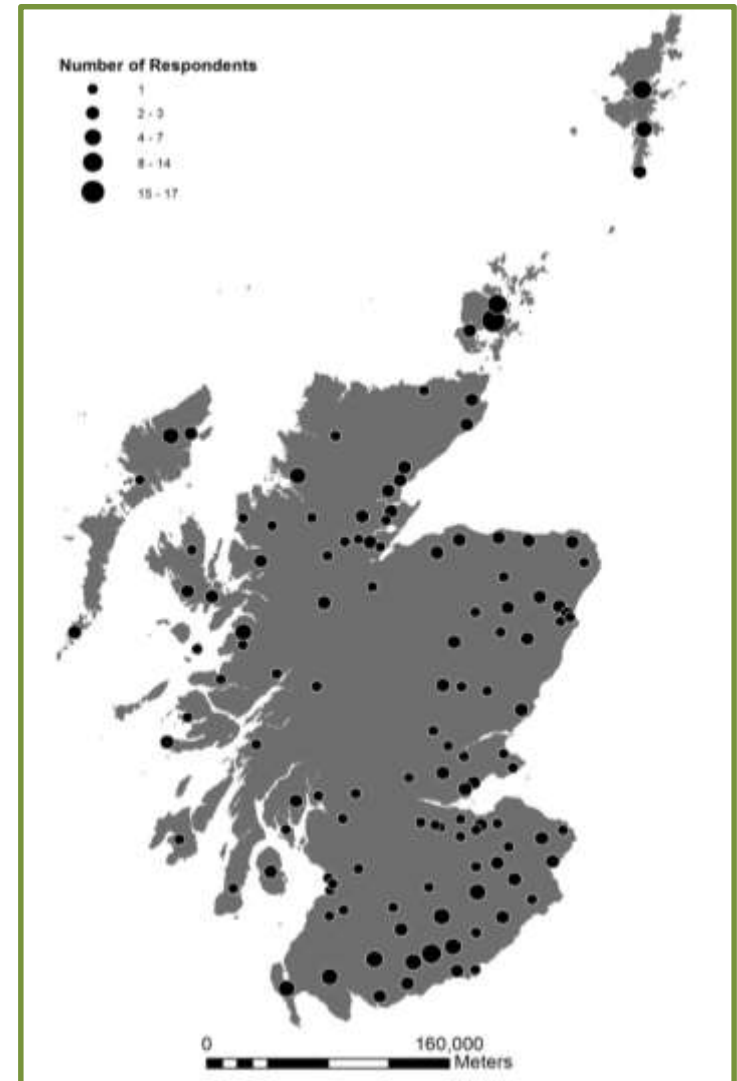   – Community Empowerment, Local Governance, Mental Health

1. **What** do we find out when we **do** use lived-experience data?
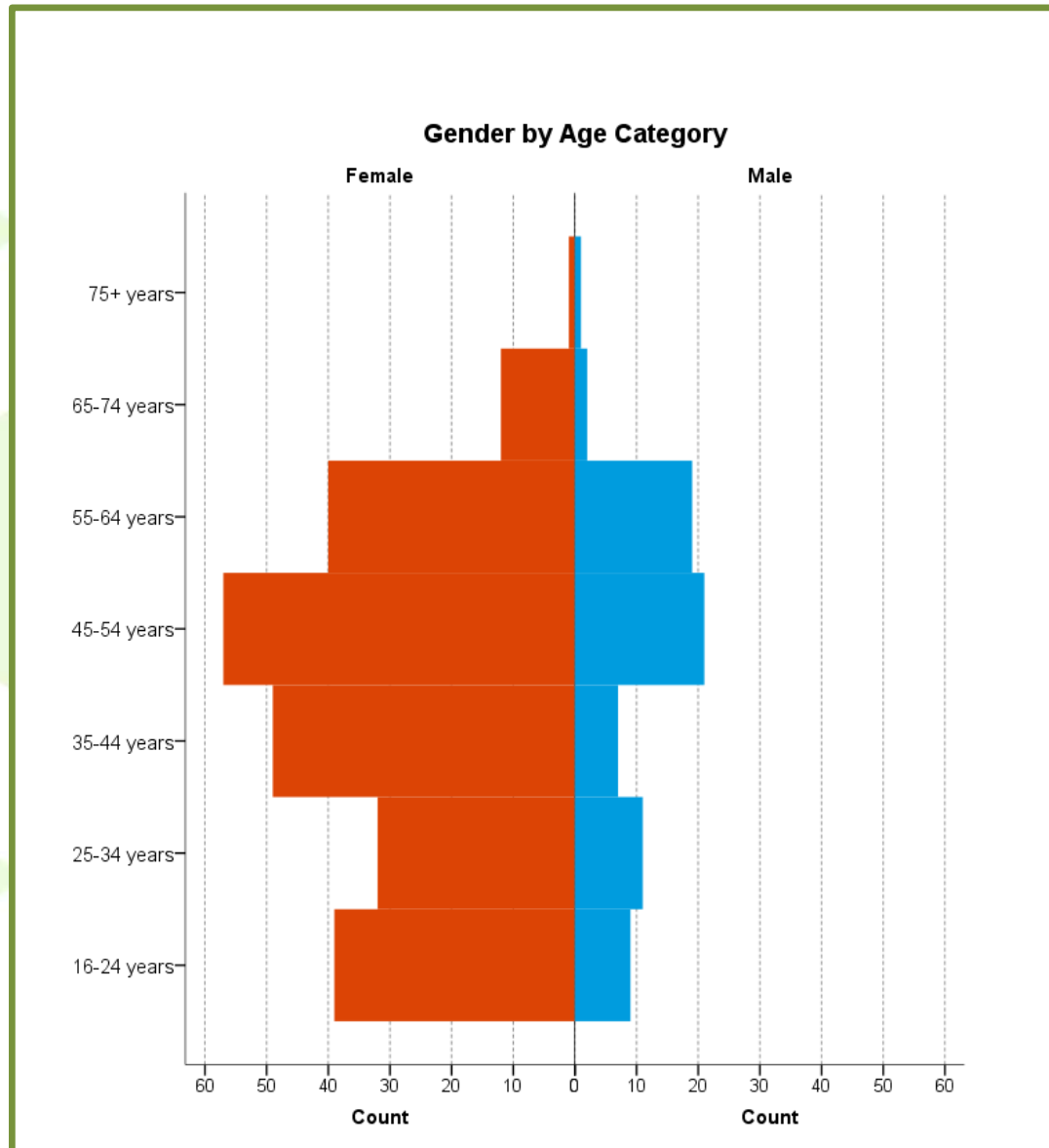
Three examples…

E.G.1: Rural mental health survey

1. **Aim:** Find out how people with mental ill health *experience* rural life
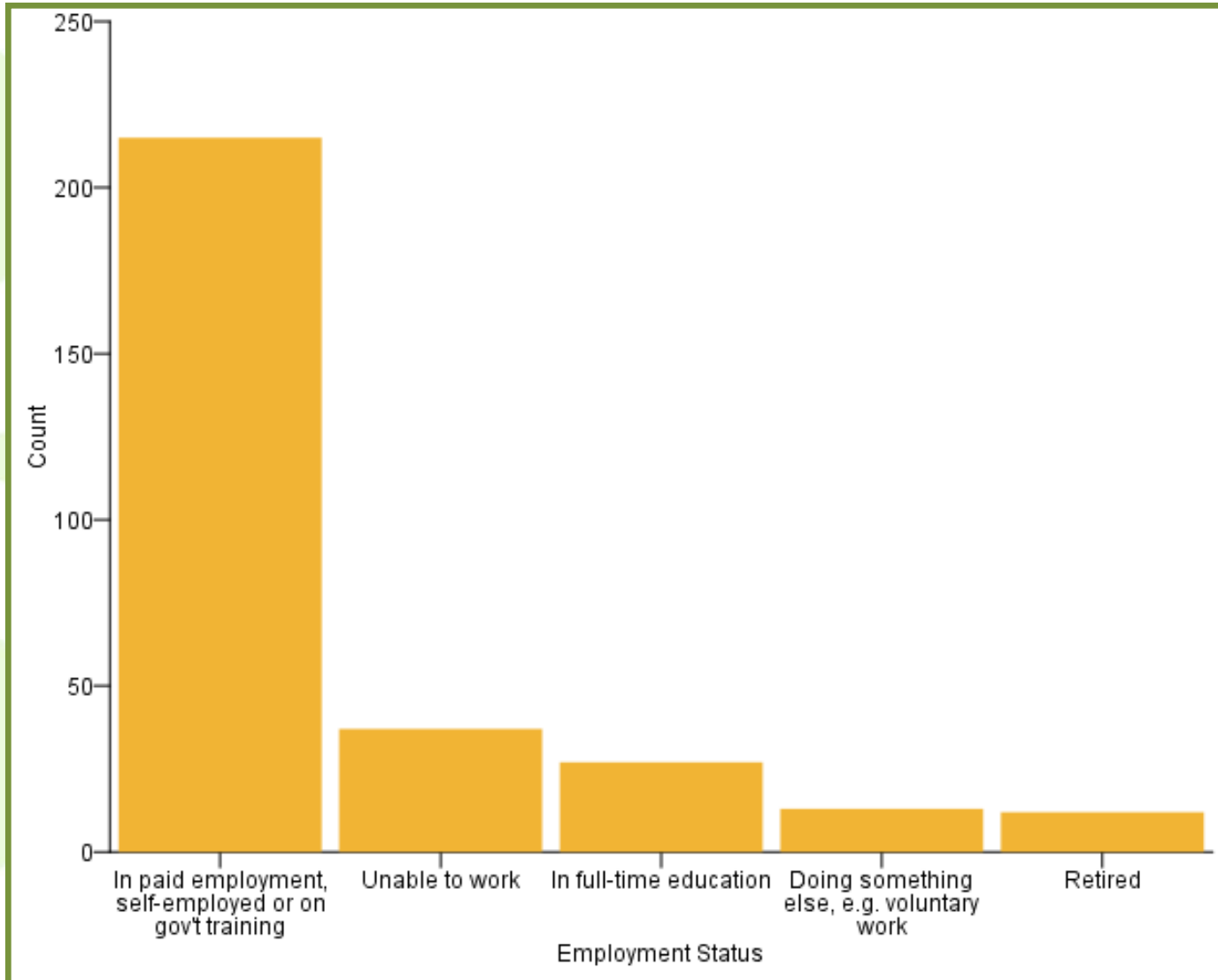
2. Across rural Scotland: **343 responses**

Gender and age of respondents

Employment status

We asked about **self-reported** issues:

14. Do you suffer from any of the following issues related to mental health and wellbeing? **Please choose all that apply.**

[ ] Generalized anxiety disorder ⬅️

[ ] Social anxiety disorder

[ ] Phobias

[ ] Depression ⬅️

[ ] Bipolar disorder

[ ] Schizophrenia/psychosis

[ ] Dementia

[ ] Anorexia

[ ] Bulimia

[ ] Binge eating disorder

[ ] Obsessive-compulsive disorder (OCD)

[ ] Post-traumatic stress disorder (PTSD)

[ ] Stress response syndrome or adjustment disorder

[ ] Suicidal thoughts and feelings ⬅️

[ ] Self-harming behaviour ⬅️

If you are currently experiencing suicidal thoughts or feelings please seek help. You can call Samaritans on 116123 (freephone), you can contact a trusted health professional.

Self-reported issue by **gender**
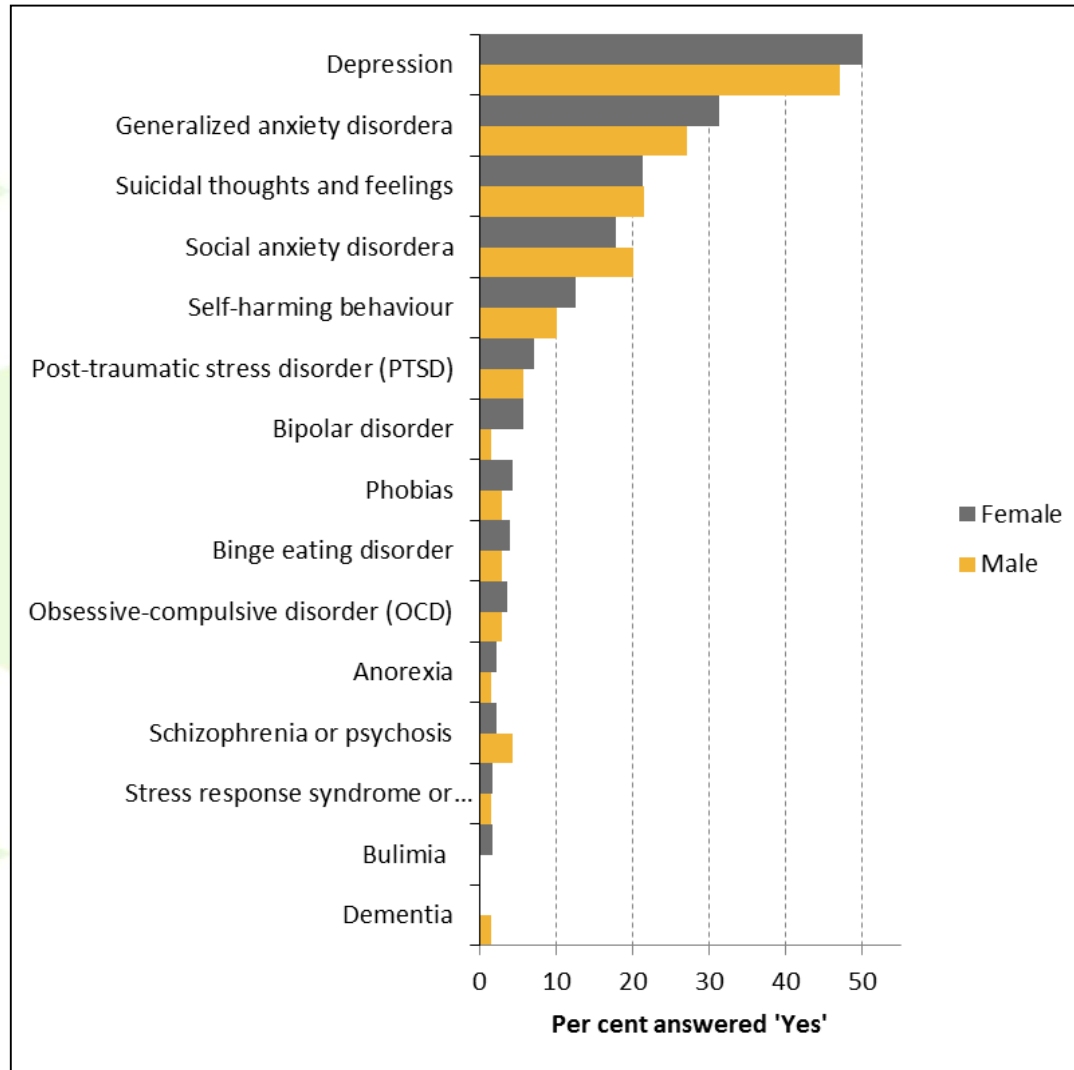
Remoteness and actual geography

Do you consider yourself to live in a remote area?
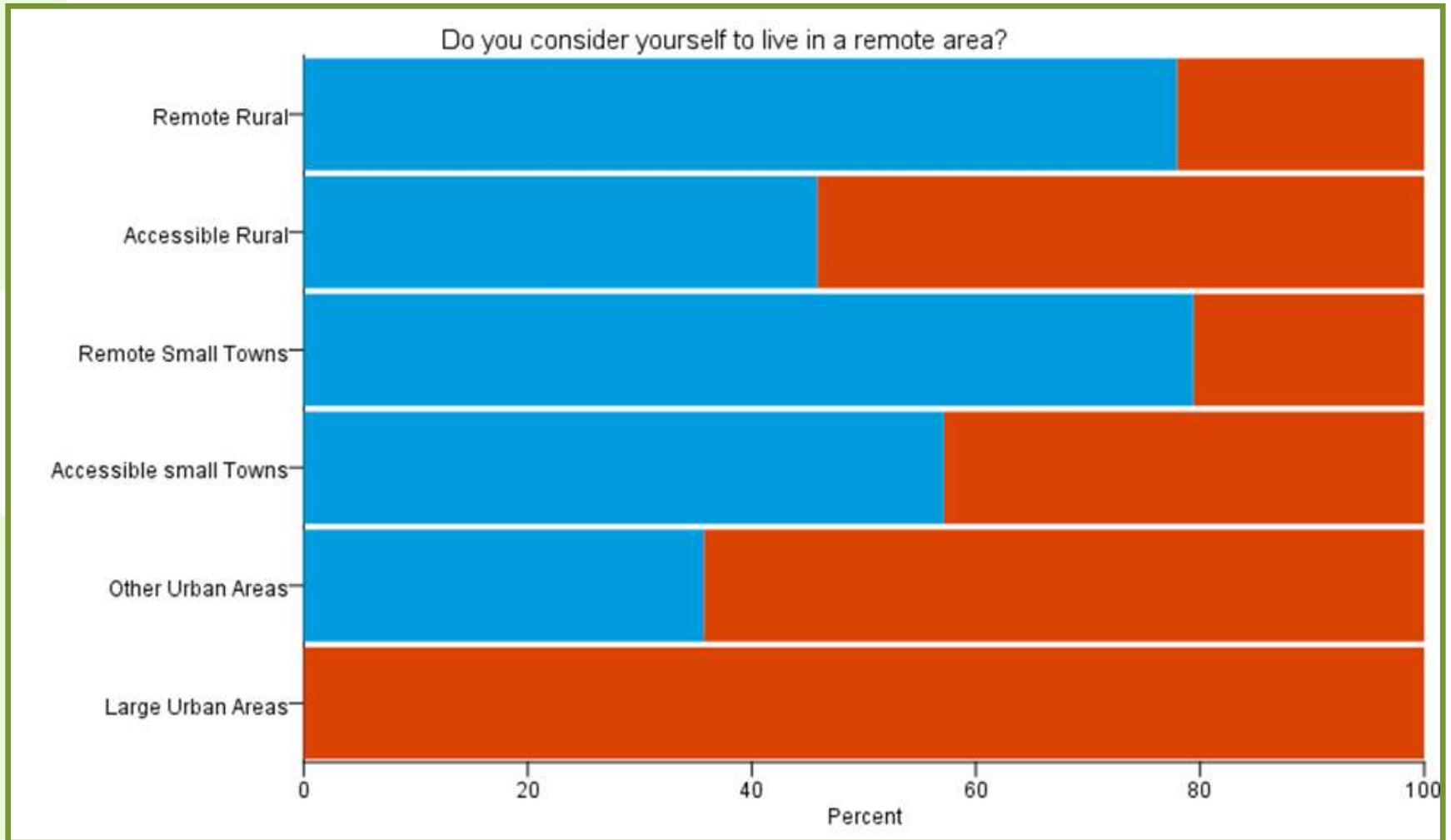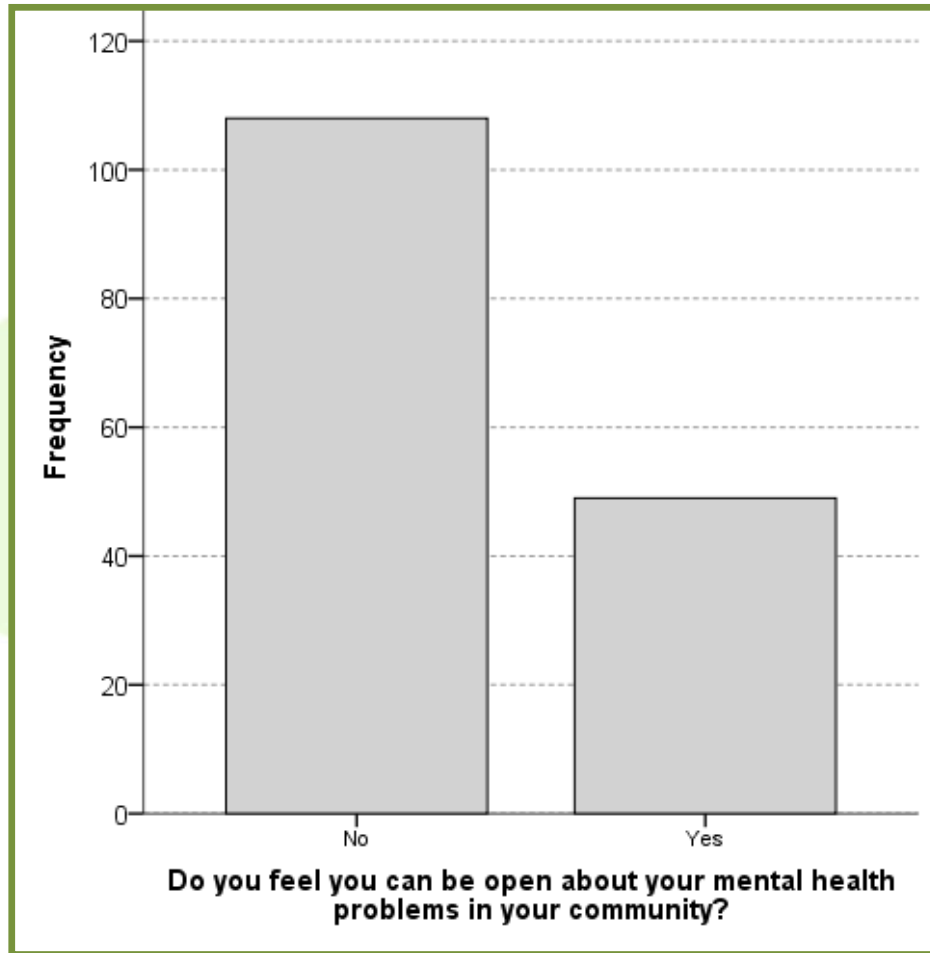
Community: support & connections

Good banter

Supportive, close

Smaller, personal community

Strong community links

Close communities

Close friends

Caring community

Familiar

Feels safe, home

SRUC

Openness?

Do you feel you can be open about your mental health problems in your community?

We asked: **Change one thing** about rural mental health services?

1. Create ways to connect **before personal crises occur** (low-level, non-clinical, informal, through trusted people and networks).

2. **Close to place of need** (including mobile services, outreach, particularly on islands).

    • Recognising significant stress of travel *to* appointments.

3. Mental health care **mainstreamed** within NHS; **parity** with physical health care.

4. Focus on **children and young people** (particularly self-harm) and reduce waiting times.

We asked: **KEY MESSAGE** for policy-makers?

1. It is an **invisible illness** – made more invisible by being rural and remote.
2. **Listen to, and respect, service users**.
3. Mental ill health does lead to **death** – it is a serious issue.
4. **Shorter waiting times** to see specialists.
5. Support **low-level contact outwith hospital environments, close to communities**
   - To make the invisible visible...

E.G.2: "Transforming Lives in Rural Scotland". Survey of Forum Members

- Raise awareness
- Reduce stigma
- Generate evidence
- Influence policy

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#IWD2019

Aims of survey:

1. Create a unique, current, evidence-base of **insights into provision *and* gaps** across rural Scotland and **suggested ways forward**.

2. **Guide future actions of the Forum**.

3. **Inform and guide policy**.

Services we provide
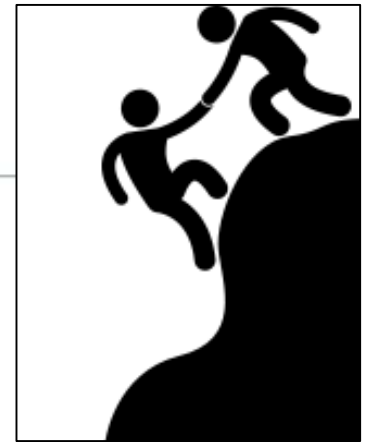
- Bringing people together
- Signposting
- Outreach
- Specialist services and support
- Physical activities (some communal)
- Expertise to policy makers, stakeholder forums and service providers
- Creating delivery partnerships

How we provide services

- Community-based
- Rights-based
- Non-judgemental
- Values-led
- Empowering service users
- Partnership focused

How we address rural social isolation

- **Connecting people** with each other

- Focussed on **what a community or person needs**

- Improving access to services through **collaboration**

Main gaps in mental health service provision in rural Scotland

Main gaps:

- Limited focus on **rural**, **personal experiences**
  - Poor fit with **people's own needs**
  - Lack of **integrated and connected** services
    - "people are not siloed…"
  - Poor fit with **rural** circumstances and relevant evidence
- **Low awareness, poor perception** => **stigma**
- Limited and reducing access to **local** services
- Lack of **pre-crisis and crisis** support
- Weak integration with **community** support
- Ever-reducing **funding**

Single <u>policy change</u> that's needed and the <u>difference</u> that the change will make

Single policy change	What difference it will make
Local: – Non-clinical settings – Third sector engagement – Partnership working – Centres – Mainstreaming "rural" and "mental health"	**Local:** – Better provision and improved outcomes for people in rural Scotland – Reduced cost to NHS – Less stigma and fear – Increased rural community capacity

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Regional: – Rurally-sensitive costing model, less centralisation and appropriate procurement – Holistic; focus on wellbeing. – Rural specifics	**Regional:** – Funding that is appropriate to rural communities – Effective, coordinated and efficient access – Partnership-working with communities

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Regional: – Rurally-sensitive costing model, less centralisation and appropriate procurement – Holistic; focus on wellbeing. – Rural specifics	**Regional:** – Funding that is appropriate to rural communities – Effective, coordinated and efficient access – Partnership-working with communities
National: – Increased support for statutory services – Community and peer-based provision and support – Human, holistic and rights-based approach – Rural focus	**National:** – Improved wellbeing – Reduced stigma – Recognition of rural – Funding for rural initiatives and services

Role for communities:

the national rural mental health forum

- **SUPPORT for communities to deliver:**
  - Financial resources
  - Expertise in rural mental health
  - Support in working together
  - Awareness-raising to reduce stigma
  - Rural specifics and characteristics

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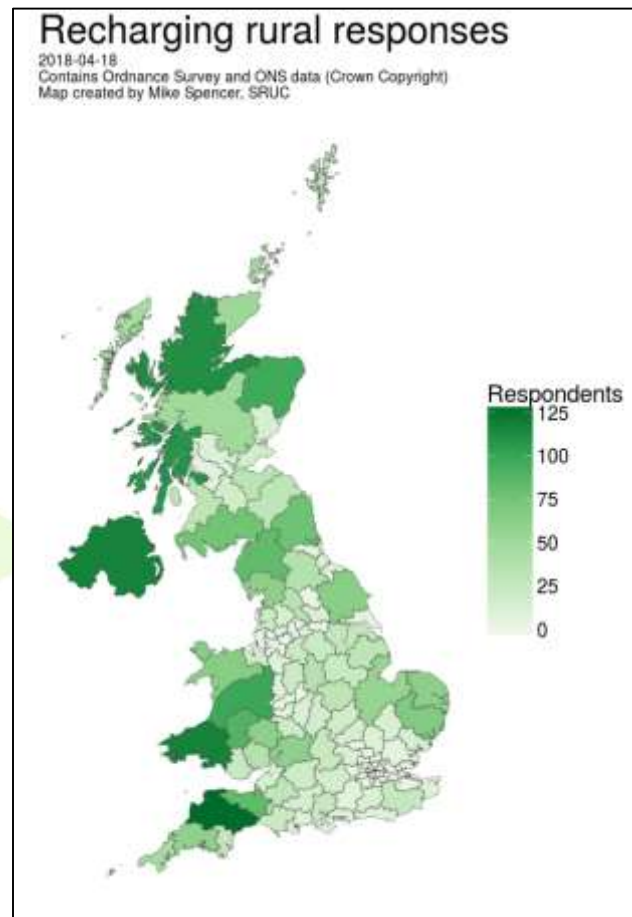 - Rural specifics and characteristics

- **SIGNIFICANT ROLE:**
  - Welcoming and inclusive communities
  - Specific types of community support
  - Addressing stigma
  - Supporting people towards recovery

E.G.3: **Recharging Rural Report 2018**

3,098 responses

- http://www.princescountrysidefund.org.uk/research/recharging-rural   **@countrysidefund**

What is "remote rural"?

1. **Layering of geographical + personal factors; place-labels *alone* are too limiting.**

2. "Disabling characteristics" combine to make life more challenging: Need a car; infrastructure limited or poor; digital connectivity poor; poor roads; ferries.

3. Limited/absent/centralised services = social isolation.

4. **Remoteness is a process happening TO people, through increasing loss + decline**

Mental health and wellbeing data:

- **Social isolation and exclusion:**
  - isolated lone-workers (particularly farmers);
  - lack of mobility due to poor public transport (particularly the elderly);
  - poor mental or physical wellbeing due to poor or distant services;
  - and the lack of social events in a central community hub.

"**High levels of depression**", where **rural** = more challenging:

- "With tiny populations, you can be defined by what you do or conditions you have. Mental illness can need to be hidden as it is often misunderstood and can end up defining how others perceive you in a negative way. People form opinions whether they have all the facts or not and it is hard to redefine yourself beyond that." [SCOT]

- "More difficult to get away from dangerous situations. In a small community it's impossible to stay safe if you are targeted - there is nowhere to go." [ENG]

Projects to improve mental wellbeing:

- **Partnerships** (3rd/public):
  - depression and suicide-focused
  - offer someone to talk to
  - improve self-esteem
  - access to therapy
  - working with arts and cinema
  - physical wellbeing as routes into enjoyment and support
- **What's needed:**
  - Mental *wellbeing* support
  - More people trained with Mental Health *knowledge*
  - More funding for mental health services **plus** arts and community projects

3. **What** can happen when we use **lived-experience** data?
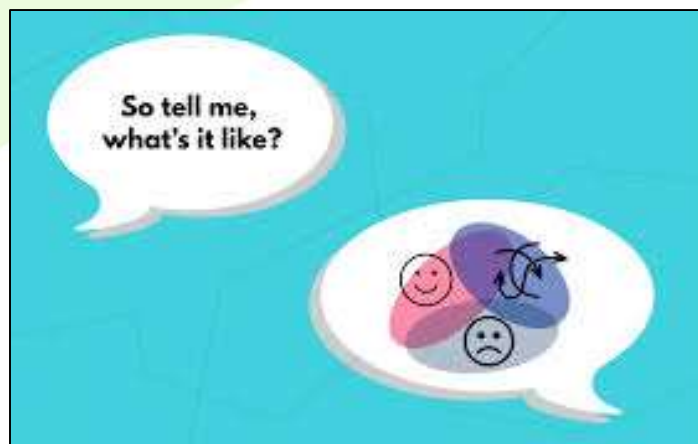
Traceable impacts:

4. On-going need to be **vigilant**

On-going challenge is to:

1. Put people's lived experience on the radar: **<u>again</u>** and **<u>again</u>**.
2. Be **assertive** about these data.
3. Accumulate evidence of **impact**.

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